"After months of research, corresponding, planning, and organizing, we have finally made it to the printers! We have received much support and encouragement to form a patient support group so welcome to the first issue of Pathlight, a newsletter for patients with pulmonary hypertension (PH), their families, and physicians. Because we live in various parts of the country, this newsletter will serve as our forum," wrote Teresa Knazik in the first issue of Pathlight, Volume 1, Number 1, May 1990.

Teresa Knazik, one of PHA's founders and the first Pathlight editor, welcomed readers to what would become a consistent way to connect patients to each other in every part of the country. Now, 20 years later, what started as a fledgling publication has grown into the official newsletter of the PH community, reaching thousands of readers across the country and the globe. Over the next 12 months, the PH community will remember and celebrate the milestones of our history: 20 years of Pathlight, 20 years since the first support group meeting around a Florida kitchen table and the formation of United Patient’s Association for Pulmonary Hypertension (UPAPH) — now known as PHA.

PHA was built on grassroots organizing and volunteer spirit. It is this spirit that brought four women together for the now famous kitchen table meeting on January 12, 1991 — a meeting that set in motion the principles that would become PHA: patient and caregiver support, awareness and advocacy, collaboration with the medical community, and hope for a cure.

The first step toward connecting patients came before UPAPH/PHA and before that kitchen table meeting. It came as Pathlight. The name, Pathlight, was derived from the founders' purpose. Dorothy Olson, one of PHA’s founders, explains, “We wanted to find ways to light
In the first years after my daughter Meaghan’s diagnosis, I was so frightened by pulmonary hypertension that I was unable to do anything to help other than to write a small annual check. That all changed when I was invited by Dr. Bruce Brundage, then Chair of the PHA Board of Trustees, to attend a Board meeting in November 2003. Within 20 minutes of my introduction, I wanted to become a part of this group of selfless individuals whose overwhelming focus was the alleviation of the suffering caused by pulmonary hypertension. No one in this group would ever draw attention to themselves, so it’s up to me to recognize their work and extraordinary dedication.

The 22 members of your current Board — and scores of past Board members — are non-paid volunteers who give without limit in this fight. They come from all walks of life, and if you or a loved one has PH, they impact your life on a daily basis whether you know them or not. They provide overall strategic guidance and direction to PHA and oversee the work of the president and the judicious use of our resources.

The Board represents every aspect of our PH community, and patients’ presence on the Board is paramount. I think of members such as Sally Maddox, a wife, mother and full-time teacher, who recently returned to the Board. She tirelessly volunteers as a fundraiser, editor of PHA News and manages the Conference awards program. I marvel at others like Rita Orth, RN, who marshals the energy to join in the fight against PH by, among other things, answering our Patient-to-Patient Helpline and serving as a support group leader. There’s Cindy Pickles, RN, a support group leader, special events fundraiser and Helpline volunteer, who also co-chairs our Conference Committee and is a fervent advocate for our cause. Of course, we can never forget those very special patients who lost their battle while in office, Bonnie Dukart, an inspirational Board Chair, and Candi Bleifer, whose contributions will be felt for many years to come.

The pre-eminent physicians in the world, who fight this illness as investigators and compassionate and expert clinicians, serve us on the Board as well. We are so fortunate to count Drs. Dave Badesch, Greg Elliott, Mike McGoon, Vallerie McLaughlin and John Newman as members of our Board. Go ahead and try to find something important written about PH research that doesn’t reference one of these superb physicians’ work in this field. Mike has served as the PHA Board Chair and currently leads our Development Committee’s efforts, and Val currently serves as the Chair of our highly regarded Scientific Leadership Council. A particular honor for me was being seated next to Dr. Robyn Barst when she served on the Board. This angel gave me another 14 years with my Meaghan.

Speaking of angels, we have nurses on our Board as well. Some of my favorite people, they are Arlene Schiro, a Nurse Practitioner who serves as current Chair of the PH Resource Network (learn more about Arlene on p.12), and Louise Durst, who served as Chair of the PH Resource Network’s Membership Committee and is now the Network’s Chair-Elect.

Caregivers are also well represented on the Board, and their efforts are characterized by an often quiet, yet burning, urgency. There’s Linda Carr (daughter Hannah), who has served as the Chair of the Board and has been directly responsible for the resounding success of our biennial International Conferences as the Committee Chair and Co-chair for years on end. Roger Towle (daughter Jocelyn) has been our Treasurer since I’ve joined this organization. He also serves as our Finance Committee Chair, and PHA’s financial well-being is due in no small part to his wealth of experience in the nonprofit financial world. Teamed with Mark Jeter (daughter Anna), banking CEO extraordinaire, our investments to secure PHA’s future have been all but assured. And of course there is Jack Stibbs (daughter Emily), also a former PHA Board Chair and current Chair of our Governance Committee. Who’d have thought you could love a lawyer? Jack is one of our most productive fundraisers who, after years of successful golf tournaments, has instituted an annual “Bug Boil” fundraiser (it’s a Southern thing).

Some of our newest caregiver members have already rolled up their sleeves and dug in. Steve Van Wormer (son Lucas) has produced a series of radio PSAs for PHA in
addition to setting up a pediatric support group. He was honored for his PHA work in 2008 by being named the co-recipient of the Julie Hendry Memorial Scholarship Award. John Hess (son Iain) has recently joined us and has already made a significant contribution. How do you like our new website? Please thank John for his efforts there.

Another group of caregivers are the ones who have puzzled me the most. Until recently, I could never understand how they could have lost a loved one to PH, yet continue to fight through their pain for all of us. I remember thinking I could never do that. These giants include former Board member Tom Linnen (daughter Mary), a significant benefactor of our organization. Betty Lou Wojciechowski (son Matthew, son Michael, and husband Jerry) — what to say about this sweetheart? She is always upbeat and ready to help. Whether it is addressing a group about PH, leading a support group or raising money through her own golf tournament, Betty Lou is leading the way. Steve White (daughter Christen), an Episcopal priest, has almost become our unofficial chaplain on the Board. Steve co-chairs our Development Committee. He’s one of the kindest, finest human beings I have ever met, and he has helped me and many others immeasurably. There’s Tony Lahnston (niece Marchelle) who organized one of the most successful online fundraisers PHA has seen. Last but far from least is Laura D’Anna, who is the Chair-Elect of the PHA Board and Chair of our Strategic Planning Committee. Laura lost her beloved sister Rachel to PH. Laura was the first to call me during my own loss and has spent hours supporting me. She and Rachel, who I never met, will always occupy a special place in my heart.

Then there’s Harry Rozakis. Harry resists classification. He was a patient, had a thromboendarterectomy and has beaten PH. Harry has been instrumental in helping to expand PH awareness and support in Southeast Asia, has used his love of golf to raise funds for PHA and chairs our Personnel Committee. I count him as one of my best friends and advisors.

Also tireless are PHA’s founders and their spouses who are Members Emeritus of our Board, and to whom we are all eternally grateful when we think of all that PHA does for us — Dorothy and Harry Olson, Jerry and Pat Paton, and Ed and Judy Simpson. Entire articles could be written about these six marvelous people who remain active in our organization and to whom we are all so deeply indebted.

And finally, Rino Aldrighetti. As our President, Rino serves as an Ex Officio member of our Board. Ask any of the people above what they think of him, and they will tell you he is most responsible for the exceptional strides we have made as an organization over the past decade. I will second that. There may be no one more dedicated to us and our cause than Rino.

So there you have it. When we meet twice a year, it is like coming home to a working family reunion. We don’t hold a 15-minute meeting and then go out to play golf. We work from early in the morning to well into the evening. Be assured we are united in cause and purpose. I, for one, have never served in a more dedicated group than your PHA Board of Trustees.

To meet PHA’s newest Board members, turn to p.8. For more information about all members of the Board of Trustees, visit www.PHAssociation.org/BoardOfTrustees.
Generation Hope: We’re not just a group; we’re a PHamily.

Going to college for the first time, dating and finding your lifelong mate, planning the wedding of your dreams, buying your first place, finding your first “real” job and raising children — these are all activities that are exciting, stressful and nerve-racking at the same time. But imagine that you have pulmonary hypertension as well. Would you be able to handle it all?

While every PH patient has difficult day-to-day choices, PHers in their late teens, 20s and 30s have unique challenges of their own. Squeezing treatments and IV line changes between classes, balancing medical bills on top of rent and tuition, and finding a mate who can look beyond your illness, IV lines, medication bottles, oxygen tanks and concentrators can be a daunting task. Sometimes it’s tough to know who to talk to or what to do next.

Even though young adult PHers are few and far apart, we share one commonality. We all have PH, and we are stuck in a generational group that tends to be forgotten because we are not the “typical” PH patient. We are young (but not kids), we tend to be active (but still have our bad days), and we are all starting our lives facing a difficult hurdle: pulmonary hypertension.

Attending my first International PH Conference in 2008 at the age of 25 was a real eye-opener. I met hundreds of PHers from the entire age spectrum, from young kids to the elderly. Best of all, I met PHers in my age group who did the same things I did. They were all very active, just like me. Most played sports and loved to travel, and we all faced the same issues: dating, school, finding a job, and making decisions about raising children in the future. While it was great to meet PHers my age, I was disappointed that there weren’t any patient-led sessions at Conference for our age group. After that Conference, it became my personal mission to become more active with young adult PHers and PHA. And before long, I was given that chance.

This fall, PHA invited a group of young adult PHers to participate in two teleconference focus groups to discuss the issues and concerns that young adult PHers are facing today. As a result of the focus groups, PHA launched a new Google group for young adult PHers called Generation Hope. Generation Hope is led by a small Advisory Board of young adult PH patients. These patients — Brittany Riggins, Colleen Brunetti, Sean Wyman and I — volunteer our time each week managing the Google group and coming up with new activities for Generation Hope to participate in and support.

We’re working hard to expand Generation Hope’s presence in the PH world. Recently we joined in on fundraising efforts to help support the Path to a Cure campaign (see p.29). Members of Generation Hope organized Virtual Unity Walks to raise funds and awareness for PH. Many of our members have been featured in awareness-raising articles about PH or have written articles and blogs about their own lives to spread the word about PH. We are excited to say that for the first time, young adult PHers will have their own patient-led session at PHA’s 9th International PH Conference. Generation Hope will also have an information table at Conference to help young adults navigate their way through this year’s event.

PHA’s Generation Hope is more than just a Google group. It’s a family of PHers who share information, tips, advice and daily experiences. We support each other through everything because we know that these are people who understand what we are going through at this time in our lives. In this group, nothing is off limits. If you need to vent, go ahead and do it. If you need some advice on a situation or have a question, go ahead and ask because we are not just strangers on the street; we’re PHamily!

If you are interested in joining Generation Hope or learning about other events or programs involving young adult PHers, please visit:

www.PHAssociation.org/Patients/YoungAdults

By Lindsay Nicol
Young Adult Advisory Board Member and PH Patient
If at First You Don’t Succeed: One Family’s Persistence Leads to Social Security Approval for 18-Year-Old Daughter

When Emily was diagnosed with primary pulmonary hypertension in September 2008 at the age of 17, we applied for Social Security Disability (SSD) for her. However, she did not qualify because she had not contributed to Social Security due to lack of work history. Additionally, because she was considered a child, she did not qualify because our (her parents’) income and financial resources were over the eligible limit. We were advised to apply for Supplemental Security Income (SSI) once she became an adult because at the age of 18, only her individual income and resources would be considered. In the meantime, she was also diagnosed with hyperthyroidism (Graves’ disease) in January 2009.

After Emily turned 18 in February 2009, she applied for SSI. Several sources said to expect denial on the first application and that is exactly what happened. In May we were notified that Emily was not eligible because “although your child’s conditions may result in some problems, they do not cause marked or severe functional limitations.” Emily then filed a request for reconsideration, and we expected the application to be denied again.

In the meantime, I contacted PSI ACCESS, a patient advocacy group that provides free Social Security representation to PH patients (Update: Caring Voice Coalition now provides the services formerly offered by PSI ACCESS; see p.63 to contact). The advocacy group provided us with a template letter to give to Emily’s physician. He submitted the letter to the SSA, highlighting her pulmonary arterial pressure numbers and the seriousness of the disease. We also submitted copies of right-heart catheterization lab reports, highlighting the same information.

On December 24, Emily received approval for disability and began to receive monthly SSI payments as well as retroactive payments from February 2009. After 10 months, it was worth the time, paperwork and anxiety.

The most difficult part of the process was the lifestyle survey, a part of the request for reconsideration. Emily had to provide a detailed description of how every aspect of her life has changed, including social situations, personal care, activities, etc. Although Emily has maintained a positive outlook since she began treatment and does not look for negative aspects of the disease, we highlighted several situations in everyday life so she could address the issues and complete the form. For example, Emily enjoys cooking but is aware that she must protect the pump and tubing from heat. Her daily routine has to include time to prepare Remodulin™ and maintain the catheter site. These examples of challenges to a patient’s normal lifestyle can potentially help a patient’s case.

Recently, PHA worked with the SSA on an informative video about pulmonary arterial hypertension. The video, which can be found on PHA’s YouTube site (www.YouTube.com/PHAssociation), contains a description of the disease and its seriousness. We’re not sure if it was part of the decision process for Emily’s case, but it may help patients who apply in the future.

Our next hurdle will be to apply for Medicaid because, although we are fortunate to have good health insurance, Emily will probably reach the lifetime maximum on her medical insurance benefits. Emily is now attending her first year at The College of Wooster and is planning to become a physician. In fact, she made the Dean’s List her first semester! Her drive and motivation will not let PH stop her from following her dreams. We pray every day for a cure, and we appreciate all the work PHA is doing to support research, patients and caregivers.

By Marge Lanzola, Caregiver and Mother to Emily Lanzola

SSI is a federal income supplement program administered through the Social Security Administration (SSA) that is designed to help aged, blind or disabled people who have little or no income. Although different from SSD because it is funded by general tax revenue and not Social Security taxes, you must still qualify as disabled as defined by SSA in order to receive SSI payments.

The SSA uses a Listing of Impairments (a list of qualifying diseases) to help determine disability. PH is referenced on this list with guidelines used for determination. For example, severe pulmonary hypertension is described as “pulmonary artery systolic pressure greater than 60 mm Hg.”
I thought Pathlight readers might find hope in my daughter’s college application essay. Monica is a senior in high school and wants to pursue a career in medicine or research in the field of pulmonary hypertension. Even though we continue to lose our fellow PHers, we do have the next generation to carry the torch. The one wish my mother, Margaret Bellinger, had was to see Monica become a doctor. I only regret that she couldn’t live long enough to see it. My mother passed away from PH in October 2009. Below is Monica’s Personal Statement to Ursinus College.

~ Coleen Makovicz, Del-Val Support Group Leader

I began my life labeled as a nonviable pregnancy, and as my mother waited for me to pass, she would rub her belly and speak words of encouragement to me. A month later she was given the miraculous news that I was alive! I still insisted on causing trouble and putting her through a tough pregnancy. I arrived six weeks early, underdeveloped, jaundiced, and unable to suck properly. I was labeled a “failure to thrive.” No one ever gave up on me, and I did thrive. At 17 years of age, I have only reached the height of 4’10”, thus leading me to the label of “that really short girl,” but my dreams are anything but short.

With my rough start, no one expected my label in first grade to be “gifted.” Simultaneously, during this time in my life, I knew there was something wrong with my mother ... She was diagnosed with a rare and terminal heart and lung disease, pulmonary arterial hypertension. It is believed to strike two people per million, though the support group I belong to believes that these numbers need to be adjusted upwardly. In my family, this disease is a majority. In fact, my grandmother, who I helped take care of up until she passed away last month, was also diagnosed with the same disease. Instead of running away from the tragedy, I ran towards learning about it.

One of my favorite books is Survival of the Sickest, and I also had the honor of interviewing the author, Dr. Sharon Moalem, for my graduation project. This book opened my eyes to the endless possibilities and discoveries that lay ahead in the field of evolutionary genetics. Dr. Moalem was encouraged to go into medicine and research because of his sick grandfather. My own inspiration came from my mother and grandmother and the other PH patients that I have become close to. They are my inspiration. Some close family friends, who have lost their battle, have created a deep desire in me to find a cure for this awful lung disease and other terrible illnesses.

