PHA Heads to Indianapolis for 2014 International PH Conference

PHA’s 2014 International PH Conference and Scientific Sessions is just around the corner, taking place June 20-22, 2014, in Indianapolis, Indiana. Known as the “Racing Capital of the World,” Indianapolis is the perfect setting to host our 2014 Conference, themed Racing Toward a Cure. Join us as we celebrate and acknowledge the determination and progress our PH community has made toward the ultimate finish line: a cure.

PHA’s Conference, the largest gathering of the pulmonary hypertension community in the world, brings together patients, caregivers and family members, nurses and other allied health professionals, physicians, researchers and leaders of PH associations from around the globe. Conference will provide three days of education, networking and support for the global PH community.

For many attendees, Conference is the first time they have ever met another PH patient, another caregiver, another kid with PH. For those who are newly diagnosed, Conference is the starting line at which they begin their race to combat this disease.

“PHA has incredible momentum right now. There is a hustle. So much is being done, but we have to do more,” says Diane Ramirez, a PH patient and co-chair of the 2014 Conference Communications Committee.

Conference is the perfect time to celebrate this forward momentum and build on our advances for the future. And we have a lot to celebrate and build on! The PH community has been active in all aspects of the race toward a cure.
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
MESSAGE FROM PHA’S BOARD CHAIR
Vallere McLaughlin, MD

When I look back on the past year, I am amazed at the progress we have made in the PH community — two new FDA-approved medications for PAH (see page 14), a new tool for communicating more effectively with specialty pharmacies (see page 25), expanding PH awareness and research, and the list goes on. With this momentum to guide us, we can look forward to a bright and exciting 2014, and you will see a glimpse of what’s to come in this issue of Pathlight.

PHA’s 2014 International PH Conference and Scientific Sessions is just around the corner. Our cover article gives you a sneak peek into this amazing Conference, the largest and most unique PH meeting in the world. As I’m sure you noticed, your winter Pathlight arrived with a Conference registration brochure attached to it. Be sure to look through this brochure to see all the excitement taking place in Indianapolis this June. I hope you will join me as we come together as a global PH community to learn, share and participate in this life-changing experience.

As Conference gets under way in June, the members of Team PHenomenal Hope, the all-women cycling team representing PHA in Race Across America (RAAM), will be approaching the RAAM finish line in Annapolis, Md. Between now and then, the PH community is coming together to cheer them on and help them raise awareness and funds for a cure. Supporters across the country have already begun participating in Unity Miles events to show solidarity with the team, and you can see some of these supporters in action on page 21. I hope you will become one!

On April 12 PHA is asking the entire PH community to join us in a day of nationwide action and solidarity with Team PHenomenal Hope. Walk or bike a PHenomenal Mile with us wherever you live. Don’t miss your opportunity to be a part of something bigger. To learn more and get involved, visit our website at www.PHAssociation.org/PHenomenalMile or contact Roni Rivera, PHA’s Special Events Associate, at 301-565-3004 x765 or RoniR@PHAssociation.org. And if April 12 doesn’t fit your schedule, that’s fine. Choose your own date, let us know, and join the PH community in our support of Team PHenomenal Hope.

In this issue of Pathlight, you will also notice a new section called PHA Chapter Happenings, starting on page 35. January 2014 marks the start of our second year of PHA chapter growth, and as our chapter structure continues to reach out across the country to raise PH awareness and encourage financial support for our cause, each chapter will be sharing stories in this section. As PHA President Rino Aldrighetti has said, “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.” The chapters are engaging audiences in their geographic areas to help financially sustain PHA’s vision and our future, and we look forward to what’s in store for 2014.

Finally, I encourage you to read through this issue of Pathlight to find hope and inspiration in the stories of so many living and thriving with pulmonary hypertension. Katie Tobias shares her reflections as a long-term survivor on page 5. Jessica Armstrong was in Afghanistan when she began to experience PH symptoms, and she shares her story in the Our Journeys section on page 10. Our friends in China received 6.4 million viewers on YouKu (the Chinese version of YouTube) when members of the iSEEK PH Center wrote a song about PH and performed as the band “Blue Lips.” See more about this experience as part of the International Highlights on page 22.

We are a busy and vibrant community with so much to look forward to in the year ahead. Thank you for all of your contributions in 2013, and I wish you all the best for a bright and meaningful New Year.

Vallere McLaughlin, MD

PATHLIGHT: A USER’S GUIDE

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.

PATHLIGHT WINTER 2014 Patient-to-Patient Support Line: 1-800-748-7274
Traveling Hope Road: A PH Patient Treks Across the Country to Learn and Share Lessons on Coping with Adversity

Last summer, PH patient Diane Leavitt drove across the country on a journey she calls “Traveling Hope Road.” As she went, she visited PH patients and others along the way, filming interviews and creating an online documentary she hopes will make life a little easier for the PH community and others dealing with life’s ups and downs.

“It was 33 days in my Ford Focus with my 6-foot-tall son and me, seeing our country and bringing awareness to PH,” Diane says. “The journey was amazing.”

Diane started in her home state of Maine where she teaches high school and college. “The idea for the cross-country trip came from a life-long desire to take such a trip. This past year was physically challenging for me, and I was concerned that waiting any longer could prevent me from doing the trip,” Diane says. “Additionally, I have a student, Josh, who battled cancer and is on the winning side right now. He and I heard many high schoolers complaining, ‘My life stinks.’ Typically, their lives were pretty great, but they were having that bad day of a coffee spill or some other mundane issue. Josh and I would smirk at each other knowingly. I want our youth to appreciate what they have and be equipped to move beyond obstacles, as the real ones will occur at some point in their lives.”

Diane received her PH diagnosis in the fall of 2011, but the search for answers to her declining ability to exercise started in the spring of 2007. “I was first told by a cardiologist that I was overweight and to just exercise and all would be fine. It wasn’t,” says Diane. With the help of her friend and nurse practitioner, Maureen Harpell, Diane persevered and finally received a proper diagnosis after undergoing an exercise right-heart catheterization.

Following her diagnosis, her role as a teacher became a source of strength. “I had to be a strong role model for my kids, both my biological kids and my students,” Diane says. “I prepared my students for the day I would be coming in with oxygen, and when that day came, it was scary for me, but I put on my smile. When one student burst into tears because her grandma had just passed away and was on oxygen, I knew right then that my journey with this condition was going to be helpful to others. I hugged her and told her I’d be the person in her life who lives with oxygen. At first it was a charade, but I grew to stay strong and just accept the condition. I began my mantra: I will live with PAH.”

And that’s exactly what Diane did as she traveled across the country this past summer. Sharing her own experiences and capturing others’ ideas about living with adversity, Diane and her son made 22 stops along their journey, staying in 16 states as they traveled to California and back.

The project allowed her to interview people with many different experiences. Her interviews brought her into contact with a Vietnam veteran who spoke on film about overcoming and moving beyond obstacles, she met people outside the PH community who were touched by her personal story and her mission and, of course, she interviewed PH patients from support groups all across the U.S. “My favorite interviews came from PH patients in the Sacramento, Calif., area,” Diane remembers. “They were so excited about the video and about the opportunity to help someone else with this condition. They also felt that it would be helpful for them to share this video with their families in the hopes of better explaining their unique situation.”

When Diane and her son returned to Maine, Diane began the process of editing the video. With help from the local school district videographer, Diane’s film is now ready for viewing, and you can access it at www.PHAssociation.org/HopeRoad.

Having completed this project, Diane feels even more strongly that anything is possible. “Folks should not lose hope and should not feel they are alone,” she says. “Reach out to the PH support groups or help lines that PHA offers. It’s an illness that is difficult to explain to others, especially our families. PHA can be a tremendous support to patients. Be sure to ask questions, be sure to find out what type of exercising you can do so that you stay in shape even though you might not be able to ‘run’ or pick things up, or whatever your limits are. Work around those limits and live with PH.”

By Megan Mallory, PHA Director, Publications, & Pathlight Editor
A Patient’s Look Back on PHighting to Breathe for 10 Years

It started out slowly, getting out of breath going upstairs or running laps in gym class. They said I had asthma. A year later, I began passing out. They said I had epilepsy. Eventually, I was gasping for air walking from one room to the other. After three years, I was finally correctly diagnosed with PH. I was 19 at the time.

That was seven years ago, and in the time since then, I have been on a roller coaster of health ups and downs. Of the 11 drugs currently on the market, I’ve been on seven.

On Sept. 6, 2013, I officially achieved “Long-term Survivor” status. I decided to revisit the college campus where I was “knocking on death’s door.” I wanted to retrace my steps — and the many stopping points along the way — from the psychology building up to my dorm. I also planned to walk from my dorm to the art building where I passed out for the eighth time, the turning point that brought us to the PH diagnosis. Now that I am “better than ever before,” I wanted it to sink in just how far I have come. I was also hoping to quiet the lingering fear that this stable and, dare I say it, good “breath of fresh air” is all just a temporary, albeit wonderful, dream.

It worked. What follows is the journal entry I wrote as I walked that day:

**Long-term survivor TODAY. Weather is perfect. In the bottom floor lounge of the psychology building writing this. The elevator was my first stop. Most days I was able to at least make it that far, still feeling okay. Well, here we go ...**

My second stop: right outside the front doors. I’m actually shocked right now how short that distance felt. My next stop, a tree in the parking lot across the street, doesn’t seem far at all. I remember leaning on this tree gasping for air. If I thought about it, I had my phone out ahead of time so that every time I had to stop, I could pretend to be texting ...

Crossing the parking lot, which is slightly uphill, was definitely my farthest distance between stopping. This is the halfway mark. Looking at these distances now, seven years later, it’s like, “WOW.” They seem so short. This reaction is exactly what I was hoping for. Next, I go around the cafeteria to a picnic table alongside the building. From this point on, it’s all steeply uphill ...

The picnic table was gone. I just kept walking. Definitely more of a workout this time. The hill got really steep. Some steps, too. Sitting in front of the dorm now, just long enough to write these few lines and heart rate and breathing are already coming back to normal.

So much is going through my mind. Above all else is the realization that my main thought right now is not: “OH MY GOD, I CAN’T BREATHE!”

From here, I go to the art building where I “inexplicably lost consciousness.” This eighth passing out episode is where the “official” PH journey begins. I keep realizing I never counted those years pre-diagnosis until this anniversary ...

I DID IT!! The hill that was almost literally the death of me was barely an issue. By the way, I’m writing this part while sitting on a bench right where I passed out. I feel physically really good. I’m glad I did this. Sitting in the spot where I nearly died, feeling calm and conscious. My breathing is fine, and it’s beginning to register just how far I’ve come.

Tore out a journal page, wrote a note and left it on the bench. I wanted a symbolic way of acknowledging the fact that I almost died in this spot. The note said: “Pulmonary hypertension — A rare, progressively debilitating lung disease that causes right-sided heart failure. Arteries in the lungs are constricted, making it increasingly difficult for the heart to pump blood to the lungs. The whole body is oxygen deprived. You are CONSTANTLY short of breath. A handful of medications can slow the progression, but today there is no cure. At some point, lung transplant may be an option for some patients.

I passed out — right here — seven years ago. A few days later, I found out I had had PH for the past three years and was now ‘knocking on death’s door.’ I was 19 years old. Today, I am officially considered a long-term survivor. Please go to www.PHAssociation.org.”

By walking away, I was symbolically leaving the past behind. And if anyone does find it, it’s a little bit of PH awareness, too.

I am a PHighter. I am a Survivor. I am PHenomenal.

We ALL are. ✶

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By Katie Tobias, PH Patient

This article is just a portion of Katie’s reflections on that day. To read her full story, visit www.PHAssociation.org/KatieTobiasReflections
Caregivers: New Year, New You?  
Try These Tips for Taking Care of Yourself in 2014

Research shows that it takes 30 days to establish a new habit and that the most successful habit changes will be implemented via small, measurable steps. Instead of trying to change everything today, pick one thing to focus on each month and slowly build up new habits.

We’ve suggested some “30-Day Habits” below for PH caregivers — pick the ones you think will work best for you and stick with them for the full month. We’ll continue to feature more 30-Day Challenge suggestions in future issues of Pathlight.

- **February:** The cold winter months may be keeping you indoors, but you can still connect with friends and family. Having a strong social support system is key to balancing healthy habits for yourself while also caring for your loved one. Find a way to connect with family or friends each day, whether you meet for coffee or talk on the phone. You can also meet new friends! Check out PHA’s opportunities for caregivers to connect at www.PHAssociation.org/Caregivers/Support.

- **March:** Try something new! Whether it’s a new recipe, a new skill or finally doing something you’ve always dreamed about but haven’t gotten around to making happen, this is the month to expand your horizons! Spend some time each day either doing or learning something new, or putting in time towards making something new happen that you’re excited about.

- **April:** Journaling offers time to reflect and give voice to your emotions and frustrations — whether you are writing, photographing, scrapbooking or expressing yourself through other mediums. If you’re not sure what your preferred form of expression is, experiment until you find it. Try to journal every day this month.

What are your New Year’s resolutions for 2014? Share your ideas for coping and caring for yourself with us by emailing Caregiver@PHAssociation.org or calling 301-565-3004 x800.

Caregiver Shout-Out!  
PH Patient Kevin Paskawych Honors His Wife and Caregiver Karen

Karen is, quite simply, my motivation. She is my light in the darkness; she is my hope. Whenever I get down, she knows how to bring me up again. When we are in public and I become compromised — which doesn’t happen very often, thankfully — she jumps into action without a second thought. And when people wonder why a healthy-looking, 31-year-old man would need his wife to help him pick something up, or need her to run and get him a water in the middle of a store, she tells them.

Karen uses every opportunity to explain PAH and educate others. She has never thought twice about her role, and early on, when she was given a chance to walk away cleanly, she stayed without so much as batting an eyelash. Everything I have accomplished in my progress with PAH, everything I will accomplish from this point forward, is thanks to her. She deserves much more than a shout-out, but this is one small way that I can say thank you for everything she does as a caregiver, as a wife and as a friend.

To read other shout-outs or to submit your own, visit www.PHAssociation.org/Shout-Out.
Patients who live without a caregiver can face additional challenges. Caregivers help PH patients cope emotionally, logistically and financially, and without a caregiver, the activities of daily living like laundry and food preparation still need to be attended to. While the challenges may seem overwhelming, many patients find themselves successfully managing life without a caregiver or even becoming a caregiver for others. We asked such PH patients to share their advice for how to survive and thrive without a caregiver, and here’s what they said:

**I manage by…**

- “Sharing through Facebook. Sometimes reading about others helps us feel less isolated. I also teach a course called ‘Living a Healthy Life with a Chronic Illness.’” — Rita
- “Taking it one day at a time.” — Cathy
- “Trying to keep up with housework a little each night, instead of letting it pile up, and keeping easy dinners in the freezer for late-at-work or ‘PH’ days.” — Brit
- “Focusing on what I can do instead of all the things I can’t do.” — Kathy

**My advice to others…**

- “I felt prepared for an emergency, but I wasn’t. I was unable to communicate with my medical team; my fever was so high that my words came out jumbled. This is why I strongly recommend PHA’s Empowered Patient Online Toolkit. It’s documentation I can carry with me at all times.” — Doug
- “If you have PH, do not sit around and feel sorry for yourself. Do as much as you can.” — Sharon
- “Make sure you take care of bigger tasks when family members are around. Have somebody for emergency backup who would know how to administer medications.” — Kristi
- “Be willing to ask for assistance when you need it, and have a handful of people you can call for help with specific tasks, whether it be emotional or physical help. It is hard doing this on your own, so make sure you have a good support network, even though they may not be physically with you.” — Brit
- “Explain your condition as clearly as possible to others. Make a list of things you need help with to let your friends and relatives know. Wear a smile, no matter how difficult. When I’m going around on a scooter with my big oxygen tank, I can either let it make me feel like everyone is staring at me and that I’m odd, or I can ignore it, smile and be happy with people.” — Kathy

Many patients spoke to the power of PHA for connecting them with other patients and resources. As Rita shares, “I started a local support group at our PH clinic. I would encourage others to join your local support groups and attend as many sessions as possible.” Matty agrees, saying, “PH and scleroderma support groups have met 95 percent of my needs emotionally; I also turn to PHA for educational videos and to the Caring Voice Coalition [for financial information].”

Navigating the PH journey without a caregiver means being proactive. Educating yourself about PH and PH resources can take some of the fear away from doing it all yourself. To ease the stress of being your own caregiver, the Family Caregiver Alliance has provided questions to ask your doctor:

1. What services will help me care for myself?
2. Where can I find counseling and support groups?
3. What agencies are available to help me with transportation or meals?
4. What public benefits am I eligible for, such as In-Home Supportive Services or Veterans Affairs Services?

Being patient and allowing time for reflection can help you gain perspective on your needs and how to articulate them. For more information about living with PH, check out www.PHAssociation.org/Patients/LivingWithPH

By Alicia Heron, Former PHA Patient & Caregiver Services Intern

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By reaching out to people who’ve been there, you’ll find support, information and hope for the future. Connect in the way that works best for you — whether that’s online, on the phone or in face-to-face support group meetings.

Get Connected:

www.PHAssociation.org/Community
Patients living with pulmonary hypertension come to terms with their diagnosis in extraordinary ways. As it turns out, we happen to have quite a few talented artists in the PH community. In our online communities, we asked those who are coping with their disease through art and crafting to share their creations with us, and we posted their work on PHA’s Pinterest page.

Some patients shared their jewelry and key chains; others shared their cross-stitch, decorated gift bags, poetry, paintings, hair ribbons and stained glass. Alex Flipse, PH patient and artist, told us that she has experimented with a variety of media, including melted crayon, in her crafts.

Art has many purposes. For some, making art can be a fun adventure. For others, it can be a way to express emotions they otherwise can’t put into words. Regardless of what you get out of it, utilizing your creativity can be a great way to release the stress that life with PH can cause.

Creating art has other benefits, too. It can be relaxing, help you clear your head, or even give you a way to make some extra income. Althea Ellison, PH patient and artist, tells us, “Art helps me take my mind off what I cannot do anymore. So I create and design jewelry. I sometimes sell pieces online. It keeps me from being depressed.”

One talented jewelry maker and patient living with PH, Catalina Lomeli, produced a PH charm bracelet. She says, “My art helps me. It keeps me busy [by keeping me focused on] only thinking about what my next design will look like.”

Studies show that you can actually strengthen your attention span when you put more focus on your work. Creating art and crafts can also improve cognition by exercising your critical thinking skills, and creativity can give you a sense of accomplishment and pride in something you’ve made yourself.

If you have never crafted before, consider giving it a try. Anybody can become an artist! All it takes is a little effort. Your community is an excellent resource for ways to learn more about arts and crafts — from local museum workshops to courses offered by city or county government programs, community colleges and local crafting stores. Additionally, the Internet is host to a wealth of crafting communities — from Pinterest to crafting blogs. PHA also offers two webinar recordings, “Creativity and Healing Though Blogging” and “Creative Expression for Wellbeing,” to help you get started. You can access these recordings in PHA Classroom (www.PHASociation.org/Classroom).

If you’re learning a craft for the first time, it’s a good idea to start with something simple to get the feel of the tools, materials and techniques. Through practice, you will also gain confidence and may quickly want to try something more challenging.

The beauty of art is that it has no boundaries. It can take you as far as your imagination can go. Where will your art take you?

Visit PHA’s Pinterest page to see more of what your friends in the PH community have made to help them cope with their disease (www.Pinterest.com/PHAssociation/Your-Art-Crafts).

By Kylie Zahringer
Former PHA Social Media & e-Marketing Intern

www.PHASociation.org
PHA’s Interns Provide Essential Contributions to the PH Cause

PHA is able to provide programs and services to the PH community thanks in part to our hardworking interns. PHA is grateful to our fall 2013 interns for all of their contributions to our shared cause.

Alicia Heron, Patient & Caregiver Services Intern, American University, Washington, D.C.

“Interning with PHA has been nothing short of inspiring and reassuring for furthering my career in public health. I was able to assist with PHA’s caregiver survey for adult PH patients, compose a number of blog posts and articles featured in the Generation Hope and PH Plus blogs and Pathlight, and connect with the PH community. Not only have I gained valuable skills and knowledge, I feel that my work has pushed PHA that much closer to attaining its mission. It was great working with a group of people who are so passionate about what they do, and I can honestly say interning with PHA has been one of the most eye-opening and humbling experiences I’ve had so far.”

Andrea Hubbell, Meetings Planning Intern, University of Maryland, College Park, Md.

“When I started my internship at PHA in May, I only had a basic understanding of the impact that PH has on affected individuals. But by the time my internship drew to a close in October, I had developed a strong admiration for the PH community’s resilience and dedication to ending PH. During my internship, I had the opportunity to help plan and attend PHA on the Road: PH Patients and Families Education Forums, the PH Professional Network Symposium and the 2013 Baltimore Walk for Hope. Through these events, I was able to meet PH patients, caregivers and medical professionals and work alongside them in the fight against PH. I encountered many remarkable people, and I can’t wait to volunteer with PHA in the future!”

Ghada Ibrahim, Advocacy & Awareness Intern, University of Maryland, Baltimore, Md.

“I joined PHA in June 2013 to complete an internship as part of my master in public health practicum experience. Working with PHA has been a rewarding experience. Everyone in the organization is very friendly and helpful. During my time here, I worked on various projects such as updating the Wikipedia page for PHA and PH, collecting data and information for the Sometimes it’s PH campaign and finding answers regarding insurance issues facing PH patients. I also helped prepare for PHA’s advocacy day on Capitol Hill and attended the event to advocate for the PH Research and Diagnosis Act of 2013.”

Shamaila Khan, Medical Services Intern, Brandeis University, Waltham, Mass.

“This past semester was the first time that I was totally away from my friends and family. I was worried that I would not find a place where I felt comfortable and at home. It was a blessing that I had to do an internship for my study program because through that program, I was able to find a home at PHA. PHA inspired me with its passion and dedication to fighting PH. Not only does PHA have the most intelligent people working hard for the cause, it has the kindest and warmest people. As a medical services intern, I was able to assist with the PH Professional Network Symposium and PHA Classroom. I also created some of the e-Learning guides available in PHA Classroom. Working with PHA has influenced my interests in medicine, and cardiology/pulmonology seems even more intriguing now!”

Kylie Zahringer, Social Media & e-Marketing Intern, American University, Washington, D.C.

“My first internship experience couldn’t have gone any better than it did with PHA. I am gaining real world experience and plan to take everything I learn with me to my careers to come. What I like most about PHA, besides its wonderful staff, is that I am treated like a co-worker rather than simply an intern. Now I feel ready to enter the real world and its workforce seamlessly. Thank you for an amazing experience!”

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.
It was dusk, and the men at the Afghan National Police (ANP) headquarters were turning on the generator that powered the electric lights in the station. We sat in a haphazard circle that stretched across the furnitureless room, our bellies full of kabob and naan bread. Late into the evening the pleasant sound of overlapping conversations mixed with laughter and the thrum of Afghan pop music. It was a perfect evening.

Two days later I lay in a hospital bed on Bagram Airfield. The doctors were initially confused about why a seemingly fit and healthy young woman would have a blood oxygen level of only 58. A CT scan quickly revealed the problem: at just 29 years of age, I had developed five pulmonary emboli (PE). The prognosis was not good. Within 48 hours I was in a second hospital, this time in Germany.

The doctors in Germany stabilized me, put me on a Coumadin® regime and sent me back to the U.S., ordering bed rest. Exactly one month later, I reported for a desk assignment at Ft. Leavenworth, Kan. Upon seeing me for the first time, the senior officer on staff remarked that I “looked awfully tan for someone who was supposedly so ill.” The next six months can only be described as my own personal hell. It was decided among those in authority that my illness was faked. The opinion among the leadership was that I had probably gotten tired of Afghanistan and that I was seeking to bilk the Army into giving me a large payout. I was threatened with exposure and termination and was forced to turn over my private medical records, including gynecological records, to a male colleague. My performance evaluation was tampered with and downgraded from a perfect score of five to a three by a first lieutenant who had never even met me. All the while, despite the fact that I did not have a car and was thus forced to walk the 12 blocks to and from work, I reported to work nearly every day, absent only when medical emergencies necessitated it.

The first such medical emergency occurred in late September 2011 when I had an extended stay in the hospital due to a very serious reaction while transitioning medications. Imagine my surprise when I returned to work, only to find that I had received an email during my absence that promised termination if I did not respond by a certain deadline. The deadline had passed.

Fortunately, I had taken great care in documenting the reason for my absence and, after several tense days, I was told that I would be allowed to maintain my employment until Jan. 20, 2012. At that point I would return to Afghanistan. I took this news well, since there was nothing I wanted more than to return to the work I loved. October was a good month for me. I was completely off Coumadin®, and the general weakness I felt while taking the drug was gone. I was cleared to resume my exercise regime and quickly returned to my daily runs. I did notice some chest pain with exertion but decided it was something I needed to work through and that exercise could only improve my condition. After just three weeks of exercising regularly, I became convinced that my body had beaten the PE and decided to see some non-military doctors for a second opinion.

Thinking back, Dr. Svetlic must have thought I was a crazy person. Here I was, less than four months after a major PE event, hopping up on her table as I announced that the purpose of my visit was to have her confirm my clean bill of health and sign the paperwork clearing me to return to Afghanistan. Instead, she hospitalized me, and there I sat, two days before Halloween, looking sullen as she explained something I had never even heard of: pulmonary hypertension. She brought in two other specialists and showed me images of my chest. I had effectively lost use of 75 percent of one lung and 25 percent of the other. My heart was working overtime to try and push through the blockages, and I was at immediate risk for heart failure. My parents were called and flew in for the conversation that no parent ever wants to have. I would not be returning to Afghanistan. Instead, she hospitalized me, and there I sat, two days before Halloween, looking sullen as she explained something I had never even heard of: pulmonary hypertension. She brought in two other specialists and showed me images of my chest. I had effectively lost use of 75 percent of one lung and 25 percent of the other. My heart was working overtime to try and push through the blockages, and I was at immediate risk for heart failure. My parents were called and flew in for the conversation that no parent ever wants to have. I would not be returning to Afghanistan. My parents would never see me married. I would never be able to have children. I was a ticking time bomb. My heart could go at any moment. At best my condition was only sustainable for another five months. And then, I saw my father cry.

Two days later I was released from the hospital and my parents and I returned to my apartment in a fog.
afternoon, Dr. Svetlic called. The University of California, San Diego (UCSD) had pioneered and perfected a procedure called a pulmonary thromboendarterectomy (PTE) for patients like me. She wanted permission to refer my case. On Jan. 17, 2012, my mother and I arrived at the Sulpizio Medical Center to meet with Dr. Auger. To put it mildly, I was scared out of my wits. Dr. Auger patiently explained the procedure and our next steps. After a battery of tests, we met with Dr. Auger again. The results were confirmed; I did have PH, but the decision was mine. Was I certain that I wanted to go forward with the surgery? I wasn’t, and it must have been written all over my face. A group of former and current PTE patients was getting together later that evening, and Dr. Auger suggested that I attend and pose my questions to “the real experts.”

That evening I nervously trudged up to the meeting place. If I’d had any expectation, this wouldn’t have been it. There sat a group of people of various ages, shapes and states of recovery. One local woman had returned for this meeting 10 years after her surgery. As we noshed on cookies and bottled water, a guy my age in a hospital gown plopped down beside me. “Man, check out this sweet scar,” he said, showing me his tattooed chest. I stared at it in amazement, surprised. “Are you gonna have the surgery?” he asked. “I don’t know,” I said. “Listen,” he said, “Do it. Seriously. It’s the best decision I’ve ever made.” He went on to tell me about his multiple genetic clotting disorders, how before the surgery he’d had one machine breathing for him and another pumping his heart. “I haven’t felt this well in years,” he said, “and my surgery was six days ago. It’s only gonna get better.” His final statement was the clincher for me: “Unless you have this surgery, you are never going to get any better than you are right now. I don’t know how bad off you are, but I figure not trying to make yourself better is the same thing as giving up.”

Three days later I had the surgery, once again embarking on a long, hard road. It was painful; more painful than I ever could have imagined. At one point before I was fully awake, my fight-or-flight response kicked in, and I accidentally tossed a nurse across the room. There’s also one more thing: something that no one tells you but that is actually pretty well documented, if you look for it. For some reason, after major surgery, some people feel depressed. At the time, I didn’t realize that these feelings were not unusual, or that I needed to discuss them with my doctor. For someone who had never felt that way before, this was a complete shock. I wanted to shut out the world, crawl into a dark hole and never come out. To be honest it would have been fairly easy to do since, in order to obtain health insurance, I had to go back to work less than three weeks after my release from the hospital. My new job was in Arizona — 2,273 miles from my family and friends on the East Coast.

But here’s where the miracle comes in. Instead of climbing into that oh-so-appealing dark hole, I decided to try out a church in my neighborhood. The very first night I made two friends. They were both new to the area, too. They planned things, made me come, even picked me up if I tried to flake; and the church was wonderful! The ministry was exactly the light I needed at such a dark point in my life. I jumped in with both feet. Soon, I was participating in a weekly Bible study group and traveling to Mexico on the weekends to do volunteer work!

It was through the Bible study group that an absolutely wonderful thing happened: I met someone special. Really special. Someone who could accept me, scars and all, and who, after I opened up to him about my illness, asked only one question: “If something ever happens, what symptoms do I look for and what can I do to take the best care of you?” He’s someone who pushes me, who makes me laugh, and who reminds me that life is still the same grand adventure it always was. We were married this past September and so, nearly two years from the day I was told my life was coming to an end, I’ve embarked on my greatest adventure yet.

Fighting for my life was one of the hardest things I’ve ever had to do, but what really makes it all worthwhile is the realization that came along the way: that mine was, and is, a life worth fighting for. What’s more, I’ve learned that sometimes blessings come to us in disguise; sometimes, they look like challenges. Although the road was a difficult one, it led me to the love of my life, to a closer connection with God and to a greater understanding of my own strength. Today, my health still brings its challenges, and there are things that are tougher than they used to be. Fortunately, I’m tougher than I used to be, too. My hope is that, by sharing my story, I’ll be able to help others find the same strength within themselves.
Q: What can PH patients and their medical providers do to help them deal with depression?

A: Upon receiving a diagnosis of pulmonary arterial hypertension (PAH), many patients are able to “adjust” and perform their activities of daily living to their capacity. For other patients this “adjustment” can be more cumbersome, taking a psychological toll on them and their family members and making them vulnerable to depression. This association may work in two directions, indicating that depression can worsen symptoms of PAH or vice versa. While symptoms of PAH develop gradually, fear of the unknown and the perceived burden can result in profound behavioral changes. It may not come as a surprise that many patients may start having feelings of resentment, frustration, anger and/or social isolation once a diagnosis of PAH is confirmed.

The association between depression and PAH has not been thoroughly explored. A recent study found that only 25 percent of PAH patients were on any antidepressant therapy (McCollister et al. Psychosomatic 2010 51(4): 339-339 e8). Screening for depression can present challenges because depressive symptoms such as loss of appetite and/or fatigue can be overlooked as part of the underlying disease process. Moreover, when symptoms are recognized, they may be ignored because they are sometimes considered part of “normal” coping mechanisms. Depression may be associated with a stigma and may be considered a sign of personal weakness. Treating physicians need to understand that a patient’s personal and cultural beliefs may impact their willingness to admit or seek treatment for depression.

Treating physicians may not always have the necessary training or time to investigate whether symptoms of depression are part of PAH or something else that is confounding its medical management. Yet undiagnosed depression can undermine management of PAH. Depression can lead to decreased compliance with medications, aggravate symptoms and even adversely affect the six-minute walk distance. The association between PAH and depression is challenging and requires a multi-disciplinary approach that includes a pulmonologist, cardiologist and primary care physician. If necessary, physicians can refer patients to mental health specialists who can ascertain how patients are coping with their disease.

Depression screening tests that have been validated by research and used extensively in other chronic conditions are available. Based on these tests, physicians can assess promptly patients who show any signs of depression. Some of the screening tools available are the Zung Self-rating Depression Scale, Center for Epidemiologic Studies-Depression Scale (CES-D), Patient Health Questionnaire-9 (PHQ-9) and Beck Depression Inventory (BDI). These scales are simple to complete and can be administered while patients are waiting to be seen by a physician.

Many patients don’t recognize that depression is a treatable condition. A combination of psychotherapy and antidepressants has been more effective than psychotherapy or medication alone. Psychotherapy involves behavior, family, cognitive-behavioral and interpersonal therapies. Patients can also benefit from exercise as it can relax both mind and body while improving mood.