I believe the opportunity to attend Ursinus College would be a fantastic step towards achieving my goal of becoming a medical researcher or a doctor of medicine. I am very dedicated. I even spent last summer at the University of Pittsburgh Health Career Scholars Academy ... This opportunity was a dream come true because it gave me the chance to learn from some of Pennsylvania’s top scholars. I visited a laboratory where scientists are studying worms to increase the lifespan of humans. I witnessed two fascinating surgeries and examined cadavers ...

Tragedies have molded me into a very passionate and determined person. I have had a lot of personal challenges in my life such as my father’s sudden death in third grade, the rare illness which my family suffers from, and the medical conditions which empower me to become a caregiver for my mother and grandmother. With each event I again carried new labels: “the girl with the dead dad” or “the girl with a sick mom.” I feel that these obstacles have made me emotionally stronger. These challenges have shown me how important it is for our country to have physicians who understand not only the patients’ needs but also the impact disease has on each patient’s family. I feel that my life experiences have exposed me to a diversity of people and personalities, so I am able to understand with firsthand experience how crucial it is to have a doctor who is truly empathetic towards his or her patients. A chance to learn at Ursinus College will prepare me for a fruitful career in a healthcare profession. I’ve had many labels throughout my life, and I’d like my next one to be “Ursinus student” followed in the future by the label “Dr. Makovicz.”

Monica stands beside the sign for Ursinus College. She was accepted and will begin her freshman year next fall.
Stories of Hope from PHA South Africa

The Pulmonary Hypertension Association of South Africa was started by PH patient Sharon Chetty and her sister Indirani Govender. After Sharon passed away, Indirani proudly kept her sister’s dream alive. In 2009 more volunteers wanted to help, and PHA South Africa became a registered nonprofit. PHA South Africa is enthusiastic about this development and would like to share the remarkable stories of some of our newly elected committee members.

Denneys Niemandt is the first chairperson of PHA South Africa. He lives in Cape Town and works full-time as a project manager for a large retail group. He was diagnosed with PH three years ago and describes his wife as his pillar of strength. He feels frustrated that so little is known about the disease in South Africa.

If you ask him how sick he is, he will say, “I do not really know. My pulmonologist is very positive. I feel good some days and very bad on other days. The biggest challenge for me is that I used to be very active, and now I get tired all the time.” Denneys is on a variety of medications, including sildenafil. Sildenafil was imported for him on a compassionate basis, and now it is officially registered at the South African Medical Council.

Gerrie Booysen is the type of person who always looks on the bright side of life. He is the father of a new-born son, GJ, and his wife, Karin, describes him as “remarkable.” Gerrie works full-time as an operational manager at the Central University of Technology in Bloemfontein, and he is a member of the management committee of PHA South Africa. He credits his faith with giving him his positive outlook on life. He believes if there is hope, there is life.

Gerrie was diagnosed with idiopathic PH in 2009, just as he and his wife found out they were expecting their firstborn. He is grateful to his medical team for assisting him on his road to diagnosis. Last year he joined a clinical trial, which made a huge difference in his quality of life.

Gerrie does not sit still. After a full work week, Saturday is his day to repair things around the house. Last year you would find him on the roof of his house with his oxygen, but his combination of medications has allowed him to cut back on the oxygen this year. While he has his good days and bad days, his message to others is to maintain a positive outlook on life.

Nicolene Muller lives in George, South Africa, and is a member of the management committee of PHA South Africa. She was diagnosed with PH in 2007.

In August 2008, Nicolene had an appointment to be considered for a lung transplant. When she arrived for the appointment, her doctor suggested enrolling her in a drug trial. She agreed, but after starting the trial, her health continued to deteriorate rapidly. She had to stop working, and she spent all day in bed and on oxygen.

In November 2008, she went for another appointment. As she arrived, she passed out. Her doctor decided that she must be on the placebo in the drug trial and decided to make sure she got the actual drug. At that time, Nicolene could only walk 120m during the six-minute walk.

After one day on the new drug, her doctors could already see a difference, and for her six-minute walk one year later in November 2009, she walked 460m. She only uses oxygen now when she sleeps. “I would like to thank God for this miracle. I received a second chance on life,” Nicolene says. “Currently, I am connected to more than 70 people via Facebook from all around the world who have the same disease as me. It is wonderful to link up with others and to realize that you are not alone in the fight against PH.”

To find out more about PHA South Africa and other associations around the world, visit PHA’s website at www.PHAssociation.org/PHInternational

Article submitted by Elzarie Devenish, PHA South Africa
International Faces of PH: Rocio Penagos Herrera

I was born with an interventricular communication, and when I was five years old, I had surgery to fix it. I remember that throughout my childhood and adolescence I was always in a permanent state of fatigue. I could not run or jump like my siblings and friends because I got worn out very quickly. My parents thought it was due to the heart surgery, and I grew up believing that I was constantly tired for that reason.

It was not until five years ago when, after several misdiagnoses, I was finally diagnosed with pulmonary hypertension. I remember that moment being very sad and difficult for my family and me. We received information about a condition that we had never heard of and did not totally understand, and we were told there was no medicine or treatment that might help me. I felt fear and sadness, and I think my parents felt that way also. None of us expressed these feelings out loud.

Shortly after I was diagnosed, I had the benefit and fortune of being selected for a clinical trial. At that time, I still had not accepted my PH and didn’t value the experience as I would now. It took me quite a while to decide to get involved and learn more about this condition, and when I joined “HAP Mexico,” the PH organization in my country, I experienced a turning point in my attitude toward the disease. Since then, I realized that being informed helps me feel much better, and it helps my family to feel more hopeful. I also realized that much more needs to be done in my country, and we can only make necessary changes through an organization.

Now I have chosen to work through my feelings about my disease and give my support to others. By opening up, I’ve discovered that I receive perhaps more than I give.

Today I am more informed, I work for the cause, and I actively let go of my sadness. I have taken responsibility for my condition, and I’m much better. There is no question of good or bad luck; it is a matter of decision. Let’s make this condition an opportunity to help each other and live to the fullest.

By Rocio Penagos Herrera
HAP Mexico

New Trustees Bring Added Vitality to PHA Board

PHA welcomes two new members to our Board of Trustees. The Board serves in an oversight capacity, ensuring that PHA’s programs meet the needs of all our constituencies. Visit www.PHAssociation.org/BoardOfTrustees to meet all of PHA’s Board members.

John Hess, term began January 2010

John Hess lives in Boulder, Colo., with his wife, Seema, and three young children, Olivia, Iain and Simon. John became involved with PHA after his son Iain was diagnosed with PH in October of 2004 at the age of five.

Leading up to PHA’s recent website redesign, John volunteered his time to help PHA select a vendor for the site overhaul. He and his daughter Olivia and Iain’s best friend Matt climbed Colorado’s 14 highest peaks in 14 days to fundraise and spread awareness of PH in Iain’s honor. John holds a Master’s of Engineering degree and currently works as Chief Technology Officer of CBJ.

Sally Maddox, term began January 2010

Sally Maddox is a math teacher and has been a PH patient for more than 20 years. She has been the leader of the Georgia Support Group since 1999. She organizes the annual GA Fun Walk for a Cure each October to raise money for PH research and patient services. She has served on PHA’s Conference Planning Committee since 2002, and is the editor of PHANews, PHA’s biweekly e-newsletter. Sally was first elected to the Board of Trustees in 1999 and is returning after a break. She lives in Rome, Ga., with her husband Shelby, who is currently serving in Iraq, and is helping to raise Shelby’s son Brandon.
PHI nding Love as a PH Patient

Does a compromised heart limit our emotional opportunities and physical capacity for love? It can. But only if we let it. Read on to see how PH patients handle the intricacies of dating and dealing with a chronic health condition.

Sorting through the Frogs

“A major part of starting and maintaining a relationship with PH is being comfortable with your situation,” Brittany, a 27-year-old PH patient, explains. “If you’re not confident that you’re well enough or emotionally stable enough for a relationship, the other person is going to see that and back off.”

Brittany is married now, but her dating life did not begin with Prince Charming. While on Flolan™, she dated a few people, and she remembers one sweetheart in particular: “When I showed him my Hickman site, his response was ‘Eww! That’s disgusting!’” Naturally, Brittany swore off dating for a while and, in that time, was able to come off Flolan™ and leave the pump behind.

Then one day her friends dragged her to a concert where she met her future husband, Daniel. “I didn’t have the pump when I met Daniel, but I don’t know that it would have made a difference,” Brittany explains. “I’ve let him know that there’s always that chance that I may have to go back on it, but he’s more worried about how much time I’ll spend in the hospital with infections than what it looks like. Being open and honest was the best thing I ever could have done because it opened the channels of communication where he wasn’t afraid to ask questions. If someone’s not willing to accept every aspect of PH, they’re not worth your time.”

Finding a Prince

Allow me to introduce you to high school sweethearts, Hannah and Joe. Hannah, now 24, was diagnosed with PH at age five, so she had plenty of time to navigate the uncharted waters of dating with PH. “I know that I am more than just a sick person,” she says. “Even though I have a disease, it doesn’t mean that I should feel guilty … or be overly cautious or reckless …”

Joe actually read about Hannah’s story in a local newspaper before he moved to the area and couldn’t wait to meet her. “Hannah has been very open about her illness with others,” he explains. “I think it is mostly because she knows she is an encouragement to others who struggle with PH and other medical complications. … When I first talked directly to her about PH, I thought about her bravery, perseverance and courage.”

Ladies and gentlemen, you might want to grab a box of tissues because there’s more. “After we started dating, I would learn a little more at a time on a regular basis,” Joe continues. “I grew more and more in love with her. I realized that part of what made Hannah herself was all that she had gone through and experienced. We talked about what life would be like, and I loved Hannah so much that my feelings for her were greater than any negative effects [PH] could have on our relationship.” Joe and Hannah are now married, and they have an adopted daughter. Joe, do you have a twin?

Saying “I do.”

The glass is either half full or half empty, and with PH, it’s easy to be thirsting for more. But, again, it all goes back to perspective. Many of us can identify with this next patient’s fears of being undesirable with a machine around her waist and a tube coming out of her chest. Though it is a constant reminder to Robin that she doesn’t get to be “normal,” her husband, Jerad, considers the pump a blessing. It means more time with his beloved wife. Six months after starting Flolan™, Robin and her hubby exchanged their vows in front of 150 people. The pump was placed in an oven mit inside a mom-made purse designed to match her beautiful ivory gown perfectly.

Like Robin, PH patient Geal believes the illness can have a positive effect on a relationship and marriage. “My husband has been my rock and foundation and also my greatest listener. I know our relationship as husband and wife has gotten stronger since my diagnosis, and we know now how fragile life can be and how it can change in a heartbeat, figuratively speaking.”

… And They Lived Happily Ever After

So, does a compromised heart limit our emotional opportunities for love? Obviously, not. But, what about the sexual side of things? With the catheter in her chest, Geal says she and her husband are more careful when they’re cuddling or being intimate, but it hasn’t changed their love for each other.

As Brittany said in the beginning, as long as you’re okay with your situation, everyone else will be too. It’s all in how you perceive yourself. That’s all that matters. If you feel sexy, then you are sexy — no matter what.

Instead of being seen as sick and fragile, we should be desired. We are a rare, hot commodity. Even with a life-threatening illness, we just keep going and going and going … in every aspect of our lives. ♦

By Katie Tobias, PH Patient

To read Katie’s story in its entirety, visit the young adult section of PHA’s website at www.PHAssociation.org/Patients/YoungAdults
Moving Mountains for PH: Meet Dr. Ray Benza and Dr. Robert Frantz

Dr. Ray Benza and Dr. Robert Frantz are no strangers to pushing boundaries, making the unthinkable possible. February 26, 2010, marked the culmination of PHA’s Path to a Cure campaign when Drs. Benza and Frantz, along with physician’s assistant Jessica Lazar, summited Mount Kilimanjaro to raise PH awareness and more than $100,000 to support research and patient programs. (Read more about Path to a Cure on p.29.) Recently, Drs. Benza and Frantz took the time to talk about their motivations on the mountain and in their work with PHA.

Look for a feature on Jessica Lazar in the summer issue of Pathlight.

What initially sparked your interest in PH?

Dr. Benza: My interest began when I was a fellow, and part of my training was taking care of patients who had PH. This was before the approval of Flolan™. My mentor, Robert Bourge, at the University of Alabama, said, “Ray, these people are really sick, and we can’t do much for them.” I got to know these patients and what wonderful people they were. Finally having medications to treat patients really furthered my interest, primarily because medications did so much, yet patients still suffered so much.

Dr. Frantz: In 1996, Mike McGoon founded the PH clinic at Mayo, when Flolan™ was getting approved. He had the vision to realize that managing PH patients would require a team and a program dedicated to treating PH. I was working in the cath lab at the time and was already somewhat involved with PH patients. Dr. McGoon asked me to join the PH clinic, and I’ve been there ever since.

How did you become involved with PHA?

Dr. Benza: When I was a fellow, PHA didn’t exist. Then as a young faculty member, I began hearing more and more about the organization. PHA represents the people so very well and makes you realize that this is not just a disease … these are people. Good doctors treat the disease, but great doctors treat the person. This was brought to life for me when I joined PHA.

Dr. Frantz: Not long after joining the team at the Mayo PH clinic, it was so clear that PHA was critically important in providing patients with the support they needed to be able to face this disease. The first PHA International PH Conference I attended was incredibly compelling. I realized that we’re all in this together, and it’s more a family — a community — that we’re all a part of.

How did you come up with the idea to raise PH awareness and funding by climbing Mount Kilimanjaro?

Dr. Benza: The idea came to me after my first climb in the Tetons. That climb was spurred by tragedy. I had gotten very close to a patient, and through that friendship, I learned a lot about what this disease can do to a person. After my friend passed, I was so frustrated that I hadn’t been able to help her. I was talking with a bunch of friends about it and one said, “Sometimes you can’t just move mountains.” And something just clicked. When you climb to such high altitudes, you can actually develop the shortness of breath that our patients experience every day. Actually experiencing this breathlessness drives home the message that we need to do something quickly. After climbing the Tetons, I knew we needed to keep pushing and I started searching for a partner to climb Kilimanjaro with me.

Dr. Frantz: Dr. Benza knows I like to climb things, and when he approached me with the idea, it sounded great. We plotted together about the climb since the 2008 PHA International PH Conference. And just recently, I lost a patient, a woman just over 50 who had been fighting this disease for several years. We’d exhausted all our options, and when I went to visit her in the ICU, I was so incredibly touched by her and her family’s bravery and her kindness, even knowing there wasn’t anything else we could do to turn her health around. She and her family are exactly the reason WHY I’m doing the climb, raising awareness and raising funds to support research. I truly believe that in my career span, we’re going to figure this thing out.

You’ve both been involved in treating PH for a long time. What advancements in the field are most exciting to you?

Dr. Benza: For me, it’s the emergence of the interest in this disease that’s been occurring since the inception...
Pulmonary arterial hypertension (PAH) is a progressive disorder of the pulmonary vasculature. Although PAH can affect men and women of all ages, it differs from other more frequently encountered cardiopulmonary conditions in its relatively high incidence in women of childbearing ages. Despite the tremendous advances in earlier disease detection and treatments over the past 15 years, the risks to the pregnant woman remain prohibitively high, and we strongly discourage pregnancy in women with PAH. This is often heartbreaking news to young men and women hoping to have children and start a family. A clear explanation of these risks requires a brief review of the dramatic physiologic changes that occur during a normal pregnancy and an understanding of why these changes are so poorly tolerated in PAH.

Pregnancy is associated with multiple profound changes in overall fluid balance of the body and requires the heart to be able to adapt. These changes are evident midway through the first trimester (6 weeks), but typically become most prominent in the third trimester, and do not fully return to normal until several weeks following delivery. Overall blood volume increases up to 45 percent, heart rate increases by 10-20 beats per minute, and the volume of blood ejected by the heart per minute (Cardiac Output, CO) increases by 50 percent. This augmentation of CO is accomplished by a gradual increase in the contractile force of the heart, coupled with a reduction in the resistance within the pulmonary blood vessels. Increased salt and water retention are essential in increasing and maintaining the increased blood volume.