Support groups are another positive way to deal with depression. By joining a support group, patients can share their experiences and the challenges they face every day. They can provide moral support, counsel each other on ways to deal with their circumstances, and end isolation. Having strong family support can also have a positive effect since families can encourage patients to maintain a positive attitude.

Finally, in light of the potential implications of depression on PAH symptoms, screening for depression can only be beneficial. Treating physicians should make every effort to properly educate patients about their disease, make screening for depression a regular part of disease management and have in place appropriate plans for patient assistance.

To learn more about PH and depression, visit www.PHAssociation.org/CopingWithPH/Depression.

Answer provided by Sameer Verma, MD; Sophy Dedopoulos, NP; and Arunabh Talwar, MD; North Shore-LIJ Health System Pulmonary, Critical Care and Sleep Medicine; New Hyde Park, N.Y.
Meet Dr. Sonja Bartolome: Treating PH in Association with Liver Disease

“PH is such a rare and poorly recognized disease that there really is a chance to make a big difference for people, and that’s rewarding on a personal level,” says Dr. Sonja Bartolome, Associate Director of the University of Texas Southwestern Pulmonary Hypertension Program. Having worked in the field of PH since the late 1990s, she knows a thing or two about treating this disease and helping PH patients. In addition to her PH experience, she is also the Director of the Liver Transplant Critical Care Program and has a special interest in PH in the setting of liver disease. She recently sat down with PHA to share her experiences as a PH practitioner.

Dr. Bartolome became interested in the field of PH during her residency at the University of Kansas when she met a patient while on call one night at the hospital. Because of her scientific curiosity and her desire to improve patients’ lives for the better, this initial introduction to the disease made a huge impact on her, and she decided to concentrate on PH throughout her fellowship.

Now with her increased interest in PH and liver disease, Dr. Bartolome is excited at the prospect of researching and helping expand treatment for patients with both diseases. As she explains, PH in association with liver disease is understudied even in the small world of PH research. PH in association with liver disease is less common than some other associated conditions, and patients are often excluded from research trials. Additionally, Dr. Bartolome says, these patients are often harder to diagnose, as many patients with liver disease already exhibit common PH symptoms such as fatigue and shortness of breath.

Throughout her long career in the PH field, Dr. Bartolome has seen a number of advances in PH treatments, and as she notes, PH patients now have more treatment options to choose from than ever before. Individual patients respond to a specific treatment in very different ways, and Dr. Bartolome emphasizes that having a range of drugs available allows patients to find not only the drug that will be most effective in treating their disease with the fewest side effects, but also the drug that best fits their lifestyle. She is excited that new therapies are being developed and that existing therapies are becoming more convenient for patients to use. “This allows patients to treat their disease but still have time to live their lives,” she says.

When asked about specific patients or cases that stand out to her, Dr. Bartolome says that she has had many different patients over the years who are special to her for different reasons. She notes that because PH specialists treat their patients over a long period of time, they really get to know them. She enjoys being able to help people help others, and when she treats a patient for PH and then that patient is able to turn around and be a positive influence in the world for their family, friends and community, she feels a special sense of accomplishment.

Dr. Bartolome encourages PH patients to empower themselves. As she explains, patients should learn about steps they can take to improve their health, including playing an active role in deciding which PH treatment is right for them. She also underscores the importance of patients creating an open dialogue with their healthcare providers by going to them with any issues or questions they may have.

In addition to her work with PH patients, Dr. Bartolome is working on more than 18 ongoing clinical trials. She actively lectures and publishes in the area of PH and participates with the local support groups. She has spoken at several support group meetings in the Dallas area.

Dr. Bartolome is also committed to PHA. She lectured at PHA’s 2012 International PH Conference and Scientific Sessions on the topic of PH in the setting of liver disease and recently presented a webinar for PHA Classroom on Chronic Obstructive Pulmonary Disease and PH. You can access a recording of that webinar at www.PHAssociation.org/Classroom/COPD_PH. For more information on dealing with PH in association with other diseases like liver disease, visit www.PHAssociation.org/PHPlus.

By Sarah Braun
PHA Medical Outreach Program Associate
Two New Treatments for Pulmonary Hypertension Approved by the FDA

Editor’s note: This fall the pulmonary hypertension community received the exciting news that two new pulmonary arterial hypertension (PAH) drugs have been approved by the Food and Drug Administration (FDA), bringing the total number of FDA-approved medications for PAH to 11. These 11 therapeutic modalities give PAH (also called Group 1 pulmonary hypertension [PH]) as many as or more treatment options than all but two of the 7,000 rare diseases identified in the U.S. One of the drugs is the first FDA-approved medication for patients with chronic thromboembolic PH (CTEPH), also called Group 4 PH. Read on to learn about the history of FDA drug approval for PAH and the two new drugs approved this past fall.

The First Nine PAH Medications

The first FDA approval for a medication specifically indicated for treatment of PAH was for intravenous epoprostenol (Flolan®) in 1995. Since then, additional medications have joined the ranks of pulmonary hypertension therapy: oral bosentan (Tracleer®) in 2001, subcutaneous treprostinil (Remodulin®) in 2002, intravenous treprostinil (Remodulin®) and inhaled iloprost (Ventavis®) in 2004, oral sildenafil (Revatio®) in 2005, oral ambrisentan (Letairis®) in 2007, oral tadalafil (Adcirca®) and inhaled treprostinil (Tyvaso®) in 2009, and room-temperature-stable epoprostenol (Veletri®) in 2010. None of them provided a cure; most received approval based on a beneficial effect on a measure (usually the distance a patient could walk in six minutes compared to patients who were treated with placebo) observed over a period of three or four months. This benefit was considered to be a “signal” that patients would be generally improved and survive over a longer period of time if they were treated with one or more of the approved drugs. Indeed, this appears to be the case since survival has improved from a median duration of 2.8 years in the era prior to treatment with these medications (as shown in a National Institutes of Health-sponsored registry in the 1980s) to more than seven years currently (as observed in the REVEAL registry).

The Two Newest Medications

Riociguat (Adempas®) was approved by the FDA on Oct. 8, and macitentan (Opsumit®) was approved on Oct. 18. Both have an impact on biochemical pathways involved in PAH, which previous drugs also targeted, but each has features that may provide additional benefit. Riociguat exerts its effect on the nitric oxide pathway, the same pathway which sildenafil and tadalafil (referred to as phosphodiesterase-5 inhibitors) act on. Whereas sildenafil and tadalafil promote pulmonary vasodilation and other beneficial effects on muscle cells lining pulmonary arteries by reducing the degradation of an important molecule in the process called cyclic guanosine monophosphate (cGMP). Riociguat, on the other hand, directly promotes the production of cGMP. The clinical effect on patients of this theoretically advantageous molecular action was tested in two types of PH patients: PAH patients and those with CTEPH due to blockage of pulmonary blood vessels from persistent blood clots. The results were reported in the New England Journal of Medicine in July 2013.

In the PAH study, (1) 317 patients were given various doses of riociguat and compared to 126 patients on placebo. After 12 weeks of treatment, those on riociguat walked an average of 36 meters farther in six minutes than those on placebo. The better distance was seen both in patients on no other PAH medication and those on other targeted PAH medications (bosentan, ambrisentan and/or inhaled prostanoids). In addition, the riociguat-treated patients demonstrated other positive effects: improved pulmonary vascular resistance, NT-proBNP, functional classification, and time to clinical worsening. They also saw an improvement in shortness of breath while walking for six minutes. The main symptomatic downside was that treated patients had four times the likelihood of passing out (4 percent of patients) than did placebo-treated patients (1 percent).

In the CTEPH study, (2) 173 patients were treated with riociguat and 88 with placebo. Patients were on no other specific medications for pulmonary hypertension. After 16 weeks, the riociguat-treated patients walked an average of 46 meters farther than those on placebo, and there also were improvements in NT-proBNP and functional classification. An improvement in six-minute walk distance was observed both in patients who were not considered eligible for surgical removal of the blockages or who had persistent pulmonary hypertension after operation.

Macitentan is an endothelin receptor antagonist, similar to bosentan and ambrisentan. In the clinical study published in the New England Journal of Medicine in August 2013, (3) 250 patients received a low dose of macitentan, 242 received a higher dose and 250 were given placebo. The study was designed in a new way — to continue the placebo arm long enough for
a predetermined number of events to occur so that it would be likely to observe a relevant difference between treatment groups if in fact there was one. Events included the first occurrence of any of the following: death, atrial septostomy, lung transplantation, initiation of treatment with intravenous or subcutaneous prostanoi, or worsening of pulmonary arterial hypertension. Patients on macitentan had fewer events during a median study period of 115 weeks: 31 percent of patients in the high-dose group had an event, 38 percent in the low-dose group and 46 percent in the placebo group. Most of the events were worsening of PH, and the better results on worsening were seen both in patients who were and were not on other treatment. When measured after six months of treatment, the six-minute walk distance for those on high-dose macitentan was 22 meters farther than those on placebo (the difference was 17 meters for those on the low dose). The main side effects were headache, inflammation of nose and throat passages, and anemia.

Summary

Two new PAH medications are now available for clinical use. Options for treatment may improve success of management. The results of the pivotal studies were positive, and there is cause for optimism. However, it is also important to have realistic expectations. The medications are not curative, and on the average, the benefits are relatively limited (in line with the effects seen in studies of current medications). Of course, even small improvements, especially when superimposed on prior treatment, are gratifying. Also, since the new medications were not compared to other medications, it is not clear yet that they truly represent an improvement or simply an alternative or increment to current treatment. Consequently, decisions regarding altering treatment to include these medications will require careful consideration.

Riociguat was not studied in combination with sildenafil or tadalafil (since this might be harmful), so that combination is not an option. Neither macitentan nor riociguat were investigated in combination with parenteral prostacyclin, so the effect of these medications given together is unknown. The risk of birth defects with both medications is high, which mandates negative pregnancy tests and dual method contraception for fertile females and formal prescriber agreements to screen patients and prescribe appropriately. Riociguat doses should start low and be increased to a dose that provides the best effect and is well tolerated. Treatment with macitentan does not require liver blood tests, though periodic checking should be considered.

The availability of an approved medication for treatment of CTEPH is clinically useful but should not delay consideration of intervention in otherwise appropriate candidates.

As with any medical treatment, discussion with the physician prior to treatment and ongoing evaluation is necessary.

By Michael D. McGoon, MD, Professor of Medicine, Mayo Clinic, Rochester, Minn.; Distinguished Advisor, PHA Scientific Leadership Council; Pathlight Medical Co-Editor

References


10 Things To Do For Better Living With Chronic Thromboembolic PH (CTEPH)

1. Learn the basics on CTEPH.................................www.PHAssociation.org/CTEPH
2. Join PHA’s CTEPH Facebook group.....................www.Facebook.com/groups/PHACTEPH
3. Join PHA’s CTEPH Google email group..................www.PHAssociation.org/CTEPH
4. Email a CTEPH patient mentor..............................www.PHAssociation.org/Mentors
5. Share your story online........................................www.PHAssociation.org/OurJourneys
7. Take our survey. Tell us how to improve CTEPH resources...www.SurveyMonkey.com/s/CTEPH
8. Attend PHA’s International PH Conference................www.PHAssociation.org/Conference
9. Join PHA to receive Pathlight, discounts and more........www.PHAssociation.org/Join
10. Come up with your own ideas and let us know! Email........Outreach@PHAssociation.org
2013 PH Professional Network Symposium Honors a Decade of Growth in the PH Field

As the vice-chair for the 2015 PH Professional Network Symposium planning committee, I’m excited to share my experiences with you from the 2013 Symposium, The Power of Teamwork: 10 Years of Professional Collaboration in PAH, which took place Sept. 26-28, 2013, in Arlington, Va. The PH Professional Network (PHPN) is PHA’s membership group for non-physician healthcare professionals, and our 2013 Symposium was a time to honor a decade of evolution in caring for each other and our patients and welcome new and exciting advancements. As always, I left Symposium feeling refreshed and invigorated with a renewed sense of hope.

The 2013 Symposium kicked off with an opening dinner on Thursday night where we reflected on the past decade and learned about how PHPN evolved from a concept to a network that now hosts a Symposium with more than 400 attendees. Over the years, PHPN has met biennially to share our practice, empower one another and celebrate our collaboration. This year at the opening dinner, Christine Archer-Chicko, MSN, CRNP; Karen Fagan, MD; Carolyn Pugliese, RN, MSN; and Crystal Weber, RN, told their stories of why they started working with the PH community and shared a few laughs along the way.

The 2013 Symposium celebrated the diversity of our disciplines, including nurses, nurse practitioners, pharmacists, respiratory therapists, physician assistants, social workers and pediatric healthcare professionals. We were offered continuing education credit and attended sessions relevant to numerous disciplines, but we came together throughout the event to network and share in our experience. The planning committee also approached this year’s Symposium with a fresh perspective, inviting the PH medical community to submit ideas for sessions, including topics of interest and speaker suggestions. This resulted in sessions that covered topics throughout the lifespan of a patient such as neonatal considerations, transitioning from pediatric to adult care, pregnancy, regenerative medicine and palliative care. And with catchy titles such as “Water You Thinking” and “The PH Pharmacist: A Prescription for Teamwork,” the sessions were not to be missed!

We heard from 64 speakers from across the country and around the world, further reminding us of our 10 years of collaborative efforts. We also honored those we have lost throughout the years and expressed our gratitude for their service to our community and to our patients. We will continue our work on their behalf.

Symposium also featured an unopposed research poster viewing session with more than 30 abstracts from a multitude of disciplines. I enjoyed speaking to many of the abstract authors, whose topics ranged from research on the latest PH treatments to the development of educational plans for new PH programs. A reception followed the poster viewing session, providing a casual environment for discussion and further networking.

The 2013 Symposium ended with “REVEALing the Future of PAH,” a session by Abby Poms, RCP, RRT, and Gregory Elliott, MD, MACP. These presenters discussed the lessons learned from the REVEAL registry and explored how we can apply these in our practice as we move through the next decade in caring for PAH patients. Some of my favorite things from this year’s Symposium included feeling inspired by those longstanding members of the PH community and welcoming and encouraging those who are new to our community.

If you missed the 2013 PH Professional Network Symposium, you will be able to see the session recordings on PHA Online University in the near future. To learn about PHPN’s advocacy efforts on Capitol Hill on behalf of the PH community just prior to the start of Symposium, turn to page 27, and to learn more about PHPN, visit www.PHAssociation.org/PHPN. As vice-chair for the planning of our next Symposium, I hope to see you in 2015!

By Michelle C. Cash, MSN, RN, APRN, Pulmonary Hypertension Nurse Practitioner, The Heart Institute, Cincinnati Children’s Hospital Medical Center, Cincinnati, Ohio
Getting from Here to There: Tips for Traveling with PH

Toting Tyvaso®? Veletri® in your valise? How does one get from here to there and back again with pulmonary hypertension?

First things first: use the buddy system. From the moment you commit to traveling, use a second set of eyes and helpful hands. Divide tasks. Double-check everything. Plan ahead.

Medical basics to keep in mind:

- Does your PH doctor know you are going? Has he or she prepared a letter explaining your condition and needs? Streamline this process by writing your own note for your doctor’s signature: “To whom it may concern: Ms. Smith has pulmonary hypertension. For this she wears oxygen and uses medicine X through a continuous pump. She is on warfarin, which can cause bleeding. She is allergic to penicillin (hives). For more information, please call Dr. Jones’ office: XXX-XXX-XXXX days, or XXX-XXX-XXXX nights.”
- How can you identify a local PH doctor and hospital? Ask your PH physician or go to PHA’s Find A Doctor Directory at www.PHAssociation.org/FindADoctor. Load your smart phone or “go to” book with names, numbers and addresses.
- Who supplies your PH drugs? Tell them your destination. Can they mail your medications ahead? Take extra medication along in case of delays from missed flights or lost luggage. Keep the medications in their regular containers with associated supplies, splitting the trip’s load between a roomy purse or backpack for carry-on and your checked suitcase. Keep your physician’s letter with these items, and present all these to security “up front.” A preemptive reveal is easier to explain than iced liquids or needles found during a security “pat down.”
- International traveler? Por favor, translate medical documents into your destination’s language.
- Carrying oxygen? For air travel tips, go to www.AirlineOxygenCouncil.org or www.HomeOxygen.org. “Bring your own O2” is the new norm for U.S. airlines. If you do not have a portable oxygen concentrator (POC), you need one. Ensure your oxygen requirements are met by this type of low-flow device, particularly if you are flying cross country. Your doctor will need to sign off on this device. Tell your airlines at least two weeks ahead to ensure that your POC is allowed. If driving, notify your oxygen company. Whether by land, by sea or by air, have the oxygen equipment you need en route and on site.
- Are you drinking water and continuing to walk? Seasoned travelers know that hydration and ambulation prevent coagulation. Lower your risk for blood clots by sipping decaffeinated liquids and moving about. If driving, stop often for rest area breaks.

Other advice to follow:

- Back to the buddy system: If your buddy cannot travel with you, buddy up with someone else. Befriend the skycap, your flight attendant, the taxi driver, doorman, maid, concierge and the “girl next door.” Everyone will help. You just need to ask.
- Do you have an ICE number? In your wallet, purse or phone, clearly note: “In Case of Emergency, call XX at XXX-XXX-XXXX.”
- Practice makes perfect. Do a rehearsal, or dry run, to the airport a time or two before the “go” date to help you feel more comfortable.
- Remember to bring your insurance card.

Information overload?

Try using PHA’s Empowered Patient Online Toolkit to help you get organized: www.PHAssociation.org/OnlineToolkit. And of course, remember:

- Sleep well.
- Eat well.
- Do not sit too much, stand too much or hide in your room.

Enjoy the going and coming as much as the “being there.” Have a great trip! Visit www.PHAssociation.org/TravelingWithPH to learn more about traveling with PH.

By Karen M. Wolf, MD, FCCP, Associate Professor of Clinical Medicine, Division of Pulmonary, Allergy, Critical Care and Occupational Medicine, Department of Medicine — Indiana University School of Medicine, IU Health Physicians

DISCLAIMER

We encourage readers to discuss their healthcare with their doctors. This newsletter is intended only to provide information on PH/PAH and not to provide medical advice on personal health matters, which should be obtained directly from a physician. PHA will not be responsible for reader’s actions taken as a result of their interpretation of information contained in this newsletter.
Understanding Misdiagnosis: Echocardiograms Are Good Tools, But Only When Used and Interpreted Correctly

**Editor’s note:** Educating the members of our PH community to be the strongest possible advocates for early diagnosis is one of PHA’s goals. By doing so, we help patients, family members and caregivers who are invested in our early diagnosis campaign. Sometimes it’s PH, gain a deeper understanding of the causes of missed and misdiagnosis. This article on the role of an echocardiogram in diagnosing PH is one of occasional articles that will appear in Pathlight to describe some of these causes.

An echocardiogram — a two-dimensional picture of the workings of the heart created through ultrasound — can be a helpful tool in diagnosing pulmonary hypertension — but only if it is used and interpreted properly, according to Paul Forfia, MD, and Fran Rogers, MSN, CRNP, both of the Pulmonary Hypertension & Right Heart Failure Program at Temple University Hospital in Philadelphia.

### Advantages of Echocardiogram

Echocardiograms (or echos for short) are noninvasive and can be used at the bedside, two advantages of this technology. They do an excellent job of helping healthcare professionals differentiate patients with left-heart disease, which is far more common, from those with right-heart disease like pulmonary arterial hypertension (PAH) or chronic thromboembolic PH (CTEPH), also known as PH due to blood clots in the lungs. Identifying cases of right-heart disease is essential because physicians manage this condition very differently from the way they manage left-heart disease, according to Dr. Forfia.

Echos also are able to uncover specific kinds of abnormalities in the right ventricle prior to a right-heart catheterization. These include enlargement of the right heart, improper functioning of the right ventricle and a flattening of the membrane that divides the heart into left and right, called the interventricular septum. Other echo findings, such as a “picture” of blood flow as it exits the right heart, can be very useful in detecting PAH and CTEPH. These clues, taken together, can help a physician figure out what might be causing PH, key information in forming a diagnosis.

### Beware of Misuse of Echos

Understanding the information obtained from an echo can be challenging, sometimes leading to incorrect interpretation or overlooking signs of PH. One common error is to rely solely on the echo’s measure of pressure in the vessels of the lung. This measure is only an estimate, Dr. Forfia says.

A study done by John Kingrey, MD, of The Ohio State University and his colleagues has found that healthcare providers may not always recognize and respond to echos showing indications of PH. Dr. Kingrey, a leader in PHA’s Sometimes it’s PH campaign, and his group studied the use of echos at a large Cincinnati hospital. Their findings, published in the medical journal Pulmonary Circulation in the April–June 2013 issue, showed that providers acknowledged possible PH only in about 23 percent of the echos which suggested PH. They mentioned the following reasons why echocardiograms may lead to a missed PH diagnosis:

- Physicians understand the limitations of echos and may have alternative explanations for the abnormal findings.
- Medicine has no widely accepted guidelines based on evidence on how to use echos to guide further evaluation of suspected PH.
- Echo reports provided to physicians after the test is performed often have several pages worth of information — so much that important details about possible PH can be overlooked.

### Knowledge is Power

Knowing more about misdiagnosis and its causes can help you be clearer, more specific and more persuasive when you communicate about the need for earlier diagnosis of PH. Use the facts in this article to strengthen our community’s ongoing call for change:

- When asking Members of Congress to support PHA’s *PH Research and Diagnosis Act*, point out that one reason PH diagnosis can be missed is improper use of available technology.
- When talking with the media about PH, explain that despite the availability of treatment and diagnostic tools, some medical professionals lack the knowledge and skills to spot PH.
- Share this article with others whose lives are touched by PH, especially those going through the diagnostic process, so that they can advocate for themselves in the healthcare system.
Examining Extracellular Calcium Sensing Receptors in PAH

**THE QUESTION:** What is the role of the extracellular calcium sensing receptor (CaSR) in pulmonary arterial hypertension (PAH)? Can inhibition of CaSR represent a possible novel target for drug therapy?

**WHY IS THIS IMPORTANT?** PAH is characterized by sustained vasoconstriction and excessive pulmonary arterial smooth muscle cell (PASMC) growth, contributing to pulmonary arterial remodeling. In PASMCs calcium is an important catalyst for vasoconstriction and proliferation. CaSR is an important mediator of calcium homeostasis and understanding CaSR function in the pulmonary vasculature may lead to the development of a novel therapeutic strategy for the treatment of PAH.

**PAST STUDIES:** CaSR is a G-protein coupled receptor found in subfamily C (GPRC2A) which, by sensing extracellular calcium, is vital to maintain normal calcium levels in the human body, yet the role in smooth muscle cells remains less well understood. It has been demonstrated that stimulation of GPCRs activate phospholipase C, which then mediates a rise in calcium concentrations. This rise in intracellular calcium increases the rate of key cellular processes such as differentiation and proliferation of PASMCs. Given our knowledge of the importance of intracellular calcium in pulmonary hypertension and the key role that GPCRs play, we hypothesized that CaSR may play an important role in increased intracellular calcium concentrations in PH. We also hope to identify ways to target CaSR as a potential therapy for patients with PAH.

**THIS STUDY:** Rats were treated with monocrotaline to experimentally induce pulmonary hypertension (MCT-PH). Pulmonary arterial smooth muscle cells were isolated from lungs of MCT-PH rats as well as normotensive (control) rats. CaSR gene expression levels were increased in the MCT-PH rats. It was also increased in PASMCs from lungs of PH patients.

To show a direct role for CaSR in increases in calcium and proliferation, silencing mRNA was used to knock down CaSR gene expression in human PH patient PASMCs. Decreasing the expression of CaSR results in significantly decreased cytosolic calcium levels and proliferation (measured as a change in cell number) in comparison to PASMCs from healthy lungs. Increasing the gene expression of CaSR in normal PASMC increases calcium levels and enhances proliferation. These findings together have led us to believe that CaSR may be important to the development and progression of PH, and altering CaSR function with pharmacologic inhibitors could lead to favorable changes in PH.

We tested the effect of an experimental CaSR blocker, NPS 2143, in animal models of PH by looking at the right ventricular systolic pressure (RVSP) and muscular composition of distal pulmonary arteries in two models of PH. Monocrotaline injected rats (MCT-PH) and mice exposed to four weeks of hypoxia (HPH) reflected the increase in pulmonary artery pressure and changes in the structure of the artery respectively. NPS 2143, while having little effect on normal animals, was shown to prevent increased RVSP in both MCT-PH rats and HPH mice. It was observed that NPS 2143 inhibited medial hypertrophy in both animal models. These findings suggest that NPS 2143 can prevent the development of PH in these animal models. We propose that this effect is achieved by blocking CaSR in order to prevent increased cytosolic calcium and unregulated proliferation in PASMCs.

**WHO MAY BENEFIT FROM THESE FINDINGS?** Patients with PAH, medical professionals and research scientists.

**THE BOTTOM LINE:** This study demonstrates that CaSR is functionally upregulated in PASMCs taken from animal models with experimentally induced PH. CaSR upregulation is linked to the rise in cytosolic calcium and subsequently increased proliferation and vascular remodeling, which is integral to the development of PAH. Inhibition of CaSR with NPS 2143 prevents the development of PH in animal models. Similar to the animal models, PASMCs from patients with IPAH have increased expression of CaSR, and we propose a role for CaSR blockers, such as NPS 2143, as a potential novel therapeutic target for the treatment of PAH.

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**LIST OF AUTHORS:** Aya Yamamura, Qiang Guo, Hisao Yamamura, Adriana M. Zimmnicka, Nicole M. Pohl, Kimberly A. Smith, Ruby A. Fernandez, Amy Zeifman, Ayako Makino, Hui Dong, Jason X.-J. Yuan

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By Dustin Fraidenburg, MD, Fellow, Pulmonary and Critical Care Medicine, University of Illinois at Chicago; Jason X.-J Yuan, MD, PhD, Professor of Medicine and Pharmacology, University of Illinois at Chicago; Kerrie Collins, BS, PhD Student, University of Illinois at Chicago
A veteran of the Race Across America (RAAM), Bernie Comeau, has written that the seven to eight months of training before an ultra-endurance event have the most influence on an athlete’s fitness level at race time. These winter months, therefore, are critical for Team PHenomenal Hope (Team PH), the cycling team entering RAAM in June in honor of PHA. Through March, the training of the team’s seven women will build the fitness needed to cover 3,000 miles coast-to-coast, nonstop, in nine days or less.

**Braving the Elements on Bikes**

Biking in the cold winter in Pittsburgh, the home of six of the seven team members, can be dangerous and uncomfortable with snow, rain and wind. Team member Anne-Marie Alderson says the team will do some outdoor biking anyway, practicing taking corners and hills under these conditions and cultivating their mental toughness.

Sara Harper, an alternate on the team and a two-time veteran of RAAM, must work her outdoor cycling plans around her asthma. Sara uses as many as eight daily asthma medications. She trains indoors on snowy days below about 20 degrees Fahrenheit. Her vigorous exercise regimen reminds her, she says, that “having asthma, the only limitations are the ones I put on myself.”

**Building Fitness Indoors**

While reducing outdoor biking time, the team will now add plenty of indoor workouts on their bikes and off. In the fall they hired a coach, Jim Bruskewitz, a triathlete who has won competitions at the national level many times and who brings 25 years of experience coaching endurance athletes. Jim is creating a training plan for the group that leaves room for each cyclist to work at her own best level of intensity. Jim will measure intensity levels with detailed monitoring equipment available on each bike, taking a baseline test of how many watts of power each woman can sustain for one hour. Each competitor will then train at various percentages of this baseline, with retests every four to six weeks.

In their own homes and gyms, team members will pedal in place on “trainers,” their usual bikes made stationary with a special device. Workouts will alternate faster and slower intervals and long and short rides. The training plan will also develop good cycling form to sustain the racers’ shoulders, necks and backs through the race.

To build aerobic strength, another chief goal this winter, the team will mix cycling with other forms of exercise. For instance, Dr. Patty George, a PH physician and team captain, will run through the winter, while Anne-Marie will swim laps. Every team member will be developing full-body strength with weightlifting, core exercises, pull-ups and push-ups.

**Getting Tournament Tough**

Withstanding weather, monotonous workouts and more develops the mental attitude and focus needed for this demanding race, in many ways similar to the challenges PH patients face. “Our team’s connection with PHA and meeting some of the patients has gone a long way in keeping me motivated,” says Anne-Marie. “It’s not just me anymore” when the challenge seems steep, she says.

Documenting workouts and their results is also a key element of winter training. Sara regularly uses a 10-point scale to rate how she is feeling physically, emotionally and mentally, adjusting her training plans accordingly. Team members’ experiments with nutrition and cycling gear will be noted in their logs, too, as they seek maximum performance.

The PH community is showing its support for Team PH by raising money for PHA and awareness of PH in the Race of Our Lives campaign from now through the race in June. Check out what we’ve been doing so far on the next page. To get involved, visit [www.PHAssociation.org/RaceofOurLives](http://www.PHAssociation.org/RaceofOurLives) or call Roni Rivera at 301-565-3004 x765. Be sure to stay up-to-date with the latest news from Team PH and the Race of our Lives by visiting our blog [Cue Sheet: Your Roadmap to Race of Our Lives](http://www.PHAssociation.org/CueSheet).

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By Mollie Katz

*Former PHA Vice President, Community Engagement*
PH Community Supports Team PH Through Unity Miles

Unity Miles events, which kicked off in August 2013 with Pittsburgh’s Walking PHor a Cure, are events that allow the PH community to show support for Team PHenomenal Hope. Since our first event, many PHA community members have embraced the Race of Our Lives theme for their personal and group fundraisers. These events have captured the spirit of the campaign: moving in solidarity with Team PHenomenal Hope and PHA. We are looking forward to adding more Unity Miles events in 2014. No matter how you move, join the Race of Our Lives!

Bike PHifty — Sue and Camm Epstein organized a 50-mile bike ride in honor of their daughter Danielle, who has PH.

Walking with Team PH — PH patient Janet Mabe, pictured top left, and Diane Ramirez, bottom left, a patient and PHA Board member, walked 135 miles collectively in solidarity with Team PH and in honor of PH patients worldwide. They chronicled their daily walks on Facebook.

Half Ironman — PHA staff member Roni Rivera dedicated her Half Ironman to the Race of Our Lives campaign and PH patients. The event consisted of a swim, bike ride and run.

The Warrior Dash — PH patient and PHA Board member Colleen Brunetti, pictured left, and her friend Heather Tomala participated in the Warrior Dash, a 5K mud run, for their Unity Miles event.

The PHenomenal Mile: Walk with us wherever you are.
Join PHA in a nationwide day of action in solidarity with Team PHenomenal Hope.

SAVE THE DATE: APRIL 12, 2014
For more information, visit: www.PHassociation.org/PHenomenalMile

PH Professional Network Supports Race of Our Lives

The PHenomenal Mile: Walk with us wherever you are.
With PH associations worldwide working for our shared cause, there is always something PHenomenal happening in the global PH community. Take a look!

- **In Australia...** PHA Australia was invited to man a table (or, as they said, “woman” a table) at the Pulmonary Hypertension Society of Australia and New Zealand (PHSANZ) Annual Scientific Meeting 2013 on Oct. 10–11 at the Melbourne Convention Centre. PHA Australia is also encouraging members to Get Blurple for PH — that means members can dress in blue and purple to raise awareness of PH. People can then take photos of themselves “blurple-ing” and post them to PHA Australia’s website (www.phaustralia.com.au), and as World PH Day draws closer on May 5, they can post photos to www.WorldPHDay.org, too!

Meanwhile... Lung-related support groups, including the Western Australia PH Support Group and Information Team (PHWA), held the “Connect Group Expo” at a large shopping center in Western Australia this past September. PHWA had an information booth with a banner and new pamphlets. The coordinators from the lung-related support groups usually meet up once a month to network and share with each other; the expo came out of those meetings.