The contractions that accompany active labor magnify these stresses on the heart and vasculature. During active contractions and maternal pushing, heart rate and CO increase by an additional 50 percent. Immediately following delivery, as the blood in the uterus is returned to the general circulation, cardiac output can increase by up to 80 percent! PAH is characterized by narrowing of the pulmonary vessel walls, resulting in increased resistance within the lungs. This high resistance increases the work on the right ventricle (RV), making it harder to pump blood through the lungs. Even in minimally symptomatic or asymptomatic patients who are feeling well, the RV has impaired ability to tolerate stress and may not be able to handle the increased blood volumes or augmented CO required in pregnancy. PAH patients often require diuretics for effective management of fluid status and cannot tolerate the increased blood volume. Furthermore, the abnormal pulmonary arteries and veins cannot relax to reduce the workload on the RV. In essence, the amount of blood that the RV can pump is relatively fixed and cannot handle the increased blood flow or increase the CO necessary to satisfy the body’s and fetuses’ metabolic needs.

What are the actual risks of pregnancy in PAH? It is important to recognize that there are very few published works on this topic, and we often rely on smaller studies and case series to answer this question. Prior to the development of PAH-specific therapy, the maternal fatality rate was exceptionally high, and reported at 30-56 percent. In this study, most of the deaths occurred within the month following delivery, and not during the pregnancy. Although the risks of intrauterine growth retardation (IUGR) are increased in PAH, the overall survival rate of the fetus is higher, approaching 90 percent. With such a high maternal mortality rate, one can understand why physicians actively discouraged pregnancy in all patients. During the past decade, our understanding of PAH has increased, and advancements in pharmacotherapy and anesthesia have improved outcomes. A recent study reviewing published cases between 1997-2007 suggested a lower mortality, ranging from 17-33 percent. It is important to recognize that these series often included patients in whom PAH was detected during the course of the pregnancy. Intravenous epoprostenol has been the most studied drug in pregnancy, and several case reports have described successful deliveries.

Despite the improvements in survival, we feel that the maternal mortality rate remains unacceptably high, and continue to recommend contraception and caution against elective pregnancy. If an unplanned pregnancy occurs, a careful assessment of the maternal medical risks of continuing the pregnancy must be weighed against the personal, religious, social and psychological effects of a therapeutic abortion. A multidisciplinary approach, involving consultation with an obstetrician, an anesthesiologist, and a PAH expert, is advised.

Answer provided by Gautam Ramani, MD, Associate Professor of Medicine, University of Maryland Medical Center, Baltimore, Md.

References:
Meet the Nurse Practitioner: Arlene Schiro

Going into the medical profession, especially critical care nursing, is not a choice one makes lightly. It takes a rare kind of person to commit to caring for a patient’s physical needs while also tending to their emotional needs. Arlene Schiro is that kind of person.

Arlene began her career in nursing in the 1970s. She completed her graduate studies at New York University and became a nurse practitioner after moving to Boston. This is where she met her first PH patient in the ’90s.

“A woman in her forties and in the prime of her life came to us for treatment of her PH. She was in the end stage, and I was just beginning to learn about Flolan™, which was the only treatment for PH at the time,” Arlene remembers. “I became the primary nurse for her care; she wanted to live so badly, and I wanted to find ways to help her. And as I helped treat her, I became very close to her. Unfortunately, despite receiving treatment, it was too late for her, and I thought to myself, ‘This is not right; how can I change this?’ In the mid ’90s there was not a lot of knowledge about PH, and it was hard to know what to do.”

“I was asked to start the program at Massachusetts General Hospital, and we had to start from the basics, developing guidelines for use of Flolan™,” Arlene says. She started online searches and made phone calls, trying to reach anyone who could help. “Then I found out about PHA and found that here was a core group of people who were looking for the same collaboration.”

Through PHA, she learned about PHA’s PH Resource Network, the professional network of allied healthcare professionals providing care for PH patients. Now, a little more than 10 years later, the PH Resource Network has grown from a handful of PH nurses to hundreds of allied healthcare professionals representing many specialties. Arlene has been involved in that growth every step of the way and has served as Chair for the past two years.

Throughout her term as Chair, she has emphasized collaboration. “We know that we can’t do this alone, and we rely on each other to develop best practices,” she says. “We help each other because we know we all need help. Our patients do better if we learn from each other’s experiences.”

Etched in her memory is a patient she treated for seven years through his PH. “I had a patient who was a burn victim after a serious motorcycle accident and then was diagnosed with PH a few years later. He had few coping mechanisms when we recommended subcutaneous Remodulin™. His PH doctor and I became part of his family. We helped him find support through other patients, and we even helped him adopt a dog once we realized that his own dog had passed away. I always try to remember that we really are like a part of their family and do have a great impact on their lives.”

Looking ahead to the next 10 years in the field of PH, Arlene envisions much more growth in knowledge and collaboration. “I see us publishing not only a lot more research, but also developing information on the care and the psychosocial and physiological impact of PH on patients so we can improve care for them.”

Arlene is also looking forward to attending PHA’s International PH Conference this summer. “The aspect of this Conference that I am looking forward to is the international component,” she says. “Thinking of what happened in Haiti, I heard someone say that there is no way we can live without helping others. That is how it is with PH too. It transcends boundaries and affects people beyond our borders, and we need to continue to try and reach out to PH patients and medical professionals everywhere.”

When asked how she maintains her own well being, she says, “Positive energy is so important! I really believe that people can absorb positive energy from each other. I like to get involved in other things that build this energy, and I think this is so important for both medical care providers and patients.”

Arlene lives outside of Boston with her husband and derives her energy from her three children. She is actively involved in ChildFund International and fosters an eight-year-old child in rural India. Arlene and her husband also work with an animal rescue group that fosters homeless puppies and places them in permanent homes. She is currently the Clinical Manager of the Pulmonary Vascular Disease Program at the Brigham and Women’s Hospital.

To PH patients reading this article, she says, “We are here with you. We need to know what we can do to help you. We can only help you if we all become a team. We are all part of this together.”

By Donica Merhazion
Former PHA Associate Director of Medical Services
Frequently Asked Questions for Newly Diagnosed Patients

What causes pulmonary hypertension (PH)?

PH is a young disease that we are still learning about. Sometimes PH can develop as a result of another medical condition, including blood clots in the lungs, chronic obstructive pulmonary disease, congenital heart disease, lung disease, liver disease, connective tissue disorders like scleroderma and lupus, and others. This type of PH is known as associated pulmonary arterial hypertension (APAH).

In some cases, no cause can be identified, and in these cases, the PH is referred to as idiopathic pulmonary arterial hypertension (IPAH). Some families have a form of PH that can be inherited. This is known as familial pulmonary arterial hypertension (FPAH).

How does my doctor know I have PH?

PH can be difficult to diagnose in a routine medical exam because the most common symptoms of PH are also associated with many other conditions. To determine if you have PH, your medical team will schedule specialized tests, possibly including a pulmonary function test and an echocardiogram. If the results of these tests point to PH, your doctor will schedule a cardiac catheterization, sometimes referred to as a “right-heart cath.” This test allows your doctor to directly measure the pressures in your heart and lungs. Right-heart catheterization is the gold standard for diagnosing pulmonary hypertension.

Could PH run in my family?

Yes, but familial PAH (FPAH) is relatively uncommon. Of the small percentage of people who do carry the PH gene, only a small number of carriers will develop the disease. Genetic testing is available to find out if you carry the PH gene.

Why is it important to see a PH specialist?

PH is a rare but serious disease, and most generalists have little training or experience in diagnosing and treating PH. Patients are encouraged to see a doctor who has undergone extensive PH study and training. A PH specialist is usually a cardiologist, pulmonologist or rheumatologist who treats many PH patients. These specialists are familiar with PH medications and side effects, and can determine which treatments or combination of therapies are right for you.

How can I find a PH specialist in my state?

The best way to find a PH specialist in your state is through the “Find a Doctor” directory on the Pulmonary Hypertension Association website: www.PHAssociation.org/FindADoctor

What questions should I be asking my medical team?

Keep a list of your questions between appointments, and don’t be afraid to ask why your doctor is running a test, scheduling a procedure, or changing a medication. At your first appointment, you might consider asking:

- How often should I come to see you?
- How often do I need to have cardiac catheterization?
- What are potential side effects of my medication?
- What do I do if the line leaks or comes out?
- How do I need to alter my daily routine to accommodate the pump?

If you wear a pump for your medication, you might want to ask:

- What do I do if the line leaks or comes out?
- How do I need to alter my daily routine to accommodate the pump?

You may also want to discuss lifestyle changes, such as nutrition and exercise, with your PH team.

What medications are available to treat PH?

A number of FDA-approved medications are available for the treatment of PH. These medications are administered in several ways: directly into the vein (intravenously), beneath the skin (subcutaneously), orally, and via inhalation. Some PH medications work by mimicking prostaglandin, a substance that PH patients tend to be deficient in. These treatments are called prostacyclins and include epoprostenol (Flolan™), treprostinil (Remodulin™ and Tyvaso™), and iloprost (Ventavis™).

Other PH medications work by reversing the effects of endothelin, a substance that PH patients tend to have in excess. These are called endothelin receptor antagonists and include bosentan (Tracleer™) and ambrisentan (Letairis™).

Still other PH treatments work by allowing the lungs to produce more of their own natural vasodilators. Called PDE 5 Inhibitors, this category of treatment includes sildenafil (Revatio™) and tadalafil (Adcirca™).
Doctors may also prescribe the anticoagulant warfarin (Coumadin™) to prevent blood clots, diuretics to reduce fluid retention, and supplemental oxygen to help patients breathe.

How will my doctor determine which treatment is best for me?
Your doctor will take into consideration the severity of your illness (referred to as your “functional class”) and the results of your cardiac catheterization to help determine which medication is right for you. As your symptoms and pressures change, your doctor may want to adjust the type and dosage of your medication accordingly.

How long do I have to live?
There’s no simple answer to this question. Every PH patient is different, and new research with the potential to improve the outlook for this disease is being conducted all the time. Your journey with PH depends on many factors, including the severity of your disease and how you respond to treatment. PH-specific therapies are available that can prolong and improve your quality of life. Once in the care of a PH specialist and on treatment, many PH patients live for many years.

How will PH affect my life?
While it can be difficult to imagine in the days and months following diagnosis, many patients develop strategies to cope with the physical and emotional aspects of living with PH and lead happy, fulfilling lives. Making small changes in daily activities can make a big impact in how you feel. Listen to your body and rest when you need to. Talk to your doctor about the possibility of supplemental oxygen if you haven’t already. With a bit of patience, planning and flexibility, many patients find ways to work, travel, exercise, and do the things they loved before diagnosis. For more tips on living with PH, visit www.PHAssociation.org/Patients/LivingWithPH

Answers provided by Shiela Bostelman, MSN, CPNP, CCTC, Pediatric Nurse Practitioner, Pulmonary Hypertension Program, Cardiology/Cardiovascular Surgery, Children’s National Medical Center

PHA Launches New Series of Educational Brochures

This spring PHA is launching a new series of brochures about pulmonary hypertension and six associated diseases and conditions. The PH and... brochures discuss the connection between PH and the following: Hereditary Hemorrhagic Telangiectasia (HHT), HIV, Liver Disease, Methamphetamine Use, Sickle Cell Disease and Scleroderma. The brochures were written by members of PH Clinicians and Researchers who specialize in the associated conditions, and translated into “patient-friendly” text with the help of PH Resource Network member Michele Gilbert, RN, MSN, APN, C, CCRN, CNN.

The PH and... brochures are being produced in two series: one for medical professionals and the other for patients and caregivers. These brochures aim to encourage medical professionals currently treating the related illness to treat pulmonary hypertension in partnership with a PH specialist. This series will also educate patients with related illnesses about pulmonary hypertension, increasing awareness about the prevalence of PH in the different disease states and raising awareness about PHA and the many resources PHA has to offer.

The brochures for patients are available online at www.PHAssociation.org/Patients/AssociatedDiseases and will also be distributed to patients and caregivers through related disease organizations and treatment centers across the United States. The brochures for medical professionals are available at www.PHAssociation.org/Medical/AssociatedDiseases. With these brochures, we hope to increase awareness about the prevalence of PH in associated disease patients and provide needed educational resources for patients and members of the medical community. For more information, contact PHA at 301-565-3004.
Medical Education Fund Gains Momentum Entering Second Year

In 2009 PHA introduced four programs as part of the Medical Education Fund: three programs geared toward medical professionals and one for patients and caregivers. These programs met needs for further education and networking in the field of PH, and PHA is excited to move forward with a second year of programming in 2010, maintaining successful elements from 2009 while also adjusting components of the programs to meet the growing needs of our community.

PHA on the Road: PH Patients and Families Education Forum visited four cities in the spring of 2009. In 2010, PHA on the Road will visit two cities in late fall following significant patient education offerings at PHA’s International PH Conference and Scientific Sessions taking place in June. In addition to these two live programs, PHA will introduce a new web-based “Virtual Patient Classroom,” featuring expanded resources for patients and caregivers. This online classroom will include recordings from medically led breakout sessions at Conference 2010 as well as additional online resources. It will be the patient equivalent of PHA Online University for medical professionals.

PHA Online University went live in October 2009 to provide medical professionals at all levels of experience and expertise with the opportunity to access the latest information on PH, engage in networking and discussion with their colleagues and earn free continuing medical education (CME) credits and continuing education units (CEUs). This year will see further expansion of the website and the courses available online.

In 2009, the PHA 30-City Medical Education Program presented information on diagnosis and management of PH in a dinner-symposia format to physicians and allied health professionals in areas that lack recognized experts or PH centers. The PHA Preceptorship Program provided a comprehensive daylong educational program for medical professionals, particularly cardiologists, pulmonologists and rheumatologists, with 10 meetings across the country. Each program will continue into 2010, visiting different cities and PH centers. CME credits and CEUs are available through both programs.

Whether you are a patient, caregiver or medical professional, we hope to see you “on the road,” on the web and around the country in 2010.

The programs of the Medical Education Fund are sponsored by Actelion Pharmaceuticals US, Inc. and Gilead Sciences, Inc. at the Platinum level and United Therapeutics Corporation at the Silver level. For more information about any of the four programs of the Medical Education Fund, visit www.PHAssociation.org/MedicalEducationFund

By Megan Mallory
PHA Publications Manager

Welcome, Rachel Wheat, Medical Membership Program Associate!

As the Medical Membership Program Associate, Rachel is responsible for promoting membership in the PH Resource Network and helping to develop the group’s knowledge and other resources in ways that will benefit the entire PH community. She provides assistance and support to each of the Network’s five leadership committees as they develop organizationally to meet their goals. Rachel also assists in organizing PHA’s biennial PH Resource Network Symposium, the largest educational event in the PH field for allied health professionals. Prior to joining PHA’s team, Rachel had just graduated from James Madison University in Harrisonburg, Va., where she earned a B.S. in Public Health Education and a B.A. in Global Justice Studies and Spanish. She can be reached by email at Rachel@PHAssociation.org or by phone at 301-565-3004 x761.

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.
TRP for Therapy of Pulmonary Arterial Hypertension

The causes of pulmonary arterial hypertension (PAH) remain unknown although many physician scientists and investigators have been busy studying the genetic, molecular and cellular mechanisms of the disease. Regardless of the initial cause, the high pulmonary arterial pressure (PAP) in patients with PAH is caused by an increased resistance to blood flow through the pulmonary vessels (artery and vein). One of the important cellular mechanisms causing increased pulmonary vascular resistance (PVR) is called pulmonary vascular remodeling. This refers to the lung blood vessel wall becoming thickened due to excessive growth of the cells in the blood vessel wall. Narrowing of the bore of the vessel because of a thickened lining and constriction of the lung blood vessels increases pulmonary vascular resistance. Since the right side of the heart must pump blood through a narrow tube, it is forced to do so at a high pressure. This is a basic principle of plumbing. This high pressure is referred to as “afterload” and it places a high workload on the right ventricle. Since the right ventricle was not designed to work at such a high pressure, it eventually weakens, a condition known as right heart failure.