- **In China...** Members of iSEEK PH Center in China won enough live audience votes to gain a spot on China’s most popular television talent show, Chinese Dreams (中国梦想秀). In the TV program, the hosts and assistant groups help the winners to achieve a dream they have. The dream the iSEEK members chose was to perform a song written by one of their own as the band “Blue Lips.” The band consisted entirely of PH patients: a professional singer, a ukulele player and three backup singers. The show was recorded Oct. 14 and aired a month later. Since then, iSEEK has been able to leverage the publicity to raise approximately 50,000 USD, make the front page of YouKu (Chinese YouTube) with 6.4 million viewers of one of their videos, and become a government-authorized NGO — a feat they have been attempting for several years. You can view a clip of the show at www.PHAssociation.org/iSEEKDreamShow.

- **In Ecuador...** In October, Amigos con Hipertensión Pulmonar Ecuador, the patient association based in Quito, held its first Patient Education Day in the Hotel Hilton Colon.

- **In Saudi Arabia...** The Saudi Association for PH (SAPH) hosted a PH Patient Support Group Meeting on Nov. 21. The meeting included new resources for patients and families in Arabic as well as activities for children. SAPH also hosted a PH Awareness Day on Dec. 4 for patients and families. This PH Awareness Day was particularly special for PHA because members of the U.S. community also participated. SAPH teleconferenced in Betty Lou Wojciechowski, Michael Ehret and Karen Lindemann, Ellen and Hooper Harris, Angie Eldam, and Trey Scott and his family in the early hours of the morning in the U.S. to share their experiences living with PH with the Saudi audience.

- **In Spain...** Cyclo-cross rider Javier Miguélez has begun a solo initiative to raise funds through the short, multi-terrain bike races for the Fundación Contra la Hipertensión Pulmonar (FCHP) in order to fight PH. He will wear the FCHP logo on his jersey and raise awareness of the foundation and its objectives in all the races he participates in until the end of 2014. Javier has opened a crowdfunding page (www.migranodearena.org/javier-angel-miguelez) and is hoping to raise 1,000 Euros for PH research.

Meanwhile... FCHP hosted its annual gala on Nov. 28. The gala, attended both by members of the PH community and by Spanish celebrities, touched on the past and future progress of ENPATHY, FCHP’s research initiative to find a cure for PH. Representatives from PHA were invited to attend, and PHA was glad to accept the invitation and begin a new chapter of collaboration in the fight against PH.

*Members of the band “Blue Lips” practice for their television debut on Chinese Dreams.*

*Cyclo-cross rider Javier Miguélez (center) during a cyclo-cross competition*
Natasha and Eugene were a young couple. Like others, they made plans for the future, loved each other and were happy. But their lives changed drastically one day when doctors diagnosed Natasha with tuberculosis (TB) — a disease much more prevalent in Russia than in the U.S. After four years of treatment, however, Natasha’s shortness of breath, cough and fatigue were not improving. Eventually in 2006, doctors realized that what Natasha had was not TB, but rather pulmonary hypertension.

Unfortunately, most Russian doctors did not have a lot of knowledge about PH in 2006. The only option was a double-lung transplant, but at that time there had only been one successful procedure, and there were essentially no transplant rehabilitation centers in the country. As a result, Natasha and Eugene decided to try clinics outside Russia. After much searching, they finally found a hospital in France that would undertake the operation, but they could not afford the cost on their own. The couple created a website and tried to collect donations from around the world. After much work raising the money and completing paperwork, the couple made their way to France. Natasha struggled but lost her battle to PH in France on June 2, 2007, and Eugene came back to St. Petersburg.

Eugene stayed strong after losing his wife, and one day he found another PH patient in St. Petersburg. After their meeting, Eugene realized it was time to start the fund he and Natasha had discussed setting up before her passing — the Natasha Charity Fund, to help patients in need of treatment for their PH. Eventually, Eugene decided a web information portal was needed as well to help educate people in the Russian PH community about PH, PH centers in Russia, how to fight for rights as patients, and how to cope emotionally with the disease.

With this decision made, Eugene set in motion what would become an online community of hope in Russia. Eugene recruited a young woman named Yana to create and run the bilingual information portal, which went live online last year. Yana was born with a congenital heart defect that doctors said would heal itself, but it has not.

Yana has lived with PH all her life. As she says, “I don’t know my body in any other condition. I don’t know how to run and not feel breathless. My life is quite calm; I’m trying not to rush. PH is part of me. Part of my life.” Although Yana grew up with little information about her disease and with doctors who did not really know how to treat her, she was still able to finish college and move to the big city. Now she welcomes the chance to save others from the lack of information and isolation she experienced.

Visitors to the information portal can indeed feel inspired and less alone by reading the stories of Russians living with PH in the “Stories” section. Visitors from outside Russia can better understand the realities of living with PH in that country from these personal experiences as well. When you visit the site, you will meet Maria, who was wrongly told to get pregnant to cure her disease, and Darya, who tries to live normally but who can’t access life-saving drugs because the state won’t provide them.

You will also meet Oksana from Belorussia, who grew up living an active life with her heart defect until it suddenly deprived her of “everything [she] loved.” But Oksana fought through it, finished college and got a job, and now has a beautiful family. Then there’s Anna, who became sick in eleventh grade but followed her dreams to become a designer anyway. While Anna cannot have children, she has a fulfilling relationship with her nephew and recently got married. Anna’s goals for the future are “to self-realize in work and creativity.” She says that she believes that with hope and faith, “we can all cope with PH.”

As Yana says, “I think I’ve found my place in this world. I know how it is to live with PH in our country when you think you’re alone, when meds cost half of a good car, when you have to fight for every breath. But I believe there is nothing impossible in the world, [all] you need is HOPE!”

Read the full stories of these inspiring Russian PH patients and explore the English version of the portal that Eugene and Yana created at http://en.ph-sos.com.

By Yana Yakovleva, Information Coordinator, Natasha Charity Fund, and Julia Friederich, PHA International Program Associate
Color PHor a Cure: A PHA Special Event Goes Viral

On Oct. 12, 2013, the Belt family and their team of volunteers in Jennings, La., hosted the first Color PHor a Cure event, a 5K walk/run where participants are doused in color along the route. The event engaged 2,400 participants and raised more than $90,000 for the Robyn Barst Pediatric Research and Mentoring Fund for PH. Josh Belt, father of 3-year-old PH patient Joel, credits much of that success to the media coverage his event received. Josh and his team of volunteers emailed and phoned reporters, asking them to cover the event, and got extra mileage from contacting reporters through social media. PHA talked with Josh about that strategy to give others ideas for successful media outreach of their own:

You had a lot of media success. Let’s hear about it.
Where did your story appear in the news?

I did four television, seven newspaper, four magazine and two radio interviews in the month or two leading up to the Color PHor a Cure event. The last interview we did was with our local ABC affiliate. They filed the report, and it aired on our local channel. Then the local ABC station forwarded it to news stations in other cities. I got lots of Facebook messages from people all over the country after it aired.

You really utilized social media to reach reporters and get your story out. Can you tell us more about that?

I’m pretty social media savvy, so I set up Facebook, Twitter and Instagram accounts in July ahead of our event in October. We had our entire event team — about 15 people — forward these events on their personal Facebook, Twitter and Instagram accounts. At first, we used social media to get friends and family excited about the event. Then we paid for some Facebook advertisements so we could get even more exposure. We got 1,000 likes on our Facebook event page within two or three weeks. Some of our posts got up to 36,000 views.

At the end of August, we “liked” all our local news stations’ Facebook pages, and then we “liked” the individual pages for all the local news anchors and reporters. Three times we had reporters contact us because of something they’d seen us post on social media.

I want to add that we also raised awareness about the event and approached reporters in more traditional ways. At the end of August, we created a press pitch to email to reporters within a 50- to 60-mile radius.

What about that strategy worked?
Is there anything that didn’t work?

I think we blew things out of the park on the social media side. I think social media helped launch and keep momentum for the event. We posted daily on Facebook, Twitter and Instagram. It was so crucial to keep people informed and build excitement about the event.

I got some criticism about some of the news pieces because some of them didn’t talk a lot about pulmonary hypertension. That was intentional. The question became, how do we get people to come to this event and learn about pulmonary hypertension if they don’t have the disease or know someone who has it? We wanted to create an event that everyone wanted to go to. Once they got there, we did everything to explain why we’re doing the event and what PH is. Half the people at our event came because they knew our family and our story. The other half came because the event was amazing.

As far as our social media strategy, everything we posted was hopeful, full of life and fun. Our motto for the race was “Great Race, Greater Cause.” We wanted people to feel like they were a part of something positive that was making a difference. They were! This was the largest 5K race in our city’s history. Now everyone who attended is a part of something bigger.

So publicity is a key to success?

We had people come from 70 cities and four states. There is no way the event would have been anywhere near as successful without social media, our website and our media successes.

To learn more about Color PHor a Cure, visit: http://colorphoracure.com. To check out the Color PHor a Cure Facebook page and see many more photos of the event, visit: www.facebook.com/ColorPHorACure. For help pitching your special event to the media, contact Elisabeth Williams, PHA’s Grassroots Campaigns Manager, at ElisabethW@PHAssociation.org or 301-565-3004 x753.
Sometimes it’s PH Gets Attention in Key Media Outlets

PHA’s Early Diagnosis Campaign: Sometimes it’s PH continues to build momentum, and the term “pulmonary hypertension” is starting to appear in more and more media outlets throughout the country, raising awareness and bringing attention to our shared cause. Check out the buzz we’re creating!

In November 2013, the Washington Post featured 38-year-old Marvin M. Lipman’s PH diagnosis story: “A lifelong nonsmoker, he was a varsity miler in college and had continued running until about two years before, when he began to slow down. Now he noted shortness of breath after walking just a few blocks.”

The High Point Enterprise in North Carolina reported on PH patients Janet Mabe and Diane Ramirez and their Unity Miles event: “Two women walking a combined 135 miles over the course of a month may not seem like an earth-shattering accomplishment. But when you consider the two women suffer from pulmonary hypertension — a rare disease of the lungs and heart that’s characterized by shortness of breath and fainting spells, and which ultimately can lead to heart failure — the accomplishment takes on a whole new light.”

The November issue of Costco Connection, a lifestyle magazine distributed to 8.5 million Costco members, featured PH Awareness Month, explained the disease and pointed readers toward PHA for resources and assistance.

And this is just the beginning as the PH community continues to grow and gain attention in the media. You can see all the Sometimes it’s PH media successes at www.SometimesItsPH.org/MediaCoverage.

Help us continue this momentum! PHA has resources to help you connect with reporters and news outlets in your area. To get started today, visit www.PHAssociation.org/PHAware or contact Elisabeth Williams, PHA’s Grassroots Campaigns Manager, at ElisabethW@PHAssociation.org or 301-565-3004 x753.

PHA Launches Specialty Pharmacy Feedback Initiative

Editor’s Note: Colleen Brunetti, PH patient and PHA Board member, shares her story of frustration with her specialty pharmacy and how her struggles led to the creation of the new Specialty Pharmacy Feedback Form. The following is an excerpt from her blog article. To read the full article, visit www.PHAssociation.org/ColleenBrunettiBlog. To access the form, visit www.PHAssociation.org/SpecialtyPharmacyResponseForm and learn more on page 41 of this issue.

What is this form, and where did it come from? Well, for me, it started back in October 2010. At that time, I was in a deep battle with my specialty pharmacy. They were having serious issues with getting my life-sustaining medication to me as promised. And then there was the pivotal moment I will never forget. At the time, I had to sign for medication delivery. When the meds didn’t show up one day and I had to wait at home again the next day, I missed an event at my son’s preschool. I was livid. …

Then a new mess surfaced. I started a new medication and had an adverse reaction. The way you track an adverse reaction is simple: get the lot number and report it to the manufacturer. But as it turned out, the specialty pharmacy’s distribution protocol at the time was ineffective in that they did not track such things. …

As luck would have it, this was around the time of a PH-related conference in Boston in 2011 where I connected with PHA president Rino Aldrighetti. Rino asked me to track the time I was spending on these issues and write a letter to PHA’s Corporate Committee, a committee made up of representatives from many of the corporations involved with PH care, to express my concerns. …

We have continued to do hard work on this issue in the two years since. I have flown to PHA headquarters twice and, along with others, met directly with leaders from one of the pharmacies. Countless emails and phone calls have gone on. A Specialty Pharmacy Advisory Board has been launched. And now, we want to hear from YOU.

Please use this form to offer feedback to the specialty pharmacies. When you have an issue, report it. When you have a word of praise or an accolade, we want to hear about that, too. Change is best made when we build on strengths. Your comments will be accessed regularly by both PHA and the pharmacies and tracked carefully for trends and areas of ongoing concern. I have worked closely with these people over the last several months. I am confident that those on the ground care a great deal about these issues and are making sure changes are made. And if anything, I want you to remember: PH has dealt us a really lousy hand. But we are never victims unless we allow ourselves to be.
I decided to visit my Member of Congress after watching a video tutorial on PHA’s website that explained how to set up a district visit. I thought to myself, “Hmmm, why not give this a try?”

With my heart beating a little faster (even for a pulmonary hypertension patient!), I put on my “professional clothes,” and I went to visit my congressman — Rep. Dana Rohrabacher (R-CA). I was armed with information about PH and the Pulmonary Hypertension Research and Diagnosis Act (H. 2073, S. 1453). My goal for the meeting was to educate him about PH and persuade him to become a bill co-sponsor.

During our meeting, Rep. Rohrabacher and his health legislative assistant listened and asked questions. At first, he explained that he didn’t want to co-sponsor any health-related bills. But thanks to the advice in the video on PHA’s website, I had earlier looked up Rep. Rohrabacher’s past voting record to see if he’d co-sponsored any PH-focused bills before — he definitely had! I reminded him that he’d co-sponsored the bill in a previous legislative session and asked him to reconsider co-sponsoring the bill. He seemed surprised and requested more information.

I learned several things from my visit. First, I NEVER would have thought that I could do something like visit my Member of Congress to educate him about PH and the PH Research and Diagnosis Act. I’ve never done anything like this before! Second, if you’re interested in meeting with your Members of Congress, research and preparation are critical. PHA’s website is such an excellent source for information and tools to help you advocate for the PH community. I also am so grateful to other PH advocates like Diane Ramirez, who via Facebook learned of my planned visit and contacted me to offer her expertise.

Talking with my congressman won’t end now that the visit is over. I plan on following up. It may take some persistence, but he will become a co-sponsor!

— By Noel Holly, PH Patient

For more information on how to visit your Members of Congress, visit www.PHAssociation.org/DistrictVisit or contact Elisabeth Williams, PHA’s Grassroots Campaigns Manager, at Advocacy@PHAssociation.org or 301-565-3004 x753.

April 2 is National PH Call-In Day: Turn Your Members of Congress into PH Advocates!

If you could ask your senators and representative to do something for the PH community, what would it be? On April 2, urge your Members of Congress to fight for more affordable and accessible treatments, more public awareness and more funding for research.

Getting involved is easy.
Visit www.PHAssociation.org/PHANationalCallInDay

Mark your calendars now: Call Congress April 2!
Despite Government Shutdown, PH Advocacy Advances

Members of PHA’s PH Professional Network (PHPN) and Board of Trustees proved this fall that PH advocacy can’t be shut down. Just days before the U.S. government shutdown in October, 80 members of PHPN sought support for the PH cause from their senators. Nurses and other allied health professionals from 30 states visited 60 senate offices, asking Members of Congress to co-sponsor the Pulmonary Hypertension Research and Diagnosis Act (H.R. 2073/S. 1453). Afterward, one advocate shared her thoughts on the event:

"PHPN Advocacy Day is fun, it’s informative, and it’s important. The first time I came I was petrified. I had no idea what to expect, but I really enjoyed it. I thought we were making a difference for the PH patients, and that was very important to me. This year, I loved the fact that Rep. Lois Capps (D-CA) came to speak with us because she’s a nurse and a representative, and she knows what’s going on. She’s close to PH."

— Sandi Van Horn, MSN, RN, MSHA, three-time participant in PHPN Advocacy Day

I’ve been wanting to meet with Reps. Butterfield and Watt for the past seven or eight years. I’ve met with their health legislative assistants and their District Directors, but I’d never met either one face-to-face. To get them both at that same time was miraculous. It was the highlight of the day. It took me eight years to get them both together, and that’s enough motivation for me to keep advocating for another eight years.

— Diane Ramirez

Many people and causes compete for congressional attention, so the PH community must keep our message out front. It’s important that your senators and representative hear about PH regularly. Get in touch and remind them to take action to fight PH. Visit www.PHAssociation.org/TakeAction or contact Elisabeth Williams, PHA’s Grassroots Campaigns Manager, at ElisabethW@PHAssociation.org or 301-565-3004 x753.