During the last 20 years, clinicians and investigators have made significant progress in figuring out the genetic and molecular mechanisms involved in pulmonary vascular remodeling and in developing new drugs for patients with PAH. Current treatment for PAH includes:

A. **Conventional therapy**, e.g., diuretics, oxygen therapy, anticoagulation (warfarin), digoxin, and exercise;

B. **Advanced therapy**, e.g., calcium channel blockers (nifedipine, diltiazem, verapamil, amlodipine), prostacyclin (epoprostenol, treprostinil, iloprost), endothelin receptor antagonists (bosentan, ambrisentan), phosphodiesterase (PDE) inhibitors (sildenafil, tadalafil), and combinations of these drugs; and

C. **Surgical therapy**, e.g., lung transplantation, living-donor lobar lung transplantation, and creation of a hole in the wall separating the right and left atria.

Furthermore, physicians are conducting clinical trials on several new drugs, e.g., serotonin antagonists (ABT-306552, PRX-08066), tyrosine kinase receptor blockers (imatinib) and vasoactive intestinal peptide. In addition to these therapies, doctors and researchers have been working very hard to find new drug targets and to try to develop new therapeutic approaches for PAH.

In pulmonary artery smooth muscle cells (PASMC, one of the three major cell types that form the lung blood vessel wall) an increase in calcium ions inside the cells is a major trigger for pulmonary vessel constriction and wall thickening. Narrowing of lung blood vessels because of vasoconstriction and vascular wall thickening, as mentioned earlier, increases pulmonary vascular resistance and pulmonary arterial pressure, and ultimately causes pulmonary hypertension. Recently, investigators have identified a mutation in the gene of the transient receptor potential channel, subfamily C, member 6 (TRPC6), in some people with idiopathic PAH. TRPC6 gene is responsible for making a protein that controls one way in which calcium ions enter the PASMC. Interestingly, the function of this protein is not affected by conventional calcium channel blockers (e.g., nifedipine, diltiazem, verapamil, amlodipine). The TRPC6-encoded calcium channels allow calcium ions to enter PASMC, causing pulmonary vessel constriction and pulmonary vascular wall thickening. When there is a variation (or mutation) in the gene (as occurs in 12% of patients with idiopathic PAH), the calcium channels which the gene is responsible for allow more calcium ions to enter the cells and, ultimately, increases PASMC proliferation and causes lung vascular wall thickening. This seems to be provoked as part of an inflammatory response. Thus, if there were a way to control the TRPC6 calcium channel in PASMC membrane it may provide another possible way to treat idiopathic PAH patients, especially those with damaging variations in the TRPC6 gene.

Of course, idiopathic PAH appears to have a variety of causes involving multiple genetic, molecular and cellular abnormalities. Mutations or variations in genes responsible for bone morphogenetic protein receptor type II (BMPR2), activin receptor-like kinase...
1 (ALK1), serotonin transporter (5-HTT) and transient receptor potential cation channel (TRPC6) have been linked to idiopathic PAH. However, mutations or variations in all of these genes have been found in only a small portion of idiopathic PAH patients. It seems like the abnormality in each of the genes is important by itself, but none of them is sufficient to cause the disease. Therefore, the causal mechanisms of idiopathic PAH may involve abnormalities in multiple genes and gene products. This leads to the notion of the “multiple-hit” theory proposed by many investigators. For instance, inheritance of mutations in TRPC6 and other genes (e.g., BMPR2, 5-HTT, ALK1), followed by exposure to viral (and/or bacterial) infection, inflammatory factors and diet pills (e.g., Fen-Phen) may cause changes in the lung blood vessels that lead to idiopathic PAH.

Genomic and personalized medicine is one of the most promising avenues for advances in diagnosis, prevention, and treatment of human disease. This refers to the concept that treatment can be tailored to the genetic make-up of an individual patient. Personalized respiratory medicine or personalized pulmonary vascular medicine will undoubtedly provide a new concept for practical use of genome-based information in clinical medicine. Personalized approaches to treatment of idiopathic PAH in the future will rely on genomic and genetic information obtained from the individual patient and the combination use of drugs targeting different genes and gene productions. Each patient with idiopathic PAH may have different genetic and molecular causes and require different therapeutic approaches. Translation of genome information from an individual patient into effective therapeutic treatment is an important research topic. Combined efforts from clinicians, investigators, and patients are needed to achieve this goal; let the new trip for therapy begin now.

By Jason X.-J. Yuan, MD, PhD, Professor of Medicine, University of California, San Diego, La Jolla, Calif., and Michael D. McGoon, MD, Professor of Medicine, Mayo Clinic, Rochester, Minn.

HELP WANTED:

Help *Pulmonary Hypertension: A Patient’s Survival Guide* remain a treasured resource for years to come!

The *Survival Guide*, an important and necessary resource for the PH community, is currently being updated twice a year. We are looking for medical professionals and patients to become part of this process through one of the following roles:

- **Patient Reviser**
  We are looking for PH patients with strong writing and editing skills and an interest in the role of writer and reviser for the *Survival Guide*.

- **Medical Professional Reviser**
  We are looking for medical professionals with an interest in the role of reviewer and editor for the *Survival Guide*.

- **Publication Content Migrator**
  We are looking for people who have experience migrating text from Quark to InDesign.

Please contact Patti at Guidewriters@PHAssociation.org to learn more!
The warm, murky water froths as several waves of lean, athletic machines fight their way to the front of the pack. Swimmers unable to escape from the flock pray to survive the gauntlet. The pack thins out as the race goes on. I leap out of the water, running to the transition zone approximately 25 minutes after the 0.6-mile swim. “Chaos” is the best description of athletes trying to find their bikes among hundreds, while rushing to change and replenish their calorie tank in the transition zone. I zoom out into the desert for a 16-mile bike ride as the blazing sun scorches my back. Pedaling with all my might, I enter transition zone two. As I jump off the bike, I grab several cold water sponges to cool my over-heated body and prepare myself for the 3.25 mile run (jog for me) in the dry 110 degree desert.

I didn’t win, but I finished the Las Vegas sprint triathlon. I am one of those adventurous types. If I come across a new trail, I take it. If the ocean is freezing cold, I swim faster. If it’s not fun, I don’t do it. I am an athlete with IPAH. Why do I do what I do? Because PHA and the PH community have made it possible for me. This community has allowed, inspired and empowered me to live my life. I learn from my past, plan a little for the future, and most certainly live in the present.

In that present, I’m not a professional athlete. I am a PH pharmacist. I was diagnosed with IPAH in 2006 as a fourth year Pharm.D. student at Western University of Health Sciences. While studying to become a healthcare professional, I didn’t know anything about the disease. PH was not part of our school curriculum, and I wanted to change that. As the class officer at the time, I organized a Lunch and Learn event to increase awareness about PAH among my colleagues. Almost everyone in the college came to my presentation. At the end, there were tears on many of the faces of the 150 students and staff in attendance.

I earned my Pharm.D. degree in 2007, but I’ve been back every year to increase awareness through more Lunch and Learn events. The most recent one was this past November. I presented an overview of PAH, which covered epidemiology, pathophysiology, diagnostic tests and drug treatments. I made the awareness session interesting by presenting limited information about a patient’s case. Then I ruled out diseases over the course of the lecture, eventually leading to the diagnosis of IPAH. Afterward, a few students emailed me for my presentation so they could present on PH to their colleagues.

It’s important to educate the next generation of healthcare providers about PAH. When I was an intern, I didn’t learn anything about it. The students and professors that came up to me after the talk told me they’d never even heard of this orphan disease. Raising awareness, however we can, is what will get us to our goal. Gail Boyer Hayes, author of Pulmonary Hypertension: A Patient’s Survival Guide, once said, “If a village is needed to raise a child, then the whole world is needed to find a cure for PH.” And that has stuck with me.

I do all I can with the energy I have. IPAH affects my life, but IPAH does not stop me from living. I went from WHO class IV to WHO class I, but as many PHers know, we have our good days and bad days. These ups and downs have taught me a few lessons. I keep my friends close and my family closer. I know I’m not alone. I strive for my best, but not perfection. To other PHers, I’d like to say: there is hope. Ten years ago they said we had two years to live, but now there are treatments. Be inspired; four years ago I couldn’t dress myself, and now I am a practicing pharmacist, an advocate for PAH awareness and a triathlete. In May, I plan to finish my first IronMan 70.3 (which consists of a 1.2-mile swim, 56-mile bike ride and 13.1-mile run) in Orlando, Florida. I can do anything, so I try everything.
PHA-UK’s Breathe Freely Campaign Flies High

As in the U.S. and many parts of the world, the guarantee of in-flight oxygen aboard airlines in the United Kingdom has not come easily. Until recently, many airlines in the UK charged for in-flight supplemental oxygen and the vast majority wouldn’t let passengers bring their own canisters or portable oxygen concentrators. PHA-UK, through a campaign called Breathe Freely, helped to change this business practice.

PHA-UK, under the leadership of its Chairman Iain Armstrong and Secretary Kay Yeowart, joined forces with the British Lung Foundation to mount this campaign. “It is incredible and, I believe, unacceptable that in the present [National Health Service], individuals have had to fund their own ability to breathe,” Chairman Iain Armstrong says.

In early fall 2009, several PHA-UK members engaged in “secret shopper” research to investigate 71 airlines that fly to and from the UK. Their findings revealed a bewildering lottery of surcharges, policies and woeful customer service facing the estimated 90,000 potential “fit to fly” disabled air travelers with lung conditions that require supplementary oxygen in flight.

Using “secret shopper” research and additional information, the PHA-UK campaign’s team was able to persuade British Airways, Cathay Pacific, Emirates, Thomson’s Airways and First Choice Holidays to drop charges for the provision of oxygen in flight. The team also influenced a great many other airlines to allow passengers to bring their own supply or portable equipment.

This airline oxygen victory comes on the heels of PHA-UK’s success in persuading N.I.C.E (National Institute for Health & Clinical Excellence), the British Government’s Drugs Watchdog, to abandon its plans to withdraw PH treatments and change the way PH would be managed in the UK.

Full details on the Breathe Freely campaign, including video from the Parliamentary debate on airlines and oxygen and the PHA-UK “secret shopper” research, can be accessed on PHA-UK’s website at the following address: www.phassociation.uk.com

Reflections from one secret shopper, 60-year-old Sonia Campbell from North London (diagnosed with PH in 2004)

I discovered that every airline had different polices/guidelines and prices. Some were fairly clear and others baffling. The final cost, depending on journey, could be high: the cost for a two-hour flight could be the same as a 10-hour flight. One required a passenger using oxygen to have someone flying with him/her. Another required you to buy an extra seat for the oxygen! I must add that the extra seat was at the price before added tax. Sometimes information wouldn’t be given until you booked your ticket, which could cause problems. There were also restrictions as to how many oxygen-using passengers can be on each flight.

Updated Media Outreach Tools Available on PHA’s Website

More than 150 people have already used free PHAware Campaign materials to raise awareness of PH in their communities by sharing their stories with local media. Now, sharing your story is even easier with PHA’s updated online Media Guide.

Visit www.PHAssociation.org/PHAware for tips and resources to help you connect with local news outlets.

- Share your personal story.
- Promote your PH events and meetings.
- Spread the word about PH with public service announcements.

Of course, PHA’s print Media Guide is still available! To order, or to learn more about joining the PH Aware Campaign, contact Elisabeth at Awareness@PHAssociation.org or 301-565-3004 x753.
Put Your Time, Talent and Treasure to Work for the PH Community

**Put Your Time, Talent and Treasure to Work for the PH Community**

For PHers may live all over the world, but through PHA, we form a community of people who care about and support one another. We invite you to put your time and talent to work by getting involved in one of the programs described below or by supporting PHA with your “treasure” by making a donation, including us in your estate plans, or becoming a member.

<table>
<thead>
<tr>
<th>Program</th>
<th>Description</th>
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<tr>
<td><strong>WEB OF FRIENDS</strong>*</td>
<td>Raise awareness and funds when you invite your friends and family to support you with a gift to PHA. You can share your story online in just minutes through PHA’s Web of Friends program. If you prefer letter writing, our Circle of Friends program is right for you. <a href="http://www.PHAssociation.org/Fundraise/Online">www.PHAssociation.org/Fundraise/Online</a></td>
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<tr>
<td><strong>OUR WORKPLACE HAS A HEART</strong></td>
<td>PHA’s Our Workplace Has a Heart lets you, your friends and your family raise both awareness and funds at work. Our creative, updated toolkit gives you step-by-step guidance on hosting a variety of friendly events that will raise funds for PHA and educate your co-workers about PH. You can also support PHA through the Combined Federal Campaign (CFC #12097) and other employee fund drives. If your company has an employer matching gifts program, you may be able to double the impact of your gift. <a href="http://www.PHAssociation.org/Fundraise/AtWork">www.PHAssociation.org/Fundraise/AtWork</a></td>
</tr>
<tr>
<td><strong>IN HONOR OF OUR LIVES</strong></td>
<td>Whether you are celebrating a wedding, birthday, anniversary or other milestone, invite PHA into your festivities. Support our cause by asking your guests to make donations to PHA in lieu of gifts or make a donation in honor of your guests in lieu of party favors. PHA’s customized cards make this easy to do. <a href="http://www.PHAssociation.org/Fundraise/AtCelebrations">www.PHAssociation.org/Fundraise/AtCelebrations</a></td>
</tr>
<tr>
<td><strong>SPECIAL EVENTS</strong>*</td>
<td>From fun walks to golf tournaments to galas — to [your idea here] — hosting special events for PHA is a great way to raise awareness and funds. Most events are planned by a team of volunteers making event planning fun, rewarding and relatively easy. We have tons of resources and staff support to help you. <a href="http://www.PHASpecialEvents.org">www.PHASpecialEvents.org</a></td>
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**Investing Your Treasure in PHA**

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<th>Program</th>
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<tr>
<td><strong>GENERAL DONATIONS</strong>*</td>
<td>Your generosity helps PH patients, family members and our medical community in so many ways. Use the envelope included in this issue or log on to <a href="http://www.PHAssociation.org/Donate">www.PHAssociation.org/Donate</a> to make a gift today to PHA.</td>
</tr>
<tr>
<td><strong>SUSTAINERS CIRCLE</strong></td>
<td>Help keep hope alive by making a monthly donation via your credit card or checking account. Monthly giving is a great way to support our cause, honor a friend or loved one, or remember someone who has passed. <a href="http://www.PHAssociation.org/Donate/MonthlyGiving">www.PHAssociation.org/Donate/MonthlyGiving</a></td>
</tr>
<tr>
<td><strong>LEGACY OF HOPE SOCIETY</strong>*</td>
<td>PHA’s Legacy of Hope Society recognizes those who have included PHA in their estate plans. Achieve your financial and charitable goals, while helping secure the future of the PH community of hope. Our print and electronic resources will help you decide if this option is right for you. <a href="http://www.PHAssociation.org/Give">www.PHAssociation.org/Give</a></td>
</tr>
<tr>
<td><strong>MEMBERSHIP</strong></td>
<td>By joining PHA, you not only receive personal benefits, you join thousands of others in supporting patient, family and medical professional services, expanding research and education, building awareness of PH, and changing the history of this illness. <a href="http://www.PHAssociation.org/Join">www.PHAssociation.org/Join</a></td>
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**CONTACT**

* Jillian McCabe: 301-565-3004 x767, Jillian@PHAssociation.org  
** Jennifer Kaminski: 301-565-3004 x756, JenniferK@PHAssociation.org  
*** Jess McKearin: 301-565-3004 x765, JessicaM@PHAssociation.org
On March 5, Jack Stibbs, a member of PHA’s Board of Trustees and PHA’s attorney, received the Service of Excellence Award for his work on behalf of youth. This award was presented by Interfaith of The Woodlands, a faith-based community service organization, during its annual “Five Who Share” awards luncheon in The Woodlands, Texas.

More than 10 years ago, Jack’s daughter Emily was diagnosed with PH at the age of five. Since that time, Jack and his family have been significant supporters of the PH community and our shared goal of finding a cure for PH. His family hosted a golf tournament to raise funds for research every year from 1999-2008, and they inaugurated a new fundraiser — Crawfish and a Cure: Annual CurePH Bug Boil — in 2008. This year, the Stibbs and CurePH are expanding the scope of their “bug boil” by partnering with The Woodlands Chamber of Commerce to host The Woodlands Crawfish Festival, scheduled for March 27 in The Woodlands, Texas. Jack and his wife Marcia are also members of PHA’s Legacy of Hope Society, PHA’s recognition program for individuals who include PHA in their estate plans. Describing her father, Emily says, “My father has sacrificed so much … and is truly a man of compassion and perseverance.”