One week later, in the middle of the shutdown, PHA Trustees Colleen Brunetti and Diane Ramirez spent a day on Capitol Hill. The bad news — they got “locked down” in a congressional office due to a security breach on Capitol Hill. The good news — thanks to the shutdown, Members of Congress weren’t as busy as usual. Diane caught Reps. Mel Watt (D-NC) and G.K. Butterfield (D-NC) in the hall for a photo.

Each time you share your story with your Members of Congress or reporters in your area, you put a face to this disease. Learn how to educate Congress and the media about PH. Visit www.PHAssociation.org/EmailSubscriptions and subscribe to one or both of these monthly alerts:

• PHA’s Advocacy Action Alert keeps you up-to-date on what Congress is doing about PH.
• PHA’s Media Action Alert gives you tips and tools you can use to get PH in the news.
PH awareness went global on Nov. 1 as we kicked off Pulmonary Hypertension Awareness Month with PHA’s annual PH Online Awareness Day. This year PHers, family, friends and co-workers took photos of themselves wearing periwinkle/purple and shared them online. Nearly 450 people shared photos, allowing us to reach more than 24,000 people through Facebook alone.

Some PHers went a step further with the idea of wearing their PH awareness. Kim Turner in North Carolina handed out periwinkle ribbons to her friends and family and painted her nails periwinkle, while Tiffany McDaniel Hutchison in South Carolina made periwinkle and zebra-print ribbons (pictured below) for her co-workers to wear. Emelia in Kansas dressed her dog up in a purple cape, and Michelle Dukes in South Carolina painted her face with zebra stripes and blue lips (pictured below).

These awareness-raising ideas are just the beginning. Read on to see all that our PH community accomplished this past November to spread PH awareness far and wide.

New National Advocacy Day Allows Nationwide Participation in Congressional Luncheon

PHA’s Congressional Luncheon took place Nov. 12 in Washington, D.C., and the event encouraged participation across the country. First, PH community members invited their Members of Congress to the Luncheon. Some PHers even made this request in person. Lynn Carey approached Rep. James Sensenbrenner (R-WI) at a town hall meeting, and a patient in Maine stopped by the district office for Sen. Angus King (I-ME) to invite him.

At the Luncheon, Congressional Members, their staff, PH patients, families and medical professionals learned about PH firsthand as patient Joanne Sperando-Schmidt shared her family’s journey with familial PH. Then Dr. John T. Berger from Children’s National Health System in Washington, D.C., provided information about PH and progress in the field. Finally, attendees enjoyed inspiring music from YouTube sensation, singer, songwriter and newly diagnosed pulmonary veno-occlusive disease (PVOD) patient Chloe Temtchine, who is the winner of the 2011 AVON National and International Songwriting Competition.

Following the Luncheon, community members visited the offices of Members of Congress to advocate on behalf of PH patients and encourage their co-sponsorship for the Pulmonary Hypertension Research and Diagnosis Act.

In conjunction with the Congressional Luncheon, PHers participated in our November National Advocacy Day. Across the country, PHers called, emailed and used social media to message their Members of Congress to encourage their support for the PH Research and Diagnosis Act. As a result of these efforts and our in-person lobby visits, our bill has received seven new co-sponsors so far.

Groups Organize Awareness Month Events

For Awareness Month, support groups went the extra mile to reach beyond what they’ve done in the past to make November even more special. This year many support groups turned their November meetings into Awareness Month celebrations with all types of fun activities from a banquet and a raffle to accepting a proclamation from their local government, declaring November PH Awareness Month. The Nashville PH Support Group held its inaugural Roberta Baines Wheeler National PH Awareness Day Conference at Vanderbilt...
University, bringing together nearly 100 patients, caregivers and medical professionals for a day of education.

Support groups and other groups of volunteers from the community also organized special events to raise awareness and funds for the cause. PHA held fundraisers out of our national and chapter offices, including the Inaugural PHA New York City O₂ breathe Gala, honoring the legacy of Dr. Robyn Barst. You can read more about special events on pages 33-37.

**PHers in the Spotlight**

PHers everywhere did amazing things to make Awareness Month special, and we’d like to highlight a few of those community members. Susie Alvarez, a patient and support group leader from the greater Los Angeles area, shared her PH story at work and convinced 15 of her co-workers to sign up through the United Way workplace giving program to give to PHA monthly.

Barbara Wilson Thompson in Tennessee set up a booth at a local craft fair (pictured below), where she raised awareness and funds by selling bracelets she had made, showing PHA’s early diagnosis public service announcement (PSA), and handing out information on pulmonary hypertension.

Colleen Steele, a PH parent in Washington state created a 9.5-minute slideshow video about her son Cullen’s story and shared it far and wide on YouTube and Facebook. Steve Van Wormer, a PH parent in California and PHA Board member, also used audio/video tools to create another podcast in his Empowered by Hope Podcast interview series. He also updated the PSAs he had created in past years with the information about the two new PH treatments approved in October. Check out all his PSAs at www.PHAssociation.org/PSASamples.

**Partnerships Help PHA Reach Untapped Communities**

PHA also reached out to our organizational partners to spread awareness to their communities impacted by this disease. The Scleroderma Foundation posted PH messages weekly in its e-newsletter, Facebook and Twitter. The COPD Foundation shared our COPD & PH webinar, honoring the fact that November was also COPD Awareness Month, and the American Thoracic Society held a PH Awareness Week.

Our partners across the globe got involved as well with awareness day events and other awareness campaigns. You can read more about international happenings on page 22.

These are just a few of the ways that the PH community used their creativity and gumption to reach beyond our numbers to raise PH awareness this November. You can read more Awareness Month stories online at www.PHAssociation.org/AwarenessMonth/News. Have a story to share? Contact Diane Greenhalgh, PHA’s Director of Web Services, at DianeG@PHAssociation.org or 301-565-3004 x759. ✉️

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**By Diane Greenhalgh, PHA Director, Web Services**

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**PHA Extends a Huge Thank You to Our 2013 Awareness Month Sponsors**

**Platinum Level**

Actelion Pharmaceuticals US, Inc.

**Bronze Level**

Gilead Sciences, Inc.

United Therapeutics Corporation

**General Sponsor**

Lung LLC

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Barbara Wilson Thompson stands beside her zebra-fied craft fair booth.

A participant crosses the finish line at the 7th Annual North Texas Zebra PHriends 5K and 1M PHun Walk.

Orlando Health Heart Institute colored their office purple for PH Online Awareness Day.
There’s No Support Group in Town: Now What?

- Is your nearest pulmonary hypertension support group more than an hour drive from your home?
- Do you want to find other patients but don’t know where to look?

If you answered “yes” to either of the above questions, you and your town could probably benefit from a pulmonary hypertension support group. But why isn’t there a group? Have you considered starting a group, but hesitated? You’re not alone. PHA spoke to leaders who have been in your shoes and were nervous about bringing a group to their town. They shared their main obstacles to starting a group along with solutions to the problems.

**Challenge: Finding Patients**

**Concern:** “The biggest obstacle that I still have to date is finding the PHers [PH patients]. We don’t have a PH clinic here in Memphis, so the PHers who are here see doctors who don’t always promote support groups or may have issues around HIPAA laws,” says Barbara Thompson, leader of the Mid-South Tennessee PH Support Group.

**Advice:** “My first PH support group was in Stamford, Conn., where we had moved after I was diagnosed. My husband and I went around to doctors’ offices (besides my own primary care physician) and hospitals in Stamford and Norwalk, placing our flyer on the bulletin boards. We announced the meeting in the newspaper’s community events pages. Eventually, we had six patients and their caregivers attend the meeting. I was thrilled and felt very fulfilled. It was a grand and successful first meeting!” says Neeta Pai, current leader of the Rochester, Minn., PH Support Group, and former leader of the Stamford, Conn., PH Support Group.

**Challenge: Overcoming a Fear of Public Speaking**

**Concern:** “I was so nervous that I had to get up in front of everyone. I worked for weeks to list the things I wanted to talk about and the order I wanted to say them. But once I started to speak, it was a piece of cake. These PHers had the same concerns I did. They had questions about things I had already dealt with,” says Deloris Peacy, leader of the Arkansas PH Support Group.

**Advice:** “To the shy leaders: try sitting in a circle or around a table so it is more like home and less formal. I have found this puts people at ease and encourages more conversation. You can also get others to do announcements or read information. As a leader, you should be encouraging the entire group to share, so go around the table and ask, ‘How has your month been going? What’s happening in your life?’” says Colleen Makovicz, leader of the DelVal, Pa., PH Support Group.

**Challenge: Living in a Rural Community**

**Concern:** “Our biggest concern is finding people! We’re so rural up here. So looking forward to seeing how this all works out for us!” says Sharon Horning, co-leader of the Sarah Peek PH Support Group of Northern New York.

**Advice:** “I always say that we are small, but mighty! Even if it starts with two or three [patients], you are stronger together! You will be great!” says Lori Funk, leader of the Syracuse, N.Y., PH Support Group.

**Challenge: Feeling Like You Lack PH Medical Expertise**

**Concern:** “I wanted to start a group from the first time I went to a meeting, which was three months after diagnosis. I was afraid I didn’t have enough time with the disease and enough knowledge about PH, so I waited. Three and a half years into PH, I still don’t feel like I know enough, but extensive knowledge isn’t required!” says Tiffany Gunderman, leader of the Long Beach, Calif., PH Support Group.

**Advice:** “You don’t have to be an expert to lead a group and facilitate conversation. You are the expert of your own story with PH, and you can always refer members to other medical resources. Also, PHA can help you with the right amount of background, knowledge and tips for referring people to other resources. We provide a Support Group Manual and orientation to help you get started. Just call us!” says Debbie Castro, PHA’s Senior Director of Volunteer Services.

**By Debbie Castro, PHA Senior Director, Volunteer Services**

**START A GROUP AND GET ADDITIONAL SUPPORT AT CONFERENCE:** If you’re interested in starting a support group in your town, PHA can help! If you plan on attending PHA’s International PH Conference and Scientific Sessions this June in Indianapolis, you’ll be invited to take advantage of special, leader-only networking meetings and trainings. Contact Debbie Castro to get started: 301-565-3004 x755 or SupportGroups@PHAssociation.org.
In early 2013, PHA’s New York Tri-State Area Chapter launched, serving the New York metropolitan region (parts of New York, New Jersey and Connecticut). With dedication from the leaders of more than 20 local PH support groups, the chapter has initiated several dynamic fundraising campaigns.

The O2 breathe campaigns, which include walks, a golf challenge and a gala, brought hundreds from the PH and medical communities together in 2013 to help raise funds to support PHA’s mission. Read about the chapter’s inaugural gala in honor and memory of Dr. Robyn Barst on page 35.

This past June, New Jersey support group leaders, Melanie Kozak and Tara Suplicki, and community member, Christina Lapatka, helped generate more than $20,000 from their third annual Power for PH — PHun Walk for a Cure.

On Long Island, support group leaders Joanne Schmidt, Linda Sullivan and Mary Bartlett were instrumental in recruiting the most participants yet at their 9th annual Long Island Fun Walk on Oct. 12, 2013. More than 450 participants reunited in Lindenhurst and raised more than $50,000. Read more on page 32.

Because of the contributions and participation of support group leaders in the New York metropolitan area, PHA is able to continue providing programs and services to patients, their families, caregivers, physicians and allied health professionals.

Fundraising, while necessary, isn’t always an easy task — which is why uniting PHA’s professional fundraisers with enthusiastic support group leaders and members is the best way to reach our common goal to prevent and cure pulmonary hypertension. If you are in the New York Tri-State area and would like to participate in upcoming fundraising events, please visit www.NY-PHA.org or call 646-568-2068.

By Im Senephimmachack, PHA Development Director, New York Tri-State Area Chapter
Long Island PH Support Group Hosts 9th Annual Walk for PH

Saturday, Oct. 12 was a beautiful autumn day in Lindenhurst, N.Y. — perfect weather for hosting our 9th annual Long Island Fun Walk for PH. The Long Island Support Group, now with a section in two counties, and with assistance from the PHA New York Tri-State Area Chapter, welcomed more than 450 attendees for a day of family fun, a celebration of our patients and angels, and a tribute to the late Dr. Robyn Barst.

This year we highlighted the story of one PH warrior (someone currently living with PH) and one PH angel (someone we have lost to PH). Their stories are so inspiring and link our whole community together in the common bond of dealing with this illness. We also honored the memory of someone very special to so many of us in the New York area, Dr. Barst. Dr. Barst cared for many members of our support group.

Over the years, we have been so very fortunate to have the help of Tau Kappa Epsilon (TKE) fraternity. Members of TKE have attended the Long Island walk for years, volunteering their time and energy and doing any job we ask of them. But this year, TKE took that generosity to new heights. Unbeknownst to us, TKE chapters at 10 campuses held PH awareness events. They gave out information about PH and collected donations. We knew something was brewing when 100 TKE members showed up on walk day. Way to represent, TKE!

As usual, these wonderful young men went to work right away, directing traffic and parking and guiding attendees to the entrance. As walkers circled the track, TKE cheered them on and handed out water. After the walk concluded, everyone piled inside for our program. Rob Guarini, the Grand Province Advisor of Long Island TKE and a close friend of PH patient and Support Group Co-leader Linda Sullivan, took the stage to share with everyone what the men of TKE had done in honor of the PH community. They presented us with a giant check for $1,000, collected at the 10 campuses. We were completely amazed by their generosity.

TKE also donated their services to our auction, and one lucky auction winner claimed the prize of TKE members’ labor for whatever project the winner chose. Many tickets went into that basket! These young men exemplify the principle of service to the community, and we are grateful.

In addition to TKE’s raffle item, our ever-popular and ever-growing auction included more than 100 lots of donated items. We extend a special thank you to everyone who worked so hard to get auction donations and to everyone who coordinated and created the beautiful baskets. The auction generated close to $9,000, a number that seems to go up each year.

At this year’s walk, we also highlighted organ donation, a topic that is so very important and that doesn’t get the attention it should. The family of one of our members set up a table with organ donation materials and encouraged walk attendees to discuss this topic now and make their wishes known.

Our families and friends continue to participate enthusiastically, and this year several of our young friends created colorful rubber band bracelets (many in PH periwinkle!) and raised $160. Another family of a PH patient worked all year knitting scarves, headbands, dolls and blankets to sell at the walk, and they also received donations from their knitting circle.

At the walk, we were very happy to talk about the two new drugs that have been approved for PHers as well as the exciting discovery of the KCNK3 mutation at Columbia University. We are seeing progress, and it gives us hope. We have power when we come together in this fight. That’s the reason why we will continue to hold events, raise money and fund PH research to the best of our ability. We do it for hope — hope for better treatments, hope for longer survival and hope for a cure. It’s within our power to fuel the progress we’re seeing. To our family and friends who come out each year to support us, we thank you from the bottom of our hearts.

If any of you as Pathlight readers have an interest in hosting a walk or other special event, I encourage you to contact Leslie Mahaney, PHA’s Senior Manager of Special Events, at LeslieM@PHAssociation.org or 301-565-3004 x742. All of us have the power to make a difference.

By Joanne Sperando-Schmidt, PH Patient and Long Island PH Support Group Co-Leader
Special Events: Walking, Golfing, Dancing and Moving for a Cure

Get Short of Breath for PH … Let’s Kick Some AsPHalt 5K Run/Walk: On Nov. 16, more than 150 people braved the chilly weather in Cedar Rapids, Iowa, to run and walk for PH. Spearheaded by PH Support Group Leader Ginger Kahler, pictured left with her two sisters, this inaugural event featured guest speaker, Traci Stewart, RN, MSN, CHFN.

7th Biennial Rochester “Reach for the Stars” PHA Gala: Hosted by Dr. Michael McGoon and his wife Bonnie, this biennial gala charmed 325 attendees and raised $228K for PHA’s patient programs, critical research and the Robyn Barst Pediatric Research and Mentoring Fund for PH. The evening included live entertainment and the raffle of a Mercedes C-Class lease.

Puttin’ PHore Poots: The Warnberg family held an invitational scramble golf tournament on Sept. 28 in Edina, Minn. Held in honor of their daughter Chelsea (“Poots”), pictured far right, this event included 45 golfers and 80 attendees at the Happy Hour and Awards Ceremony, raising more than $3,500 for PH research and patient and family serving programs.