According to Interfaith, in addition to his contributions to the PH community, Jack has devoted his time to helping others over the years, enriching the lives of young people and helping to raise money for various events. Jack has assisted and provided fundraising knowledge and support for several fundraising activities benefiting children and youth, including the Rett Syndrome Stroll-a-Thon and the B-SIMP Golf Tournament. He is currently involved with planning a dodgeball tournament for children and youth.

**WHO WANTS TO CURE PH MORE THAN YOU?**

**DEFEATING PH CAN BE MORE THAN A WISH. IT CAN BE YOUR LEGACY.**

PH hasn’t just touched your life. It’s the major issue you or a loved one must confront every day. So defeating this condition for all time has taken on a very special, very personal meaning.

Please consider making a legacy gift to the Pulmonary Hypertension Association. It will help us expand the fight against this condition and continue our work to advocate for new PH research, raise awareness within the medical community and provide patient support. It will also serve as your personal expression of ongoing support for the people and families bonded together in their struggle with this disease.

Personal contributions represent a major source of funding for PHA. Please contact us to find out about the many ways you can make the legacy gift that keeps on fighting. Call us at 301-565-3004 x767 or email Giving@PHAssociation.org. Visit our website for more information at www.PHAssociation.org/Give
In November, during Awareness Month 2009, PH patients and their friends, family and medical professionals shared their hope for the future. They talked with reporters, elected officials and their neighbors about their vision of a world where PH is easily diagnosed and easily treated, even cured. By channeling their hope into action, these everyday heroes helped propel the PH community toward the time when that vision is a reality.

In these pages, we’ve highlighted just a few of the hundreds of Awareness Month victories the PH community has to celebrate. We hope they’ll inspire you to continue the progress we’ve made by sharing your own story. There’s no need to wait for November; PHA staff can help you get started today.

Spreading the Word through the Media

During November and early December, PHA identified 20 news stories that included profiles of PH patients or physicians, 19 of them PHA members.

One of those stories was about Norma Morey from Massachusetts, who kicked off Awareness Month with a huge victory when her story appeared in her local paper on October 31. “I just want people to know, if your doctor tells you [that] you have emphysema and they put you on medicine that doesn’t seem to be working, ask. Go further. Find out,” says Norma. It took seven years for Norma to be properly diagnosed, which is one reason she’s now so committed to raising awareness.

PH patients Carol Lindstrom and Annette Markin, along with other members of the PH awareness group known as the Periwinkles, were featured in multiple papers in Nebraska for their efforts to secure Awareness Month proclamations. Nebraska Governor Dave Heineman signed a proclamation making November Pulmonary Hypertension Awareness Month during a visit from the group (pictured below).

PH patient Diane Ramirez appeared in the fall issue of the Davidson County Focus. The article quotes her as saying, “Because of my story of survival and strength, I am now a committed patient advocate trying to share my story with other patients, at-risk individuals and the medical community.” Twenty-two thousand copies of the magazine were distributed to 100 locations in Davidson County, North Carolina, including all hospitals, doctors’ offices and physical therapy centers.

If you would like to share your story with the media, PHA can help. Visit www.PHAssociation.org/PHAware or call 301-565-3004 x753.

Requesting Proclamations for PH Awareness Month

November saw the presentation of more than a dozen Awareness Month proclamations to members of PHA’s grassroots advocacy network, the 435 Campaign. Campaign member Doug Taylor (pictured below) shared these words of wisdom about his experience requesting a proclamation: “November’s designation as Pulmonary Hypertension Awareness Month brings many opportunities to further the cause of PH awareness and education. One of those opportunities is asking state and local governments to issue proclamations or resolutions recognizing the designation. For years, I sat back and watched others request and get awareness proclamations from their county councils, city councils or even their governors, and I thought, ‘I wish I had connections like that.’ This year I found out that getting a proclamation doesn’t require connections. I requested four proclamations and two were approved. There really is no down side to requesting a proclamation recognizing November, and as it turns out, it doesn’t require connections in government. All it takes is the courage to ask.”

PHA knows that city or state proclamations were presented in Idaho, Maine, Nebraska, South Carolina, Tennessee and Texas. If you know of others, please...
educating members of congress

At PHA’s 2009 congressional luncheon, Jeanette Morrill outlined her PH journey, which includes a 20-year wait between being diagnosed and meeting another patient. Pam Pederson shared her family’s PH story, from the loss of their young son to the challenges faced by their daughter since her diagnosis 20 years ago. Dr. Paul Hassoun helped the audience of PH patients, family members and congressional staff better understand how PH impacts the body.

The luncheon included special guests Rep. Kevin Brady (R-Tx) and Mrs. Annette Lantos, wife of the late Rep. Tom Lantos. Rep. Brady has sponsored a PH specific bill in the house of representatives since 2000. This year PHA honored him and rep. Lois Capps (D-CA) with our distinguished public service award. Mrs. Lantos gave moving testimony to the need for additional PH research, describing her granddaughter Charity’s struggles since her recent transplant.

PH patients came from five states to attend the congressional luncheon, traveling from as far away as Maine. They didn’t stop to rest after lunch, though. Instead, they visited Members of Congress and shared their stories, building additional support for the Tom Lantos Pulmonary Hypertension Research Act of 2009. One visit led directly to the introduction of the bill in the Senate! (See p.24 for more on the PH bill in the Senate and how you can help move it forward.)

To find out more about how you can get involved and spread PH awareness all year long, visit www.PHAssociation.org/GetInvolved

by katie kroner
PHA director of advocacy and awareness

Thank you for caring…
Thank you for sharing…

Every individual can make a difference. This is something that we see every day at PHA and it is something we saw with each donation to PHA’s 2009 end of year fundraising campaign. Your support helped us meet the generous $22,500 matching challenge from Pfizer, and it will help support the PHA programs and services that so many depend on. Together we will change the future of pulmonary hypertension and its impact on our community. Your gift is a testimonial to the work PHA has done and support for all that remains to be done. Our heartfelt thanks to all!!

Pathlight Survey Results are In!

PHA wishes to thank the many readers who responded to our brief Pathlight survey. You, our readers, rated Pathlight on three questions and sent helpful and informative comments and suggestions. The graph below shows the average response we received to each question. This is your publication. Your involvement shapes Pathlight into a useful and effective newsletter for the PH community, and we thank you.

Question 1: Pathlight reflects the voice of the PH community and all of its constituents.
Question 2: Pathlight provides information that helps PH patients live better daily lives.
Question 3: I look forward to receiving Pathlight every quarter.

Strongly Agree
Strongly Disagree

4.3
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Pathlight Spring 2010

PH Helpline: 1-800-748-7274
Advocacy in Action

By Katie Kroner
PHA Director of Advocacy and Awareness

Patient Visit Leads to PH Senate Bill: Your Follow Up Needed!

After regular contact from the Pennsylvania PH community and a visit from PH patient Colleen Connor and her family during PHA’s 2009 Congressional Luncheon, Senator Bob Casey agreed to introduce the Tom Lantos PH Research and Education Act in the Senate.

Now, it is up to the PH community to move the bill forward and let Senator Casey know he did the right thing by getting your senators to co-sponsor.

The bill (S. 2803) is identical to the one that passed the House of Representatives in 2008, and you can ask your senator to co-sponsor it in one of three easy ways:

» If you are able, schedule a visit with staff at your senators’ nearest offices.

» If a visit isn’t an option, consider using PHA’s advocacy talking points to make a phone call.

» Or use PHA’s pre-written message to easily create and send an email to your senators right from our website.

Appropriations Bill Provides Continued Funding for PHA

In mid-December, President Obama signed the fiscal year 2010 appropriations bill for the Department of Health and Human Services. The legislation includes “$250,000 for the Pulmonary Hypertension Association, Silver Spring, Md., for a pulmonary hypertension prevention and awareness initiative.”

This is the third year that PHA has received federal funding of this kind for its awareness initiatives. The funding supports our PHA Online University and PHAware Campaign.

Fiscal year 2009 funding also supported a relationship that is new for PHA — a short-term contract with public relations firm Environics Communications (ECI). ECI’s work to raise the profile of PH and PHA among health reporters has resulted in several news hits including print and radio interviews with PHA President Rino Aldrighetti.

New Insurance Guide Available and Still Growing

With the launch of our new website, PHA’s Online Insurance Guide is one step closer to being complete.

Visit the insurance section to:
• Learn about your insurance rights.
• Find materials to help you make a claim or appeal.
• Learn how you can get involved with building our insurance program.

Stay up-to-date! Sign up to receive email notifications when we add a new section. Visit www.PHAssociation.org/Patients/Insurance or contact Margaret at 301-565-3004 x773 or Margaret@PHAssociation.org.
Southern California Support Groups Excited to Welcome PHA’s International PH Conference and Scientific Sessions

Southern California is home to many vibrant pulmonary hypertension clinics and support groups, and our groups are found all around this region, including the major metropolitan areas of Los Angeles, San Bernardino, Orange County and San Diego.

Our Southern California groups organize golf tournaments (the Wojo Group of South Orange County), fun walks (San Diego), silent auctions (Harbor-UCLA) and even holiday parties that take place on boats (Newport Beach, see p.28). Our groups bring together families with young children who have PH (Los Angeles Pediatric), and provide all patients with support and education. Group leaders include patients, parents, caregivers and medical professionals, and some of our leaders are working to launch the first Spanish-speaking group for patients in the area.

The leaders of the Orange County support groups are excited to help serve on the “local welcome committee” for PHA’s International PH Conference this summer. And they are looking for local volunteers for assistance in the weeks leading up to Conference. Please contact Betty Lou Wojciechowski at bettylouwojo@hotmail.com for more information.

If you plan to travel to California for PHA’s International Conference this summer, be sure to check out the local support groups!
Caring for the Community, Coping through Cartooning: Profile of a Support Group Leader, Leslie Polss

Shortly after being diagnosed with pulmonary hypertension, Leslie Polss, from southeastern Penn., sought information on the disease by attending PHA’s 2004 International PH Conference and Scientific Sessions in Miami, Fla. It was the first time she met another patient, and it was also the first time she was encouraged to participate in her local support group. As Leslie explains, “Vivian, a member of the Delaware Valley PH Support Group, noticed my name tag and that I was from her area. She told me about the local group, and when I returned to my room, I had a message from the leader of the group. I wasn’t convinced that I would attend because I didn’t think of myself as a ‘support group’ kind of person and didn’t think I would go regularly. But I did. And it turns out the group gave me exposure to research and a way to get connected to what’s going on.”

Just two years later, at PHA’s next International PH Conference in Minneapolis, Minn., people would start to recognize Leslie by her name and her skill. Leslie is an artist who copes with her PH by drawing cartoons. She created a line of PH-specific cartoons called SOB (shortness of breath). They were a hit at her local support group, and her doctor used her art in a chapter about patients’ stories in a PH textbook he created for medical professionals.

As Leslie continued to come to support group meetings with some regularity, she found herself becoming more and more involved, not only with her artwork but also as a leader and a speaker on PH topics. She currently helps lead her local support group, and she was a speaker at several sessions at the 2008 PHA International PH Conference and Scientific Sessions in Houston, Texas. She shared her insights as a patient and an oxygen user in the workplace, offering tips on how to manage a heavy schedule, workload and the disease. She also spoke as a panelist at “Words for Wellbeing,” a session describing the health benefits of creative expression. She’s been asked to speak at PHA’s 2010 International PH Conference in Garden Grove, Calif., to motivate and inspire others in the PH cause.

As someone who did not initially see herself as an active member of the PH community, Leslie was surprised when PHA originally asked her to create artwork for PH campaigns. She says, “When you first asked me to do this, I thought, why would you want to talk to me? I haven’t done anything great. I haven’t done huge events and haven’t raised tons of money. But I am happy to use the talents that I have; it allows me to do something for the organization that not a lot of people can do.”

That was in 2005. Fast-forward five years and her work is everywhere. She has contributed artwork for logos, banners, postcards and much more. If you’ve ever received a meeting announcement for a local support group, you’ll instantly recognize her work, and she continues to contribute. Leslie also designed the kids mascot for PHA’s upcoming 2010 International PH Conference (see p.49).

We are excited to hear that she is making her SOB cartoon strip into a graphic novel. To see more of Leslie’s SOB cartoons, visit www.sobtoons.com.

By Debbie Castro
PHA Director of Volunteer Services

Why a Cartoon Strip on PH?
Leslie in Her Own Words...

I am a little surprised by the reaction about it, but one of the things I’ve said in the past is that the appeal of the cartoon, the strip, is its ability to express all the indignities of life with PH without being too heavy about it. It’s a nontaxing way of letting people know what it’s like.
### Latino Support Group Launches in South Florida

In November 2009, 22 Latino members of the PH community — eight patients and 14 family members — met for the first time in South Florida with the goal of providing hope for life and raising PH awareness among the Latino population. They plan to meet monthly, and follow their motto that, “Life is a matter of positive attitude more than physical limitations.”

Led by PH patients Migdalia Denis, Nora McKeehan and Mónica Ossorio, the first meeting of the Latino Support Group of South Florida saw the emotional relief of its participants as one of its biggest achievements. “Everyone introduced themselves and shared their personal PH journeys. Although this was our first time together, we created a comfortable and warm atmosphere where we could freely express our deepest feelings. All of us cried and laughed a lot; it was very emotional,” Migdalia remembers.

In addition to emotional support during that first meeting, the group leaders provided some general information about PH, distributed brochures in Spanish about PH symptoms and treatments, and addressed the topic of depression in PH patients with the aim of helping them manage emotions.

For future meetings, they plan to host different specialists to give patients and family members useful insights about both serious and informal topics related to PH. They will also distribute new informative guides for patients in Spanish.

The Latino Support Group of South Florida is the fourth Spanish-speaking PH support group in the U.S. The other three are based in Texas (one group) and Puerto Rico (two groups). Find out how to contact these groups by visiting the support groups section of PHA’s website at [www.PHAssociation.org/LocalSupportGroups](http://www.PHAssociation.org/LocalSupportGroups).

### PHA Unveils New Spanish Outreach Program

For nearly 20 years, PHA has been the go-to source of information and support for pulmonary hypertension patients in the U.S. This year we’re excited to offer new programming to our Spanish-speaking community here and abroad. Thanks to the work of volunteers and PHA International Intern Laura Gil Gonzalez, we’re able to better connect with the many Spanish-speaking patients, families and medical professionals in the PH community. From support groups in Texas, South Florida and Puerto Rico — where PHA support group leaders and volunteers have been pounding the pavement to create stronger communities — to the brand new (and much improved!) Spanish resources web page, PHA is excited to be able to better serve our Spanish-speaking community.

If you’re a Spanish-speaking patient, friend or medical professional, the PH community needs you!
Support groups help to create a sense of community for patients and provide education, support, and awareness to both patients and caregivers. And our support groups also know how to party! While most meetings throughout the year provide valuable education, support and idea sharing, our groups like to let their hair down at least once a year for a holiday celebration and gathering.

In 2009 economic challenges and changes in pharmaceutical company guidelines affected the way drug companies sponsor support group meetings. To address these challenges, PHA worked with pharmaceutical companies to launch the PHA Support Group Central Fund, which provides financial assistance for support group meetings throughout the year and allows many of our groups to host their regular holiday parties.

Holiday events took place everywhere from Florida to Hawaii and Maine to Arizona. At the Newport Beach Support Group holiday meeting in California, they got their towels ready, broke out the flip-flops and sunscreen and held their party on a boat! Okay, maybe the weather was not completely amenable to wearing flip flops, but this was a fantastic party idea for a group located in an area not covered in snow. Over a delicious dinner, the group discussed plans for future activities, upcoming meetings and the quickly approaching 2010 PHA International PH Conference and Scientific Sessions being held in their own backyard.

In South Carolina, the Midlands PH Support Group met in mid-December and had 45 people attend their “Hope for the Holidays” meeting. Group leader and PH patient Doug Taylor excitedly informed PHA that they had a fantastic presenter, Dr. Vic Tapson, Professor of Medicine at Duke University. They also gave out donated door prizes and had “scrumptiously good food,” Doug says.

The Minnesota PH Support Group held its holiday party on January 9, 2010. About 40 patients, caregivers, family members, medical professionals and pharmaceutical representatives enjoyed food, fellowship and a gift exchange. “It was a feast for the holidays to celebrate everything we have accomplished with our patients and support group,” explain group leaders Stephanie Layer and Kim Faber. “Our first and most important goal is to help and support PH patients and their families through good and bad times, and we feel it is so important to take time twice a year to celebrate life! ... We want to thank the PHA Central Fund for granting us the funds needed to put on this event.”

In total, 22 support groups held holiday meetings sponsored by the PHA Support Group Central Fund. The Fund is currently made possible by sponsorships from Actelion Pharmaceuticals US, Inc. at the Platinum level and Teva Pharmaceuticals at the Bronze level. For more information about the PHA Support Group Central Fund or to apply for funding, contact Greg at 301-565-3004 x758 or Greg@PHAssociation.org.

By Greg Gershuny
PHA Grants Coordinator

Newport Beach Support Group members party on a boat.

Members of the Midlands PH Support Group in South Carolina enjoy clowns around at their holiday party.

Members of the Minnesota Support Group gather for their holiday party.
Summit Success: PHA’s Kilimanjaro Team Conquers Africa’s Highest Peak

On Friday, February 26, Dr. Robert Frantz (Mayo Clinic), Dr. Ray Benza and physician’s assistant Jessica Lazar (both from Allegheny General Hospital) reached the 19,341 foot summit of Mt. Kilimanjaro in Tanzania, Africa, in an effort to raise global awareness of PH and funding for PHA’s cutting-edge research program and patient services.

Preparations for the team’s seven-day ascent up Africa’s tallest mountain began last summer as Dr. Benza and Jessica ran their hospital’s stairwells and the hilly Pittsburgh terrain, and it continued well into the 2009 holiday season as Dr. Frantz ran in the frigid temperatures of the state he dubbed “Minne-snow-ta.” This training, coupled with a long and difficult trek, paid off once the team stood at the roof of a continent.

Jessica remembers her first glimpse of the mountain as both spectacular and intimidating. “At one point,” she says, “I saw light and dark and thought it was the clouds but realized it was the mountain.”

In addition to raising funds and awareness for PH, these dedicated healthcare professionals scaled the heights to gain a better understanding of what it means to be a PH patient. Exposed to extreme altitudes with low oxygen levels, the team developed a temporary case of pulmonary hypertension.

Of his mountaintop experience, Dr. Benza says, “It was simply astounding being on the top of that mountain … and today it was hard to breathe with each step. We were stressed. It’s exactly what our patients feel … so it really gave us even much more of an appreciation for what our patients have to suffer every day of their lives. And that really, really endeared us to them that much more.”

At press time, the climbers’ campaign, named Path to a Cure, has raised more than $110,000. PHA thanks Actelion Pharmaceuticals US, Inc. for their support of the climb as the Path to a Cure Matching Partner, matching every donation up to $50,000, and Gilead Sciences, Inc. for donating the services of their public relations firm, Weber Shandwick. Learn more about Path to a Cure and be part of the journey at www.PHAssociation.org/PathToACure

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The team displays the Path to a Cure flag at Mt. Kilimanjaro’s summit.

STORY CONTINUED FROM PAGE 10

of oral medications. Everyone wants to learn more … to develop better drugs. And there’s an energy surrounding new research that’s so vibrant.

Dr. Frantz: Actually, I’m trying to keep looking forward. We’ve come a long way, and having treatment options is a blessing. But what’s most exciting to me is that we’re on the cusp of a new approach to treating PH. To get there, though, we need to keep the torch burning for PH research and encourage patients to continue to participate in clinical trials. These are what keep us moving forward toward discovering new and better ways to treat PH.

What have you learned through treating PH patients?

Dr. Frantz: All of us need to make every day count: helping others, enjoying a nice piece of art, writing a letter, enjoying nature, visiting with friends. By facing such a difficult diagnosis, so many PH patients become aware of the true priorities in life and choose not to waste time on the “small things.” I’ve learned by watching my patients live this way to cherish the “moments” in life.

What advice do you give to your patients?

Dr. Benza: I try to give my patients a sense of hope. This is a scary disease, but it’s not as scary as it used to be. We have treatments. Sometimes things slip, but we have ways to catch those slips and navigate around them. There are many, many things we can do to improve life span and quality of life. And there are lots of different therapies coming down the pipeline.

Any parting thoughts to share with our readers?

Dr. Benza: I’m continually struck by the bravery and the good spirit of the PH community. All of us trying to treat PH are incredibly lucky to have PHA.

Dr. Frantz: I’ve learned that climbing a mountain is like treating PH. Put one foot in front of the other. Don’t look too far ahead; don’t look too far behind. We just need to keep moving forward, and we’ll get there.

By Christa Donald, PHA Associate Director of Medical Services
Unity Walks Take Place across the Country
Walkers Show Support for Mt. Kilimanjaro Climbers

Walkers pose together at the first of more than one dozen live and virtual Unity Walk events to support the Path to a Cure and Kilimanjaro climb team. This walk took place at Allegheny General Hospital (AGH) on Jan. 29. The symbolic walk — hosted by the Pittsburgh, Penn., PH Support Group, climbers Dr. Benza and Jessica Lazar, PA-C, and the team at AGH’s Gerald McGinnis Cardiovascular Institute — raised more than $3,250 toward the climbers’ goal of $100,000 for PH research and services.

On Feb. 19, about 100 Actelion employees and friends in south San Francisco, Calif., walked 1.9 miles along the water’s edge to honor the Path to a Cure climbers’ efforts. Other employees throughout the country wore commemorative shirts and a pedometer with the goal of walking at least 1.9 miles throughout the day. Approximately $2,500 was raised toward the campaign.

The Wojo PH Support Group of South Orange County, Calif., and the Newport Beach PH Support Group joined forces to host a successful Path to a Cure Unity Walk on Feb. 20. PH Support Group Leader Betty Lou Wojciechowski (pictured left) says, “Our PH Unity Walk on Saturday was amazing! We had about 40 participants who each walked 1933 feet (since Kilimanjaro is approximately 19,330 feet). Our goal was to raise $1,000, but miraculously, we actually raised exactly $1,933!”

Donning PHA signature T-shirts, participants raised PH awareness while strolling through Hanes Mall at the Winston-Salem, N.C., Unity Walk on Feb. 23. Over a dozen walkers came out to demonstrate their support of the Kilimanjaro climb team, and together they raised several hundred dollars for the Path to a Cure campaign.
Rochester PHA Gala: Looking Back Over a Decade of Memories

Last November 21 marked the 5th Biennial Rochester, Minn., PHA Gala, a series of events that has raised nearly $400,000 since its beginnings in 2001. The night’s theme, Reach for the Stars — Karaoke for a Cause, marked “a turning point in terms of raising awareness,” says Dr. Mike McGoon, a PH-treating physician and one of the gala organizers. A fresh new concept reminiscent of an American Idol-like karaoke contest, the event attracted attendees who had no prior understanding of PH.

To celebrate the longstanding awareness-raising achievements of the Rochester Gala throughout the years, PHA spoke with Dr. McGoon and his wife Bonnie McGoon, who have both been instrumental in organizing the Gala and who were able to offer a unique perspective on its evolution over the last decade!

2001: “We trusted the idea that if the cause is good, it will just have to be successful — and it was, [thanks to] great support from a variety of sources: friends, patients, donors and PHA. This gala set the stage and enthusiasm for continuing in future years.” Pictured below is a red Corvette which was generously donated by the Schoenleben family and raffled off at the event.

2003: This gala continued to be a formal affair, built upon what “seemed to be a successful formula,” expanding the night’s activities and keeping the focus on raising PH awareness and funds for patient support programs at PHA. A serendipitous turn of events had the McGoons’ own daughter win the event’s car raffle, “but hey, she bought her own raffle ticket!” they explain.

2005: Beginning in 2005, the Rochester Gala began incorporating themes. Titled PHenomenal PHifties, the McGoons explain that the night lent itself to creative and impressive costumes among attendees — and some great dancing.

2007: For the 4th biennial, the gala planning committee turned back the clocks a decade to host the PHenomenal PHorties, which “turned out to have certain relevance — a time of struggle and success,” says Dr. McGoon. Described as one of the most fun galas, the night included the Amazing Hondo who “brought great magic, and actually turned his show into an impromptu extension of the [gala’s live] auction … [as he] got an audience member to auction off his very loud sports coat,” Dr. McGoon remembers. In the photo below, Hondo (pictured left) stands with Dr. McGoon.

2009: The McGoons describe Reach for the Stars — Karaoke for a Cause as “a big step in trying to broaden the awareness of the gala in the community by including an honorary chair who brought a new enthusiasm and the ability to more broadly publicize and raise awareness about the gala and its cause, by incorporating a theme that encouraged participation, and by pairing the evening gala with an afternoon discussion session for medical professionals…. [PHA Board member] Betty Lou’s and [PHA Board Chair] Carl’s stories indelibly affected everyone who was there.” Steve Lange, honorary event chair and Editor of Rochester Magazine, says, “I have a much deeper understanding of PH, and, maybe more importantly, of the people who work so hard behind the scenes to make a difference in the lives of those with PH. It was very moving to be part of a group and an event in which the people cared so deeply for the cause.” In the photo to the right, event contestant Dr. Robert Frantz does his best Bob Dylan. Photo courtesy of Rochester Magazine.
Nickels and Dimes Closer to a Cure: High School Students “Help Change a Child’s Life”

The students of Marion County High School (MCHS) in Guin, Ala., know what it takes to make a difference. In November the close-knit high school hosted an Awareness Month project “Help Change a Child’s Life” in honor of 9th grade MCHS student and PH patient Caitlin Barley and in memory of PH patient Katelyn Stovall. Throughout the week of November 9-13, students collected pocket change, sold periwinkle awareness bracelets, and sold lavender hearts to line the halls of the school. Together, they raised $1,351 for PH research. We asked some of the MCHS student organizers — Mrs. Beckon’s 11th grade honors Literature/English class — to tell us more about their special week.

**Why did you decide to do a fundraiser centered around pulmonary hypertension?**

We have a student in our school who is affected by PH. Since we are a small school, and more like a family, we wanted to do something to help.

**Who helped organize the event?**

We had a general assembly where the idea was presented to the school as a whole. The organization came from administration, but the fundraising was up to the students.

**How long did it take you to plan the project? What were the different features of “Help Change a Child’s Life”?**

Again, since we are a small school, we are able to move quickly. The fundraiser was just a week, and we had something different [to collect] each day — pennies, nickels, dimes and quarters. We also sold bracelets, purple hearts, and the junior class even designed and sold T-shirts. Friday was “Lavender Day” and the announcement of the class that had raised the most funds.

**What was the most memorable part of the fundraiser?**

When we sold our hearts (each class had 50) and posted them around the school, we realized that we had helped, even if in a small way, to raise awareness.

**What was the most fun aspect of the project?**

Competing with the other classes and winning the pizza party!

**About how many students do you think participated throughout the week?**

We have about 220 students in the 7th – 12th grades and all were involved in one way or another.

**Anything else that you would like to add?**

We hope that we might inspire others to join the fight to help those who battle pulmonary hypertension on a daily basis. Together we can do more! ♦

By Jessica McKearin
PHA Special Events Manager

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Students gather together on Friday, “Lavendar Day.”

MCHS students Caitlin Barley, a PH patient, and Jeremy Vaughn show off fantastic shirts with the catchphrase “Peace, Love, PHenomenal Hope.” Eleventh graders designed and sold the shirts to support “Help Change a Child’s Life.”
## PHA Upcoming 2010 Special Events

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<thead>
<tr>
<th>Event Date</th>
<th>Event Description</th>
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<tr>
<td>Sat., April 17, 2010</td>
<td>2nd Annual Scramble for a Cure</td>
<td>Angel Park Golf Club, Las Vegas, Nev.</td>
<td>Contact Jack Nino at 702-250-2214 or <a href="http://www.scramble4acure.com">www.scramble4acure.com</a></td>
</tr>
<tr>
<td>Sun., April 18, 2010</td>
<td>It’s All PHun and Games</td>
<td>Dave &amp; Busters, Westminster, Colo.</td>
<td>Contact JoAnne Willis at 303-579-2410 or <a href="mailto:willis.joanne@comcast.net">willis.joanne@comcast.net</a></td>
</tr>
<tr>
<td>Sat., April 24, 2010</td>
<td>4th Annual Spur a Cure for PH</td>
<td>Phoenix, Ariz.</td>
<td><a href="http://www.cureph.com">www.cureph.com</a> or Amy Moseley at 602-885-191 or Trish Duque at 602-369-4376</td>
</tr>
<tr>
<td>Sat., May 22, 2010</td>
<td>Inaugural Southwest Virginia Fun Walk</td>
<td>Radford, Va.</td>
<td>Contact Jonette Robinson at 540-731-4175 or <a href="mailto:jrobinson1@peoplepc.com">jrobinson1@peoplepc.com</a></td>
</tr>
<tr>
<td>Sat., June 5, 2010</td>
<td>RACE 2 CURE PH — The Taylor Caffrey Memorial 5K Run/Walk</td>
<td>Anaheim Hills, Calif.</td>
<td>Contact Shari Caffrey at <a href="mailto:shari_caffrey@sbcglobal.net">shari_caffrey@sbcglobal.net</a> or 714-280-1479</td>
</tr>
<tr>
<td>Sat., August 1, 2010</td>
<td>Strike Out PH: Inaugural Boston PHun Bowl</td>
<td>Boston, Mass.</td>
<td>Contact Rosanne Huber at 847-752-8196 or <a href="mailto:jrh6163@yahoo.com">jrh6163@yahoo.com</a></td>
</tr>
<tr>
<td>Fri. &amp; Sat., Sept. 17-18, 2010</td>
<td>New England “Swinging for a Cure” Golf Tournament and PH Forum</td>
<td>Scarborough and Portland, Maine</td>
<td>Contact Jeannette Morrill at 207-695-3042 or <a href="mailto:morrill@dishmail.net">morrill@dishmail.net</a></td>
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</tbody>
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For more special events coverage, visit [www.PHAssociation.org/SpecialEvents](http://www.PHAssociation.org/SpecialEvents)

To view a complete, up-to-date listing, visit [www.PHAssociation.org/Events](http://www.PHAssociation.org/Events)

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### Girls Basketball Teams Shoot Hoops for Hope

The four New Trier High School girls’ basketball teams of Winnetka, Ill., hosted the “New Trier Girls Basketball Shoot-a-thon for PH” to raise support for PHA and to honor fellow student and PH patient Sarah Rossi. The 70 student athletes secured sponsors for their shoot-a-thon, held on Feb. 1, and organized a raffle and PH awareness table. Their goal was to raise $5,000, and they succeeded in raising more than $7,100.

A week after the shoot-a-thon, during a Friday girls varsity basketball game, the team presented Sarah with the fundraiser proceeds. Leading up to the game, players wore original “Let’s follow the path for a CURE” T-shirts. “They wore the shirts to school, as did Sarah, on the Friday of the game,” says Liz Rossi, Sarah’s mom.

“They felt it was important not only to raise money for pulmonary hypertension, but also to raise awareness of this disease that is affecting one of their own classmates. The community of girls and their families really stepped up to the challenge of supporting Sarah and the PH cause.”

PH patient Sarah Rossi, second from left, with members of the girls varsity basketball team.
EDITOR'S CORNER

Hello again, PH community, and welcome to another edition of Persistent Voices. As a PH patient, I am always looking for inspiration and any and all pearls of wisdom to help me manage my illness. If you feel the same way, this edition of Persistent Voices will not disappoint! We feature four incredible women, all sharing their poignant stories. They represent a true cross section of patients, some newly diagnosed and others managing PH for many years. Through every story, each of them looks for meaning in their journeys. I hope you find them as inspirational as I did. Enjoy!