2013 JFK Tower Golf Tournament: Last year 116 golfers gathered in White Plains, N.Y., for the JFK Tower Golf Tournament. The day included brunch, 18 holes of golf and a dinner banquet with more than 145 attendees. Deborah and Steve Abraham created this annual event to help their daughter, Rachel, battle PH and to provide the community with a way to support a great cause.

2nd Annual Fresno 6MM/BBQ: On Oct. 19, PH patients, families and community members came out to walk for the cure in Fresno, Calif. Check out the cool T-shirts! Do you see a zebra anywhere?

PHA San Francisco Bay Area Chapter’s O2 breathe ‘Swim for a Cure’: Dr. Jeffrey Sager, Director of the Cottage PH Center, and SteadyMed Therapeutics CEO Jonathan Rigby raced in an open water, 1.2-mile swim on Sept. 29 in San Francisco Bay’s chilly 55-degree water. The PH community turned out to cheer them on.
### PHA Upcoming Special Events

<table>
<thead>
<tr>
<th>Date</th>
<th>Event Description</th>
<th>Location</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Friday, March 7, 2014</strong></td>
<td>Chicago PH Dinner &amp; Auction ◆</td>
<td>Schaumburg, Ill.</td>
<td><a href="http://www.Midwest-PHA.org">www.Midwest-PHA.org</a> or 855-ZEBRA-55 (855-932-7255)</td>
</tr>
<tr>
<td><strong>Friday, March 28, 2014</strong></td>
<td>Trivia Night ◆</td>
<td>St. Louis, Mo.</td>
<td>Amanda McKee at 314-831-4520 or <a href="http://www.Midwest-PHA.org/TriviaNight">www.Midwest-PHA.org/TriviaNight</a></td>
</tr>
<tr>
<td><strong>Saturday, March 29, 2014</strong></td>
<td>The Woodlands CrawPHish Festival</td>
<td>Town Green Park along the Woodlands Waterway, Texas</td>
<td><a href="http://www.woodlandscrawfish.com">www.woodlandscrawfish.com</a></td>
</tr>
<tr>
<td><strong>Saturday, April 5, 2014</strong></td>
<td>Sacramento Unity Miles Walk (pending) ◆</td>
<td>Sacramento, Calif.</td>
<td>Lisa Brundage O’Connell at <a href="mailto:LisaOConnell@SF-PHA.org">LisaOConnell@SF-PHA.org</a></td>
</tr>
<tr>
<td><strong>Saturday, April 12, 2014</strong></td>
<td>Walk 2 Cure PH: The Ellie Godina Memorial Walk</td>
<td>Euclid, Ohio</td>
<td>Missy Godina at <a href="mailto:melissagodina@sbcglobal.net">melissagodina@sbcglobal.net</a> or 216-261-0334</td>
</tr>
<tr>
<td><strong>Saturday, April 12, 2014</strong></td>
<td>Spur a Cure for PH</td>
<td>Phoenix, Ariz.</td>
<td>Trish Duque at <a href="mailto:trish.duque@gmail.com">trish.duque@gmail.com</a> or Amy Moseley at <a href="mailto:atmoseley@cox.net">atmoseley@cox.net</a></td>
</tr>
<tr>
<td><strong>Saturday, April 12, 2014</strong></td>
<td>The PHenomenal Mile (see announcement on page 21 of this issue of Pathlight)</td>
<td>Everywhere</td>
<td><a href="http://www.PHAssociation.org/PHenomenalMile">www.PHAssociation.org/PHenomenalMile</a> or Roni Rivera at <a href="mailto:RoniR@PHAssociation.org">RoniR@PHAssociation.org</a> or 301-565-3004 x765</td>
</tr>
<tr>
<td><strong>Saturday, April 19, 2014</strong></td>
<td>6th Annual Scramble for a Cure</td>
<td>Las Vegas, Nev.</td>
<td>Jack Nino at <a href="mailto:Jack.Nino@igt.com">Jack.Nino@igt.com</a> or 702-250-2214</td>
</tr>
<tr>
<td><strong>Saturday, April 26, 2014</strong></td>
<td>O₂ breathe Fleet Feet Fun Run for PH (pending) ◆</td>
<td>Santa Rosa, Calif.</td>
<td>Lisa Brundage O’Connell at <a href="mailto:LisaOConnell@SF-PHA.org">LisaOConnell@SF-PHA.org</a></td>
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</tbody>
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For complete and up-to-date special event information and listings, please visit PHA’s online calendar at www.PHAssociation.org/Calendar
O₂ breathe Gala Honors Dr. Robyn Barst’s Legacy

The Inaugural PHA New York City O₂ breathe Gala, honoring the legacy of Dr. Robyn Barst, took place on Nov. 7, 2013, at the Lighthouse at Pier 61. The evening paid tribute to Dr. Barst’s contributions to the fight against PH in three ways: through reflections from her patients, colleagues and husband; through performances from two female PH patients who celebrated the hope and progress Dr. Barst’s efforts created; and through raising funds to continue the research that will bring us to her goal of curing PH. Enjoy the photos below of the event. All photos courtesy of Serio Gonzales, Jr., unless otherwise noted.

Carl Hicks, PHA Executive Vice President, reflects on Dr. Barst’s passion for the fight against PH and her care for his daughter who had PH.

Chloe Temtchine performs her song “Be Brave,” a song that was inspired by her diagnosis of pulmonary veno-occlusive disease (PVOD), which causes PH.

Chloe Temtchine introduces her oxygen tank, which she has named Steve Martin. Steve wore a tie for the event.

Craig Melvin, MSNBC anchor and NBC News correspondent, served as Master of Ceremonies. He is pictured with PHA N.Y. Chapter Executive Director Gina Parziale (center) and President Rino Aldrighetti (right). Photo courtesy Ann Rice.

Emily Stibbs reflects on her memories as a pediatric patient of Dr. Barst. She remembers the compassionate care Dr. Barst provided to her young patients.

Joanne Sperando-Schmidt shares how Dr. Barst’s care and expertise helped her and her brother, who both have PH.

PH patient Jennifer Lombardi (right) performs a salsa dance.

Samuel Barst, MD, Dr. Robyn Barst’s widower, shares the personal side of his wife through photos and stories. He attended the event with daughters Nomi and Lindsey.

Dr. Erika Berman-Rosenzweig shares her experience working with Dr. Barst and elaborates on the impact Dr. Barst had on the PH field.
PHA Chapter Happenings: Midwest

PHA Midwest Chapter Marks Its First Anniversary and Looks Toward a Bright New Year

The Midwest Chapter proudly celebrates its first year as a part of the PH community and looks forward to 2014 and beyond with hope and enthusiasm. We are proud to serve this vibrant community as the PHA headquarters’ “boots on the ground” in the Midwest region, spreading PH awareness and helping to fund the vital patient and family services that PHA provides. We’d like to share a few highlights from our first year and give you a sneak peek of what’s to come in 2014.

Over the summer, the PHA Midwest Chapter and friends celebrated our inaugural year through music, hosting fundraising events at concerts with the musicians Sting and Brian Wilson of the Beach Boys. These special concerts provided an opportunity to support PHA while also enjoying the sights and sounds of our vibrant area.

We also hosted a number of walks in 2013. The first walk took place in Wisconsin in June, raising both PH awareness and funds for the cause. At our O2 breathe Walk in Chicago (Palatine, Ill.) in September, we welcomed more than 100 walkers to our cause. And for those who wanted more of a challenge, PHA was well represented this fall at the following events: the 2nd Annual Take a Breath for PH Half Marathon in Michigan; the Naperville, Ill., Half Marathon; and the Chicago Marathon.

We’ve also been spreading awareness through sharing the image of blue lips throughout the area. As you can see in our photos below, we’ve been busy, and we have plenty of enthusiasm to share with others about the PH cause!

As we look ahead, we’re excited to give you a glimpse of just a few of our upcoming opportunities for getting involved in spreading awareness and supporting PHA. We’ve got the Chicago PH Dinner & Auction coming up on Friday, March 7, in Schaumburg, Ill. We’re also really excited about the St. Louis Area Trivia Night on Friday, March 28, in Maryland Heights, Mo. A little later in the spring we will be moving our feet in the Annual Stride for a Cure 5K Run & Walk on May 5, in the Chicago Botanic Gardens in Glencoe, Ill. More information about these events and registration is available on the PHA Midwest Chapter website at www.Midwest-PHA.org.

If you are in our area, we welcome your support and involvement. Contact us through our website or by calling our chapter office at 855-ZEBRA-55 (855-932-7255). Thanks for your support in 2013, and we look forward to great things throughout 2014!

By Geoff Gephart
PHA Executive Director, Midwest Chapter

*Images left to right: Anthony Platek runs the Chicago Marathon in memory of his mother, who lost her battle with PH in the spring of 2013. Anthony dons blue lips as he helps our chapter spread PH awareness. PH community supporters celebrate an “Evening of Wine-ing” at our Midwest spin class in November. We shared these Blue Lips Lollipops with the local community to help draw attention to the breathlessness that PH patients experience.*
Adults living with pulmonary hypertension often develop a unique perspective regarding the onset of their illness, the quality of their lives, and their hopes and dreams for the future. Kids living with PH develop unique perspectives as well, and that is why 11-year-old Lucas Van Wormer, son of PHA Board member Steve Van Wormer, was invited to deliver keynote remarks at PHA’s San Francisco Chapter’s inaugural Empowered by Hope Gala this past November.

Lucas and fellow PH patient 8-year-old Maddie Bonpin (featured below) represent hundreds of California infants, children, adolescents and young adults who now benefit from an expanding network of highly skilled pulmonologists and cardiologists trained in the early diagnosis and treatment of pediatric PH.

Whereas in prior years these specialists might have elected to affiliate with well-established pediatric programs in the Bay Area or Greater Los Angeles, or perhaps with developing programs in Sacramento and San Diego, a new breed of practitioners is making its way into hospitals along the Central Coast, in the Central Valley, and deep into the Inland Empire east of Los Angeles and Orange counties.

The work done at these pediatric PH centers and by individual practitioners up and down the state is impressive; each program is worthy of recognition and each of the clinicians practicing in outlying communities is deserving of commendation.

As we look ahead, we see a bright future on the horizon for San Francisco’s PH community and our greater global community. The Robyn Barst Pediatric Research and Mentoring Fund for PH, having already surpassed the initial fundraising goal of one million dollars, is poised to establish mentoring programs for promising pediatric researchers and practitioners across the country. At the same time, the implementation of PHA’s chapter fundraising model builds upon the concept of self-sufficiency, helping PHA to grow stronger and move toward our ultimate goal — a cure.

The San Francisco Bay Area Chapter welcomes the opportunity to contribute to the fulfillment of these entirely achievable goals throughout the golden state of California, extending the concept of “Empowered by hope” to include the additional imperative of “Inspired toward action.” If you are in the San Francisco Bay area and would like to join us in our efforts, we’d love to hear from you. Visit our website at www.SF-PHA.org or call 415-529-5707 to get involved today.

Meet Pediatric PH Patients Maddie and Lucas and Learn about Their Care

Madeleine “Maddie” Bonpin was born with a hole in her right-side diaphragm. At only two weeks of age, Maddie underwent successful hernia surgery at the University of California San Francisco (UCSF) Benioff Children’s Hospital. “This is how our family’s journey with PH began,” says Maddie’s mother Liza (pictured at right with Maddie and their family). “Now, eight years later, Maddie is an active and energetic third grader under the care of a truly remarkable team of doctors.” Among that team is Dr. Jeff Fineman, pediatric critical care specialist at Benioff, and pediatric nurse practitioner Emma Olson. Liza adds, “We’re so lucky and blessed to have landed at UCSF! Maddie’s doctors collaborate on her treatment plan, which has allowed her to live her life to the fullest. It also has allowed us to share this incredible journey with her.”

Lucas Van Wormer was diagnosed with PH while still in pre-school. Lucas admits, “When I first heard that I had PH … I was worried and nervous. I did not know what PH was or what it meant.” After waking up one night to severe chest pain, a pain he had never felt before, he told his parents Steve and Marina that “my heart hurts.” Taken by ambulance from one Los Angeles hospital to another, Lucas ultimately arrived at the University of California Los Angeles (UCLA) where he began receiving the medical care he so desperately needed. Seven years later, Lucas is thriving under the care of Dr. Juan Alejos. Marina, Lucas’s mother (pictured above with Lucas), says, “We consider ourselves the luckiest family in the world because of the care our son receives at the UCLA PH Clinic. Dr. Alejos has been on the cutting edge of PH pediatric patient care. His approach to treatment and his relaxed manner have helped Lucas continue to live a wonderful life and as normal a life as possible with PH.” Read more about Lucas on page 43.
this year, from the debut of two new drugs to the introduction of a PH-specific bill in Congress and everything in between; we continue to persevere, not once taking our foot off the gas.

In just a few short months, our collective energy will come together and multiply at the biggest event our community has ever seen. Check out the registration brochure attached to this Pathlight to see what we have planned in Indianapolis, and look throughout this issue for tips to prepare. Planning your trip? Check out our travel tips on page 17. Newly diagnosed? Look below for information on how to apply for a Conference scholarship. Are you a support group leader? Conference has special offerings for you. See page 30. Unable to attend Conference? You can still contribute by nominating an Outstanding Member! Learn more on page 39.

Kristine Green, a 2012 Conference attendee, describes the vitality of the event and the PH community. “Everyone truly embraced the opportunity to interact, learn and share,” Kristine says. “PHA has created a community of patients, caregivers, researchers and physicians dedicated to helping each other and making advances to finding a cure.”

As PHA moves toward the horizon of an exciting future, what better time or place to gather than the crossroads of America? See you in Indianapolis! We’ll race you there.

By Rebecca Gifford, PHA Meeting Planning Associate

Want to Attend Conference? You May Be Eligible for a Scholarship

At the 2012 International PH Conference and Scientific Sessions in Orlando, Fla., 279 PH community members attended as the recipients of a Conference scholarship. For PHA’s 2014 Conference, PHA is providing this financial assistance once again to those who otherwise would not be able to afford the trip to this life-changing event. Applications are available online at www.PHAssociation.org/Conference/Scholarships. To request a paper application, please contact 301-565-3004 x763 or Scholarships@PHAssociation.org.

You are eligible to apply for a scholarship if:

- You are a PH patient.
- You are a caregiver of a pediatric PH patient.
- You are a PHA member in good standing. To check your membership status, call 301-565-3004 x756 or email Membership@PHAssociation.org.
- You did not attend the 2012 Conference on a full scholarship.
- You are currently a support group leader and/or a Support Line volunteer. You are eligible even if you attended the 2012 Conference on a full scholarship.
- You are a confirmed speaker or panel discussion leader at the 2014 Conference. You are eligible even if you attended the 2012 Conference on a full scholarship.

If you have questions about your eligibility or the Conference scholarship application process, contact Danielle Clifford, PHA’s Meeting Planning Associate, at 301-565-3004 x763 or Scholarships@PHAssociation.org.

PHA is able to provide this financial assistance thanks to the ongoing generous support we receive to the Conference Scholarship Fund. To see a list of supporters, visit www.PHAssociation.org/Conference/Scholarships/Contributors. To donate to the Conference Scholarship Fund, visit www.PHAssociation.org/Conference/Scholarships/Donate. Your assistance could help bring a PHriend to Indianapolis in June 2014.

Availability of scholarships is dependent solely on the funds raised for this program. The Conference Scholarship Committee regrets that it may not be able to fund all worthy requests.
Know Amazing PH Patients, Caregivers or Medical Professionals? Nominate Them for PHA Outstanding Member Awards

At every International PH Conference and Scientific Sessions, PHA recognizes the unique contributions of select individuals in the PH community through the PHA Outstanding Member Awards. PHA is currently accepting nominations in the following categories:

**Outstanding Allied Health Professional**

This award is given to an allied health professional (nurse, physician assistant, technician, therapist, etc.) who contributes to the PH community through any combination of the following: raising awareness, participation in advocacy efforts, fundraising, service to PHA, and providing kind and compassionate care to PH patients. The 2012 recipient of this award was Mary Bartlett, NP.

**Outstanding Caregiver**

This award is given to a non-patient caregiver who focuses his or her efforts on the needs of a loved one with PH and who exemplifies dedication to the PH community through any combination of the following: raising awareness, participation in advocacy efforts, fundraising, service to PHA, and helping to provide the public with a voice and face of the PH community. The 2012 recipient of this award was Jennifer Davis.