— For the Cure, Joanne Sperando-Schmidt, Persistent Voices Editor

As Karen copes with five diagnoses, she remains committed to furthering our cause through advocacy and being involved as she can. She vows to continue to live “a life of persistence.” This is one of the pearls of wisdom that I’m going to write down and post where I can read it every day.

— Joanne

Karen Janjanin (Rehoboth Beach, Del.)

When I first spoke with PHA staff members about writing for Persistent Voices, they suggested I write something similar to what I posted on PHA’s website in Our Journeys. At first, I thought that was a great suggestion; but the more I prayed about the article, the more I wanted to write from a different perspective. After all, this article is not for Our Journeys, but for Persistent Voices.

If anyone is interested in my journey with PAH, you can read it at www.PHAssociation.org/OurJourneys. That story ended sometime in 2008 when I was waiting for the results of liver biopsies done in October of that year. My husband and I were told on December 18, 2008, that I am in fourth stage liver disease. Of course, we asked what stage came next, and the doctors said, “None.” Not too good to hear. I admit that I came home, went into our bathroom, closed the door, slid down on the wall and cried. After all, we had finally gotten my PAH under control, and I was living my life to the fullest and enjoying it very much. Fourth stage liver disease? Sounded kind of unfair to me. Once again, I had a choice to make. I could sit there and wallow in my new diagnosis — I was also told I have portal hypertension — or I could continue on. I was facing another fork in the road, another hurdle to jump, another choice to make. So I made my decision. I decided to remain persistent.

I looked up “persistent” in Webster’s Dictionary and found the following: “refusing to relent; continuing, especially in the face of opposition, interference, etc.; stubborn; persevering.” As I considered what I would write in this article, I realized that this definition fits me quite well. I can claim, with all certainty, that I am nothing if not persistent! What a wonderful way to live life: full of endurance, perseverance and hope. Any other choice leads to a dead end. So, as I write this article, five days after turning 50 and three days after having a biopsy to see if I have cancer again, I am praying that someone reading these words will see the blessing of a life of persistence.
As a person with PAH, scleroderma, primary biliary cirrhosis, portal hypertension, osteoarthritis, and other chronic illnesses, I have choices to make every day. It is my experience that we can allow these illnesses to define us, or we can define ourselves and live with these illnesses. I have chosen the latter. I am, first of all, a child of God; I am a wife, a daughter, a Sister in Christ to many, an advocate for myself and others. I live my life determined to use every day that the Lord gives me so that I may serve others. My perspective was not always this way. We all know the devastating effects of a PAH diagnosis; it can seem as if life is over and, for all of us, life is never the same again. We all deal with doctors, medical tests, financial strains, and the loss of living life as we once knew it, but I have learned that a PAH diagnosis is not the end of life. It can be, if we choose, the beginning.

After surviving congestive heart failure in 2007, I completely changed my lifestyle. Instead of living for myself, I began to live with a focus towards serving others. My husband and I changed our diet and, together, we ate low sodium meals, salads, fruits, and other healthy foods. We walked on the beach and spent time together, reveling in the new chance at life we were given. With the support of God, my husband, my church family and a few treasured friends, I was able to experience life to the fullest again (or perhaps for the first time).

In 2008, I decided to join PHA’s 435 Campaign, and I began to routinely call Senate and Congress members to try to bring PAH to their attention. In November 2009, all that work culminated in a trip to Washington, D.C., to advocate for the Tom Lantos PH Research and Education Act. The day was a personal success for me: I was able to travel to Washington, see the Capitol Building, see the first Bible ever printed, meet with congressional health aides, and spend time with other PH patients and PHA staff. I realized a personal achievement when I walked up the steps to the Lincoln Memorial — no oxygen required! Being an advocate for PH patients is a wonderful way to spend time and experience “persistence” at its finest.

We all need to educate ourselves and advocate for pulmonary hypertension awareness. We all need to be persistent in our efforts to bring our disease into light. We must all become persistent voices in our fight to find a cure for PH, and we must never lose our hope that one will be found. I challenge every patient and caregiver reading this to become or remain persistent. I challenge you to find hope in your situation and to use your life to encourage others. We are all precious beings in the eyes of God, and we are all loved. PHA has given each of us a wonderful opportunity to stand united in our battle against PH. We can all contribute in some way, and each of us has an obligation to do just that. But we must begin with ourselves. We must be determined to endure whatever we face and to tackle life with knowledge, education, hope, faith, patience, kindness, love and joy. Make no mistake, we are all in this together and for some reason. We are blessed with so many dedicated caregivers, physicians, nurses, researchers, support groups, newsletters, websites to connect through, conferences to attend — the opportunities are endless. The choice is ours. I have dared to hope and to live each day with joy and the promises of God. I challenge you to run this race with me.

On Christmas a lovely woman, who I adore and who knows my struggles, gave me a plaque with a quote on it from the prophet Isaiah, and I would like to close with that quote: “... those who HOPE in the Lord will renew their STRENGTH. They will SOAR on wings like eagles; they will RUN and not grow weary, they will walk and not be faint.” (Isaiah 40:31) This is what I believe and how I live. My prayer is that each of you will do the same. May God bless you.
Kimberlee’s story strikes a common chord for many of us — a misdiagnosis of asthma that leads to the loss of time to treatment. But her positive attitude and reminder to live each day, one at a time, is inspiring and brave.

— Joanne

Kimberlee Ford (Forestville, Md.)

My name is Kimberlee; I am 31 years old, and I would like to share my PH story. Around April of 2009, I started to feel sluggish all the time, and it became difficult for me to walk up the stairs. It got worse so I scheduled a complete physical with my primary care physician (PCP). A month later, I still felt awful so my PCP referred me to a pulmonologist, and I was diagnosed with asthma. Despite the diagnosis, my symptoms continued to worsen, so my PCP referred me to a cardiologist, and I scheduled an appointment for August.

On July 27, the day after I saw my PCP, I was at work and could barely walk. I had horrible chest pains, and I left work early to go to my parents’ house. After driving 45 minutes on the Capital Beltway around Washington, D.C., I made it to my parents’ house and collapsed on their couch. The ambulance came and I was taken to the emergency room, and the doctors could not figure out what was wrong.

They transferred me to another hospital which specializes in cardiology. I was in intensive care because I had blacked out for four days. Some people didn’t think I would make it. Upon waking up, the doctors told me that I had primary pulmonary hypertension. I was transferred to a recovery ward for eight days where I was seen daily by medical professionals from pulmonary, cardiology, neurology, radiology, and physical therapy. The team was great but not well versed in PH, so they brought in PH specialists. I was released on day 12 with prescriptions, supplemental oxygen, and “Dos and Don’ts” — one being not to get pregnant.

I was happy I made it home a week before my 31st birthday. I had to give up my apartment and move in with my parents so they could care for me. I am currently unable to do some daily living activities alone, and I am not able to return to work or school. I know that I will be able to return to work and nursing school and live a somewhat normal life one day. For the time being, I am living one day at a time while continuing to see my PH specialist and pulmonary physical therapist, eating a heart-healthy diet, and educating myself about PPH and my insurance plan.

I pray that my PH will not get any worse and will one day get better because I would love to get pregnant and have children of my own in a few years, if it is God’s will for me. I read that PH is a deadly, incurable disease, but I believe the only cure for PH is trusting God Almighty. I have good and bad days, but the good outweigh the bad. PH has changed my life emotionally, physically and financially, and through all of this, I am very thankful for my parents and my wonderful PHriends.
While a PH diagnosis is devastating at any age, it must be particularly challenging to our young adults who are just starting out in the world and pursuing their dreams for the future. Katie shares her diagnosis story and courageously moves forward with her life.

— Joanne

Katie Welch (Alpena, Mich.)

Freshman year of college … something a lot of people are scared of. I was one of those people. My fears were, of course, the normal concerns of classes, books, and meeting new people. Little did I know that during the course of the year, something else would scare me even more.

The first time there was even a hint that something was wrong I was at the University of Michigan Mott Children’s Hospital for a preliminary appointment for surgery to repair abdominal hernias. The doctor was listening to my heart and noticed something abnormal. The second beat was louder than it was supposed to be. They sent me to the pediatric cardiologist for a clearance appointment. I didn’t get cleared. Instead, an appointment was set for the next week for a heart catheterization. I got back in the car amazed at how one thing could turn into something completely different in just a couple of hours.

The heart catheterization was one of those things that I hope I never have to go through again. My mom was not allowed in the room with me. I didn’t know what was going on most of the time, but thankfully, I was able to listen to my iPod. All I could see were the doctors’ masked faces, and all I could feel was them probing around my leg with something. When it was finally over, I couldn’t even sit up for hours. All I wanted to do was go home. Instead, I was admitted into the hospital until the tests were in and the doctors could determine what to do next.

When doctors walk into your hospital room with fake smiles on their faces, you know something’s up. Standing at the edge of my bed, they started in with, “We got the results of the test back, and it looks as though you have primary pulmonary hypertension.” I pretty much tuned out after that. I could only take so much in just a couple of days. Hearing things like “24-hour pump” scared me even more. I had just started college. How was I going to deal with this? All I wanted to do was to get out of there.

It was a week before my 18th birthday, which put me into an even worse position. I was going to be in charge of my medical decisions all too soon. I needed time to figure things out. The doctors only gave me a week to think about everything since my pressures were already pretty severe.

I weighed everything carefully. I chose not to go on the pump. I didn’t know how to tell my parents, but it was a decision I wanted to stick with.

I waited to announce my decision until we were at the University of Michigan the next week to meet with the doctors. Walking into that room, I had a feeling that everyone already knew what I had chosen, but I also knew that I had to voice the words or I would back down on the decision. Thankfully, the doctors proposed something else. They suggested oral medications that were still being tested on PH patients but had shown pretty good results so far. I jumped at that chance.

As of now, I am still on oral medications. It is an amazing feeling because I can function as most people do, and I do not have to explain to people about my condition unless they really need to know.

Story continued on next page.
Currently, I am going to the local community college full-time for a journalism degree, participating in a local weekly Bible study, skating as much as I can, hanging out with friends and working part-time at a local fast food place. Sure, going to college is a little difficult sometimes when I know I’m going to be missing some classes for doctors’ appointments, but professors have been amazingly understanding and have worked with me so that I don’t get too far behind. My friends worry a lot, especially when they see me getting too tired, but I know it’s just because they care. Long shifts at work can be tough to get through but, then again, that can be normal for everyone.

Living with PH has been difficult, but it has also taught me a lot. It has shown me how we need to live every single day to the best extent we can because we never know what’s going to happen the next day. For me, the hardest part of living with PH is explaining it to new people because it’s hard to get them to understand sometimes.

Kathy is a long-term survivor whose honest account of life with PH has “blessings and limits.” Her experience of being misdiagnosed with anxiety reminds us to always, always pursue answers until we’re completely satisfied. Her attitude of seeing her diagnosis as an opportunity to live life to the fullest shows her spirit and courage.

— Joanne

Kathy Levitt (Boca Raton, Fla.)

I have had primary pulmonary hypertension (PPH) for almost half my life. I have forgotten what it feels like to be healthy. I cannot remember what it is like to jump out of bed full of energy and so excited for the day to begin. I miss spending hours at the gym or going on trips to other countries. PH has taken a lot from me. However, it has also given me many blessings. I appreciate life so much more. I take nothing and no one for granted. I have learned to let go of anger and bitterness and to embrace the time I have here with my family and friends. PPH has led me down the unexpected path my life has taken — a path that includes my amazing husband, Brian, and my wonderful daughter, Emily.

It was 16 years ago this spring when I started to notice the physical symptoms of PPH. Of course, at the time, I had no idea what was going on. I was becoming more and more out of breath when I climbed stairs, and I started having dizzy spells and palpitations. I was in my junior year at college, and I was feeling pretty good about myself. So, these physical issues were a true mystery.

I spent my last semester of college in Florence, Italy, studying art. As an artist myself, it was so amazing for me to see works of art by da Vinci, Raphael and van Gogh up close. However, my shortness of breath was getting worse and worse. There were many stairs in Europe. In fact, I had to climb five flights to get to my dorm room. It took me 30 minutes to get there. I remember having to stop every four or five steps to catch my breath. My heart was pounding so hard I thought it would jump out of my chest. I was scared, but the idea of any disease never crossed my mind. I mean, why would it? I was 24, healthy, and getting ready to graduate.

Over the next three years, things went from bad to downright grim. I lived with the ever-worsening physical symptoms and visited several physicians to see what was going on. They all told me it was anxiety. It was all in my head. I went to an anxiety support group for 15 weeks, started seeing a psychiatrist, and began taking anti-anxiety medication. I was listening to anxiety tapes and reading books
on how to deal with it. I had no idea where all of this came from, but everyone seemed to think I was making myself sick. No one, not even my parents and I, questioned the doctors treating me. When I was 26, I got married during all of this “drama,” and I continued to work on overcoming my “anxiety” even though my symptoms were worse than they had ever been. It was getting so bad I could not even shower myself. I was out of breath sitting and watching TV. I had begun to completely doubt myself, and I felt I was losing grip with reality. There was even talk about putting me in a mental hospital since I was afraid to leave my house. I was not able to leave. I could hardly move.

One night, I was so weak that when I sat up in bed, I fainted right there. I woke up a few minutes later and had Brian call the paramedics. They took me to the hospital, and the nurses were shocked to see my oxygen was 52 percent. They gave me oxygen and took a chest X-ray. The right side of my heart was so big it was touching my ribcage, and later they found a hole in the septal wall from my high lung pressures. They immediately put me in the cardiac intensive care unit (CICU). For the next two weeks, they performed every test known to man. This was so surreal to me because I had been convinced for so long that my symptoms were psychological. Well, reality hit me hard and it hit even harder when I found out what I had all this time.

When the doctors informed my family and me that I had PPH, the attending physician told Brian to make my final arrangements because I was not expected to live another six months. As shocking and frightening as the news was, I was relieved to finally know what was wrong with me. I thought, no matter what they found, they could fix it. Well, it was apparently not that simple.

My parents, thankfully, had a more aggressive attitude. My dad went online and found PHA. Back then, it was a relatively new organization. They were very helpful and told him about a new drug that had just been approved for PPH — Flolan™. Although it seemed scary, I was willing to try anything to save my life. A few months later we flew out to California, and within a few days, I was in the CICU having a catheter placed in my chest. That was 13 years ago this May.

Now, here I am, getting ready to celebrate my 40th birthday. I am still married to Brian, and we adopted our beautiful daughter, Emily, almost 11 years ago. I have been through quite a lot in my life. I have come to the reality, reluctantly, that I will be sick for the rest of it. However, I am here, and I am grateful. I remember when we were thinking about adopting a baby, the doctor I was seeing at the time advised me not to, stating that I may not live very long. I looked at him and told him, quite clearly, “Healthy people die every day, doctor. There are no guarantees for me, and there are no guarantees for you either.” He agreed with me.

I still have this attitude to this day. No one knows when his or her time is up. I hate it when people say PH is “terminal.” I do not see it as a death sentence. I see it now as an opportunity — an opportunity to appreciate life and the people in it. It is a rare perspective to have, and it is a gift. People with PH have a long and hard road to follow, and it is a path we do not choose — it chooses us. However, we can choose how to take the road. We can fight or we can give up. We can live life to the fullest or we can dwell on what could have been. We can feel sorry for ourselves or we can teach others how precious life truly is. It is difficult to be positive all the time, and no one should expect us to be, including ourselves. Living with a chronic illness is never easy, but it is what it is. •
Come One, Come All to PHA’s 9th International PH Conference

Excitement is mounting as PHA’s 9th International Pulmonary Hypertension Conference, Riding the Wave to a Cure, draws near. This biennial PH conference, taking place June 25-27, 2010, at the Hyatt Regency Orange County in Garden Grove, Calif., will be the largest conference in the world where PH patients, families, physicians and other medical professionals will interact to share information and ideas for the advancement of PH knowledge.

You might wonder just what is so special about attending an International PH Conference. If you are an adult PH patient, a child PH patient, family member or PH-treating medical professional, Conference will change you forever.