**Outstanding PH Citizen**

This award is given to a PH patient who exemplifies dedication to the PH community through any combination of the following: raising awareness, participation in advocacy efforts, fundraising, service to PHA, and helping to provide the public with a voice and face of the PH community. The 2012 recipient of this award was Jeannette Morrill.

**Outstanding Support Group Leader**

This award is given to a support group leader who provides a welcoming environment for patients, families and friends of PH patients; champions and serves PHA by leading local efforts to raise awareness; leads and participates in advocacy efforts and acts as a PH ambassador to the general public. The 2012 recipient of this award was Nicole Cooper.

**Outstanding Young PH Citizen**

This award is given to a PH patient under age 30 who exemplifies dedication to the PH community through any combination of the following: raising awareness, participation in advocacy efforts, fundraising, service to PHA, and helping to provide the public with a voice and face of the PH community. The 2012 recipient of this award was Sean Wyman.

**Julie Hendry Memorial Scholarship Award (non-patient volunteer)**

In memory of Julie Paton Hendry, daughter of PHA founding members Pat and Jerry Paton and PHA’s first full-time non-patient volunteer, the Julie Hendry Memorial Scholarship Award was established to help a non-patient volunteer attend Conference. This award is given to a PHA member who actively supports PHA (e.g., working with support groups, raising awareness or fundraising). The award, up to $1,000, is to be used for Conference registration and transportation. This award is self-nominated, and applicants can be extended family, friends and supporters who help to further PHA’s mission. Professionals employed in the care of PH patients are not eligible to apply. The 2012 recipient of this award was Jaclyn Burdick.

**Outstanding Physician**

This award recognizes an outstanding physician who has been most notable in his or her service to PHA and in promoting excellent clinical care, research, education and advocacy on behalf of PH patients. The 2012 recipient of this award was Raymond Benza, MD.

The nomination period closes March 4, 2014.

For more information on the PHA Outstanding Member Awards, or to nominate someone, please visit www.PHAssociation.org/Conference/Awards or call 301-565-3004 x764.
Visit PHA’s online education resources to get the latest PH information. All you need is an Internet connection, and you can participate from anywhere.

**Highlighted Recordings**

- “Chronic Obstructive Pulmonary Disease and PH” led by Sonja Bartolome, MD
- “Surviving Survivor’s Guilt” led by Maribeth Duncan, ANP-BC
- “Chronic Thromboembolic Pulmonary Hypertension: What You Need to Know” led by Richard Channick, MD, and Amanda Harvey-McKee, patient
- “Exercise-Induced Pulmonary Hypertension” led by Abraham Babu, BPT, MPT, PhD

To view these recordings and see what’s next, visit [www.PHAssociation.org/Classroom](http://www.PHAssociation.org/Classroom).  

**PHA Online University** is PHA’s premier educational site for medical professionals. Learn more about PH with course offerings, PHA’s quarterly medical journal (*Advances in Pulmonary Hypertension*) and webinars.

**Highlighted Recordings**

- “ABC’s of Teaching Adult Patients” (Course ID: 2315) led by Jennifer Priziola, PharmD, BCPS, and Jessica Brewer, MSN, RN — *Nursing, Pharmacy, Respiratory Therapy, and Social Worker* credits available
- “The Nursing Role in Managing and Providing on IV Prostanoid Therapy” (Course ID: 2271) led by Natalie Kitterman, BSN, RN, CCRP
- “Pediatric Pulmonary Hypertension” (Course ID: 2320) led by Michelle Cash, MSN, RN, APRN

Learn more about our upcoming webinars at [www.PHAOnlineUniv.org/UpcomingWebinars](http://www.PHAOnlineUniv.org/UpcomingWebinars).

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**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 continuing 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](http://www.PHAssociation.org/BME)

**Upcoming BME events:**

**CTEPH: State of the Art 2014**  
A Multidisciplinary Symposium  
Feb. 28 - March 1, 2014  
Estancia La Jolla Hotel  
La Jolla, Calif.

**The Alfred P. Fishman Symposium: New Treatment Approaches to Pulmonary Hypertension**  
April 26, 2014  
Sonesta Hotel Philadelphia  

To view a full list of educational opportunities for medical professionals, visit: [www.PHAOnlineUniv.org/Calendar](http://www.PHAOnlineUniv.org/Calendar)
If you’ve resolved to be a more informed insurance consumer in 2014, PHA can help. Here are five resources to help you better understand and resolve common insurance challenges.

1. **Know Who to Ask:** PHA and the Caring Voice Coalition (CVC) work together to help PHers address their insurance challenges.
   - PHA offers general insurance information at [www.PHAssociation.org/Insurance](http://www.PHAssociation.org/Insurance) or 301-565-3004 x753.
   - The CVC team can help you with everything from selecting the Medicare plan that’s right for you to applying for Social Security Disability Insurance: [www.CaringVoice.org](http://www.CaringVoice.org) or 888-267-1440.

2. **Know Your Rights:** The Affordable Care Act (sometimes referred to as ObamaCare) prohibits insurers from refusing to give you coverage even if you have a pre-existing condition. It also prohibits annual and lifetime caps in new insurance coverage and waiting periods of greater than 90 days before private insurance coverage begins. To learn more,


3. **Use Your Coverage:** Learn more about filing a claim or appealing an unfavorable insurance decision at [www.PHAssociation.org/Patients/Insurance/FileClaim](http://www.PHAssociation.org/Patients/Insurance/FileClaim).

4. **Stay Informed:** PHA’s Coverage Connection blog provides regular updates on insurance news of interest to the PH community. Visit [www.PHAssociation.org/Insurance/CoverageConnection](http://www.PHAssociation.org/Insurance/CoverageConnection).

5. **Get Inspired, Get Involved:** Read insurance success stories from the PH community, or share your own insurance advice. Visit [www.PHAssociation.org/Patients/Insurance/Victories](http://www.PHAssociation.org/Patients/Insurance/Victories) or call 301-565-3004 x773.

By Katie Kroner, PHA Director, Advocacy & Awareness

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**Treatment Delays? PHA Can Help.**

Are you facing treatment delays that originate with a specialty pharmacy?
Do you have an outstanding specialty pharmacy relationship that you wish others in the field would replicate?

PHA’s Specialty Pharmacy Advisory Board is dedicated to gathering feedback about how well specialty pharmacies are serving PH patients and using that feedback to promote improved service.

Submit your comment at [www.PHAssociation.org/SpecialtyPharmacyResponseForm](http://www.PHAssociation.org/SpecialtyPharmacyResponseForm)

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**It’s Not Too Late to Support PHA’s End of Year Campaign!**

A new year has started, but there’s still time to make your impact on PHA’s End of Year Campaign. The passion and generosity of supporters like you enable us to continue the important work of serving the PHA community through support, education, research, advocacy and awareness and so much more. To see the ways your donation makes our work possible, view our Catalogue of Hope and make your gift today!


If you’ve already given to the End of Year Campaign, please accept our gratitude and know that your gift is working hard to make life better for the entire PHA family.
Dr. Michael McGoon doesn’t have PH. His vision is a world where no one else does, either.

Michael McGoon, MD, a PH-treating physician and member of PHA’s Scientific Leadership Council and Board of Trustees, has been inspired by PHA’s work and the stories of its members. “PHA is a unique organization,” Mike says. “From a medical perspective, it’s amazing to see a group of patients, caregivers, researchers, physicians and allied health professionals all working toward a common goal.” His wife, Bonnie, has been just as involved.

To read how Mike and Bonnie continue to devote their efforts to defeating PH, visit www.PHASassociation.org/Give/McGoon.

Like the McGoon family, you can strike a blow against PH by designating PHA as a legacy beneficiary. Your contribution will help shape a brighter future for all those affected by PH. For details, call us at 301-565-3004 x767, or email Giving@PHAssociation.org. Visit our website for more information at www.PHASassociation.org/Give.
PHENOMENAL YOUTH

INTERVIEW WITH PH PATIENT LUCAS VAN WORMER AND HIS DAD STEVE


How old are you? Lucas: I’m 11 years old and in the 6th grade.

When were you diagnosed with PH?
Lucas: I was 4 years old.

What are your favorite activities and hobbies?
Lucas: I like reading and drawing.

What different things have you and your family done to raise awareness of PH?
Lucas: I was the keynote speaker at the PHA San Francisco Chapter’s fundraiser in November. I was excited because it was something I had never done before, but I was also nervous. When I got to San Francisco, I was excited to see the Golden Gate Bridge.

I’m also the child ambassador for the annual Taylor’s Wish 5K. The 5K has been my favorite event, and lots of people come.

Lucas’s dad, Steve: We’ve created several PSAs (public service announcements) on pediatric pulmonary hypertension research. We engage the general public as well as the PH community to work together for that greater good. We are also working to create a series of animated cartoons geared toward PH.

Why do you and your family think it’s important to raise PH awareness?
Lucas: To raise money and make new medicines and try to cure PH. My dream is to find a cure for PH.

Lucas’s dad, Steve: While there are 11 drugs approved for adults, none is approved for kids. It’s important to keep research and awareness alive.

What message do you want to pass on to other kids who have PH?
Lucas: Take it easy on yourself. Don’t do things you think are too hard for you. Fight through because one day there will be a cure.

Interview conducted by Alicia Heron, former PHA Patient & Caregiver Services Intern

Lucas speaks to the crowd at the PHA San Francisco Bay Area Chapter’s Empowered by Hope Gala this past November. You can view Lucas’s presentation at www.PHAssociation.org/LucasAtSFGala
On Jan. 5, 2008, I fainted and fell down a flight of stairs. My family rushed me to the emergency room. The next morning I was diagnosed with idiopathic pulmonary hypertension at the age of 11.

For the two weeks before, I had been constantly out of breath, dizzy, and I frequently vomited. My heart was under so much strain that the right ventricle was enlarged two to three times its normal size, and the right valve was stuck completely open. The doctors gave me about two weeks to live and highly recommended a heart and lung transplant. Since my heart was under great pressure, my doctors put me in a wheelchair to lessen the strain. I was also placed on oxygen to help me breathe better. I was unable to walk, run, play, and just be a normal active 11-year old girl.

But then my heart healed itself spontaneously. My doctors were completely stunned. My heart still shows damage, but it functions just like a normal healthy heart. Although I still take daily medication to keep my lungs working properly, I strongly believe that this was a miracle from God.

Now I’m 17 years old. After almost six years, my mantra is to dance like no one is watching, sing like no one is listening and live like nothing can stop me. My mother would agree that I intentionally exceed and push all of my limits. Now don’t get me wrong — PH still prevents me from living out my biggest dreams. I cannot become a pilot or join the military, which is very annoying to me.

Nonetheless, there are always plenty of other options. I must always remain positive and always look at the bright side of life, even though it can be difficult sometimes. The quote “Never give up. Never surrender,” from Galaxy Quest, is dorky, yet inspirational, and I find myself living by it. One of my biggest accomplishments is just being happy and content with the life God gave me.

In the course of living my life with PH, I have discovered photography and art. Through the lens of a camera, I can stop time and capture life’s most beautiful moments. Through photographs and paintings, I can show people beauty and sometimes hidden meanings. Most people take one look at me and assume that I am a normal teenage girl. As soon as I tell these people that I have a heart and lung disease that was once thought to be fatal, they become amazed and stupefied. Through photography and art, I can demonstrate and suggest to others to take a look beyond initial appearances.

I believe that everything happens for a reason. Being diagnosed with PH helped me to become more spiritual. God gave me this illness, and I believe that His reason was to make me a better person. It may be quite unusual, but I consider PH a blessing rather than a curse. Without this disease, I would not be the person I am today.

I thank God rather than blame Him for my illness. Life isn’t meant to be perfect or completely joyous. Everyone has ups and downs. “Don’t cry because it’s over, smile because it happened,” is a quote I find encouraging. Even though life can be discouraging, always be positive and keep your head up.

By Julie Brock, PH Patient

Take a look at two of Julie’s photographs below. If you would like to see more of her photography, visit her blog at www.julliane-brock.blogspot.com.
Michelle Liu is an EMT doctor and the parent of Esther, a 3-year-old living with PH. Since Esther’s diagnosis, the Liu family has started a pediatric support group and been a top fundraiser for both the Baltimore Walk for Hope and the Robyn Barst Pediatric Research and Mentoring Fund for PH, raising $10,000 since August 2013. PHA spoke with Michelle about her support group and her involvement in the fight against PH.

Tell us about your family’s PH journey.
Esther was diagnosed in October 2012. We’re a military family, and we were stationed in Italy but on vacation in Holland. Esther had been jumping on the trampoline, and then she collapsed. Within two days, she was diagnosed with PH and was in the ICU. They transferred us to a PH specialist in Holland. She had another cardiac arrest for 40 minutes, so they started treating her with Flolan® immediately. She slowly recovered. She stayed in Holland another month as an outpatient starting her other medications. Now we live in Washington, D.C., and she’s in preschool.

What led you to start a pediatric support group?
I’m an EMT doctor, and I know how important it is for families to connect with other people who are going through the same thing. But at the same time, I feel like, as a doctor, I can also provide reassurance about little things like taking care of the central line. I always wonder, “How do people get through this every day without a medical background?” I see it as something else I can contribute as a doctor in terms of patient education. Especially for newly diagnosed patients and their families, I think I could be of help to them.

What was the biggest challenge to starting a group?
It’s still a challenge — getting people to respond. The first meeting had a huge response, and everyone attended. But some of those who have responded to my recent emails have explained that they are inundated with activities for all of their kids, and they don’t have time. But even if only one or two families show up, that’s still a meeting.

What was the biggest reward?
Meeting kids who have been living with PH for years gave me hope for my daughter.

What are your future hopes for your group?
I had an adult patient whose daughter was graduating from high school, and when he heard about my daughter, he told me the story of his daughter. Then he started telling me about his support group, a yearly BBQ meet-up organized by his cardiologist. They would get to see their kids play together and grow up together, and that was their support. And that encouraged me. Even if we could just get together yearly and encourage one another and see the kids grow up together, become friends and know they are not alone with this rare disease, that would make me happy.

Your family is one of the top fundraisers for both the recent Baltimore Walk for Hope and the Robyn Barst Pediatric Research and Mentoring Fund. Can you speak about why fundraising is important to you and what your hopes are?
I feel that Dr. Barst’s commitment to finding a cure deserves fundraising. Someone has to carry the torch, and I hope that there will be a doctor like her to continue her legacy. As a doctor, I’m not engaged in PH research myself, but I know how important it is to mentor people who are. PH research is thriving and cutting edge — genes being found, new medications — and that also motivates me to support it.

As for the Baltimore Walk for Hope, I really love the FirstGiving website because it makes fundraising easy. I started fundraising in August 2013, and I feel like all the support that we’ve gotten through fundraising has motivated me to do more. It was a great event, and all the people on my team felt the same way. It was a big day for our families and our friends.

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

Interested in starting a pediatric support group? Contact SupportGroups@PHAssociation.org for information!
Passages is PHA’s way of honoring those who have lost their battle with PH, as it has been since the very first Pathlight was published in May 1990. As we learn of patients’ passing, we inform the PH community. PHA extends sympathy to the families and friends of those who are gone but not forgotten; each Pathlight is dedicated to their memory.

The accuracy of this list is very important to us. Please contact the PHA office at 301-565-3004 x746 or Passages@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.

PHA’s Legacy of Hope Society

To honor those who have included PHA in their estate plans or whose legacies have been realized, PHA created the Legacy of Hope Society. PHA is pleased to recognize the following members. 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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DONATIONS LISTED WERE RECEIVED BETWEEN SEPTEMBER 1 AND NOVEMBER 30, 2013.
PHA IS DEEPLY GRATEFUL TO THE PH COMMUNITY FOR ITS EXTRAORDINARY SUPPORT.

TAKE A LOOK! Sustainers Circle Members Recognized 🎉
PHA recognizes members of our Sustainers Circle in the donations listed. Look for a symbol to see who has made a sustained commitment to donate to PHA on a monthly basis. If you are not a member of our Sustainers Circle but are interested in joining, visit www.PHAssociation.org/Donate/SustainersCircle or call 301.685.3004 x756. You may also use the remittance envelope enclosed in this issue of Pathlight.
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