What we love most about Conference:

- Experiencing the hope for a PH cure in action!
- Joyful “old” friend reunions while also making new friends.
- Learning the latest information regarding PH treatment, medications and research.
- Sharing new and renewed strategies to support each other on this journey. We also call this empowerment.
- Enjoying an open dialog and direct communication among medical professionals, patients and caregivers — a unique opportunity to interact with medical professionals in a casual environment.
- A weekend of fun, learning, sharing and networking with lots of love and hugs.

It is extremely difficult to put into words the benefits of spending a weekend with more than a thousand people who understand exactly what you are going through. You have to experience it to believe it.

See you in sunny California!

Linda Carr
Cindy Pickles
2010 PH Conference Co-chairs

Visit www.PHAssociation.org/Conference for more information. You can register online or call PHA at 301-565-3004 to request a paper form.

Conference Volunteers Needed

The International PH Conference is PHA’s largest event and we need your help to ensure everything runs smoothly. Whether you are a local from the Southern California area or traveling from outside the country, you can volunteer to assist PHA at the Conference! As a volunteer, you can help prepare registration bags, serve as a room host or partner with PHA staff to complete necessary tasks as your health and capabilities allow. To volunteer during Conference, check the volunteer box on your registration form. You will receive an email with questions regarding your availability. If you would like to volunteer prior to Conference, contact Debbie, PHA Director of Volunteer Services, at Debbie@PHAssociation.org or 301-565-3004 x755.

Calling All Fashion-Forward PHers!

Do you have a unique way to dress that hides, or shows off, your pump? Sign up to model in the popular PH Fashion Show at Conference! This year, the PH Fashion Show will be held Saturday evening at the Founders’ Dinner. If you are interested in participating, email Jillian at Jillian@PHAssociation.org to sign up! All ages welcome!
Be a Social Butterfly in Southern California

More networking opportunities than ever before at PHA’s 9th International PH Conference will give you the opportunity to spread your social butterfly wings! One of the greatest benefits of attending a PHA International PH Conference is the chance to meet others living with PH from across the country and the globe.

NEW! Conference Buddies: Making friends at Conference is easier than ever! Meet someone new right off the bat by signing up for a Conference Buddy. Call Emma at 301-565-3004 x777 or email your name and address to Buddies@PHAssociation.org. In the subject line, indicate whether you are a: FIRST TIME ATTENDEE or RETURN ATTENDEE, ASSOCIATED ILLNESS PATIENT, YOUNG ADULT, PARENT, or CAREGIVER.

Patient and Caregiver “Meet and Greet”: For those arriving at Garden Grove early, the informal Patient and Caregiver “Meet and Greet,” taking place on Thursday, June 24, from 6:00 p.m. – 8:00 p.m., is an excellent opportunity to reconnect with old friends from past conferences and to make new acquaintances early.

Network with a Medical Professional Breakfast: PHA’s popular “Dine with a Doctor” is now an exciting networking breakfast on Saturday, June 26, allowing patients additional time over a healthy breakfast to talk with medical professionals who specialize in different aspects of PH care.

First Time at PHA’s International PH Conference?

With more than 1,300 attendees expected, dozens of exhibits and a schedule full of educational sessions and support group meetings, your first PHA Conference can be anything you want it to be. Here are a few highlights to help you plan your weekend:

» To find a roommate or to carpool to Conference with others, visit “PHA Conference Room-Share/Ride-Share Board” at www.PHAssociation.net/PHABoards

» Meet other PHers attending Conference for the first time at Friday morning’s Meet-up for Newly Diagnosed Patients and First-Time Conference Attendees.

» Sign up for a Conference Buddy to be paired with a friendly member of the PH community who can show you the ropes of Conference. Just email your name and address to Buddies@PHAssociation.org with “FIRST TIME ATTENDEE” in the subject line, or call 301-565-3004 x777.

» The Medically Led Breakout Sessions on Saturday and Sunday offer a wealth of valuable information. Pick and choose topics that interest you — from treatment and research to lifestyle, associated conditions and pediatrics. A limited number of sessions are also offered in Spanish. Sessions that may be useful to first-time attendees or new patients include “Basic Research in PH” and “Understanding PH – The Basics.” View the complete listing of session topics on the Conference website.

» The Founders’ Dinner and Fashion Show, Conference favorites, are now together in one amazing evening of fun and inspiration! On Saturday evening, hear from the PHA founders who started their journey to make PHA the organization that it is today. Then watch pump-wearing PHers show off the latest fashions and ingenious ways to hide (or flaunt!) their pumps.

» If you are unsure about traveling, visit the e-Learning Events archives (www.PHAssociation.org/Classroom) to review the March e-Learning Event Traveling to Conference and check PHA’s Travel Tips on the Conference website for ways to help you plan your travel (www.PHAssociation.org/Conference).
Empower Yourself with PHA’s Skill-Building Workshops

Not only does PHA’s International PH Conference offer you the opportunity to educate yourself through the medically led and patient/family led breakout sessions, the staff of PHA also hosts unique skill-building workshops throughout Conference to help empower you to strengthen the PH community in your own way. Sessions will be held during the medically led breakout sessions throughout the weekend (on Saturday and Sunday) to allow you to pick and choose how you want to expand your knowledge. Read on to learn more about the workshops.

Creative Connections: Tips for Networking During (and After!) Conference — More than a thousand people attend PHA’s International PH Conference, but how do you find other patients and connect with them? When you return home, how can you immediately connect with patients for support? This session will give you tips on how to maximize your time and connect with other patients during Conference, and it will show you how to find a local support group or start your own group once you return home.

From your Hometown to Capitol Hill: Become Your Own Advocate — In the PH community, powerful change begins with a few strong voices. No matter what your experience level or physical ability, you have what it takes to make a difference through legislative advocacy. Expect to leave this session with the knowledge, tools and inspiration to educate and build relationships with your elected officials.

Media Matters! — The most effective media coverage about PH includes personal stories, your stories. Join a panel of print and broadcast media experts and discuss the advantages of raising awareness through the media and how you can embrace them.

Put the “Special” in Special Events — This workshop will bring together a panel of experienced PH special events organizers to share their experiences putting on successful fundraisers, ranging from golf tournaments to gala dinners to fun walks and other creative ways to spread the word in local communities.

Words for Wellbeing — Medical research links creative endeavors, such as expressive writing, to reduced symptoms and improved health. This session will provide you with ideas, prompts and tips regarding writing for your own health, as well as guidelines and considerations when writing for Pathlight or other PHA publications. Please feel free to bring your own writing to share with the group!

PHA 2.0: Using the Web to Fight Against PH — The Internet can be a powerful tool in the fight against PH. Learn how you can spread awareness about PH and raise funds for the cause from the comfort of your own home computer. You’ll hear from PHers about how they have successfully used online tools, such as Facebook and Twitter or PHA’s e-tools for e-Advocacy and personal fundraising pages, to raise awareness and funds for the cause. You’ll be able to sign up to receive action alerts or messages to forward to your online networks.

An Ocean of Education: Medically Led Breakout Sessions

The Medically Led Breakout Sessions provide a vast and varied wealth of education for attendees at PHA’s International PH Conference. There is something for everyone. This year, PHA will bring together more than 120 experts in the PH field — including International PH Conference favorites Dr. Raymond L. Benza, Dr. Richard Channick, Dr. Jeffrey A. Feinstein, Dr. Vallerie V. McLaughlin, Dr. Ronald J. Oudiz and Dr. Victor F. Tapson (just to name a few) — to present nearly 40 educational sessions over the course of two days.

Topics cover a wide variety of interests and needs in the PH community, and many topics were suggested by past Conference attendees. Topics include therapies (oral, infused, inhaled, combination and transitioning); lifestyle issues (fitness, nutrition, intimacy issues for men and women, coping strategies and palliative care); diagnosis; PH and associated illnesses such as scleroderma and adult congenital heart disease; pediatrics*; select sessions in Spanish and more.

Visit www.PHAssociation.org/Conference/MedicallyLedSessions for an up-to-date listing of all session topics and speakers.

*See the Family PHocus section on p.51 for information on pediatrics at PHA’s 9th International PH Conference.
Riding the Wave to a Cure Across the World
Extended International Programming Empowers Global Leaders at Conference

Since our first event in 1994, our PH Conferences have had a reputation for galvanizing the global PH community. This year’s event promises bigger and better programming to support our international partners and make new friends!

* PHA’s First International Leaders’ Summit, Thurs., June 24 — There are more than 50 PH associations operating worldwide. This day-long event will invite leaders of those groups to teach lessons, share skills, and collaboratively problem-solve. Topics will include: Organizing and Engaging Grassroots Involvement, Awareness-raising and Working with the Media, Educating Medical Professionals, Fundraising, and Patient Education.

* International Reception, Fri., June 25 — A PHA International PH Conference tradition, Friday evening’s International Reception is the perfect setting to get to know Conference attendees from outside the U.S. This year’s event will give attendees an opportunity to strengthen friendships with leaders and Conference guests from every continent.

* Advancing our Cause: Strategy Meeting, Sat., June 26 — Previously the “International Meeting,” this re-focused hour-long session is an opportunity for association leaders to reconnect during Conference and assess the goals of the international fight for PH awareness and a PH cure.

* Global Representation, every day! — Since 2002, international leaders have been invited to share presentations and accomplishments at Conference. In 2010, we’ll feature video clips from associations at plenary meals, promote associations at the international booth and ensure the opportunity to network and speak with interested attendees.

For the most up-to-date information about how YOU can expand your horizons, visit www.PHAssociation.org/Conference/IntlLeaders

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Scientific Sessions and New CME Opportunities

As more and more physicians, researchers and allied health professionals gain knowledge of pulmonary hypertension, educational opportunities for medical professionals at PHA’s International PH Conference continue to grow! The learning begins on Thursday, June 24, with two educational dinner forums, one for members of PH Clinicians and Researcher and one for PH Resource Network members, to discuss the latest in PH research and care.

The Scientific Sessions Inflammation and Growth Factors in PAH begins on Friday, June 25, and offers a day-long education program that will lead medical professionals through a series of Continuing Medical Education (CME) sessions enabling them to exchange and absorb new ideas in PH research and treatment. The Scientific Sessions will feature experts from related fields applying their knowledge to the study of PH along with poster sessions with abstract presentations. New to the 2010 Conference will be three additional CME sessions on Friday and Saturday geared toward those new to the PH field.

For more information to pass along to your medical professionals, visit www.PHAssociation.org/Conference

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Participate in Research for a Cure

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

The new Conference Research Room structure will minimize the wait time for patients interested in participating by allowing you to complete Research Room forms prior to arriving at Conference. If you are interested in participating, check the box on the registration form and PHA will follow-up with additional information.

Pre-registration to participate is not required. Visit www.PHAssociation.org/Conference or email Researchroom@PHAssociation.org to learn more.
Help PH Patients Attend Conference: PHA Conference Scholarship Fund

PHA has seen a 50 percent increase in the number of requests for scholarship assistance over our last International PH Conference in 2008. PHA is committed to helping as many PH patients as possible attend this life-changing event, but we cannot meet this challenge alone. PHA is grateful to the current sponsors of the 2010 Conference Scholarship Fund:

- Actelion Community of Hope Fund
- Gilead Community of Hope Fund
- Pfizer Community of Hope Fund
- Rochester, Minn., PHA Gala Community of Hope Fund
- Barbara L. Smith Scholarship Endowment Fund
- Mason Hoffman Scholarship Fund
- Dean and Tammy Hazen Tribute Scholarships
- Harbor-UCLA PH Awareness Scholarship
- Heather Massey Memorial Scholarship
- Michelle Carr Memorial Scholarship
- PHA Staff Scholarship

A donation of any amount can help turn a PH patient’s dream of attending Conference into a reality. Find out how you can help at www.PHAssociation.org/Conference/Scholarships/Donate.

Notes of Thanks & Remembrance

Would you like to acknowledge someone special to you in the PH community and show how much you appreciate their support? Notes of Thanks & Remembrance (in honor, in memory, in appreciation of) will be featured in the Conference program for $25/entry (40 word maximum). Your donation will support the Conference Scholarship Fund in helping patients fulfill their dream of attending Conference. Notes of Thanks & Remembrance are due by May 1 for inclusion in the Conference program book. Send your notes to Jillian at Giving@PHAssociation.org or call 301-565-3004 x767 or ask her for more information.

Thank You, 9th International PH Conference Sponsors!

As Conference draws near, PHA would like to thank the following companies for sponsoring activities that support and enrich our program. Sponsorships are continually updated; the most recent list of sponsors can be found on the International PH Conference website at www.PHAssociation.org/Conference/Sponsorships.

DIAMOND SPONSORS

Actelion Pharmaceuticals US, Inc.
- Conference Registration Brochure
- Pre-Conference Meet-ups
- Unraveling the Mysteries of PH Dinner
- Young Adult Mixer
- Support Group Leaders Networking Lunch
- PH Video Journeys*
- The Daily Wave Newsletter
- Conference T-shirts*
- In-room Wireless Access
- Conference Handout Book
- Fellows Scholarship Fund
- Scientific Sessions Luncheon
- Scientific Sessions and PHCR Dinner Forum
- Actelion Community of Hope Patient Scholarship Fund

Pfizer Inc.
- Journeys BlogosPHere Internet Station
- Children’s Program
- Conference Giveaway
- International Leaders’ Summit*
- International Reception*
- Advancing Our Cause: International Strategy Meeting*
- Filming and Distribution of Selected General Sessions
- Notebooks
- Scientific Sessions Poster Session
- CME Credits
- Young Researcher Awards
- Pfizer Community of Hope Patient Scholarship Fund

Gilead Sciences, Inc.
- Founders’ Dinner including Fashion Show
- PHA Chair’s Reception
- PH Resource Network Dinner Forum
- Filming of Scientific Sessions
- Gilead Community of Hope Patient Scholarship Fund

GOLD SPONSOR

United Therapeutics Corporation
- Conference Program Guide
- Scientific Sessions Program Book and Abstracts
- PHA Folders

SILVER SPONSOR

LungRx
- Volunteer Training
- Scientific Sessions Continental Breakfast
- Next Generation of PH Leaders Breakfast
- PH Video Journeys*

BRONZE SPONSORS

Teva Pharmaceuticals
- Conference T-shirts*
- Conference Evaluation Gift
- Scientific Sessions Flash Drive

Accredo
- Scientific Sessions Coffee Breaks
- Friday Conference Coffee Break
- Registration Desk

GENERAL SPONSORS

CVS Caremark
- Souvenir Room Keys

CuraScript
- Patient Rest Stop

*Indicates a co-sponsorship

All confirmed sponsorships as of March 15, 2010.
not only does PHA’s new website sport a fresh new look, it has loads of fresh new content. On the old site, information about pulmonary hypertension and tips for day-to-day living were in a fact sheet section that was somewhat difficult to navigate. We didn’t just move that section; we created two entirely new sections.

The **About PH** and **Living with PH** sections on our new site include simple, clear information developed from *Pulmonary Hypertension: A Patient’s Survival Guide* and other source materials. This material was then reviewed by medical professionals. The sections also link to useful fact sheets for more information.

The **About PH** section includes information on symptoms of pulmonary hypertension, the various diagnostic tests and treatment options, the different types of PH and much more. In the **Living with PH** section you’ll find tips for maintaining a healthy physical, social and emotional lifestyle; you’ll learn how to prepare for travel; and you’ll learn what to do if you find yourself in an emergency situation.

Check out these new sections as well as others (**PH Kids**, **Young Adults with PH**, **Associated Diseases**, **Caregivers**, **Parents of Children with PH** and **Research** on our newly revamped website, [www.PHAssociation.org](http://www.PHAssociation.org), and let us know what you think. Send your feedback to our webmaster, Diane, at Web@PHAssociation.org.

PHA thanks our website redesign sponsors.

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**STORY CONTINUED FROM PAGE 1**

The way to awareness.”

When *Pathlight* was first published in May 1990, the issue was just six pages long. Fifty copies were created at Kinko’s and mailed to every PH patient the founders knew about, and to doctors and university hospitals.

Although the first issue looked vastly different from what you hold in your hands today, key elements of the newsletter have remained the same over the years. For instance, the regular column “Ask a PH Specialist” began as “Dear Doctor” in that first issue, and “Passages” was known as “In Memory” and included three names. Every issue — from that first issue through today — is dedicated to the memory of PH patients who have gone before.

As we celebrate 20 years of this publication, we also take a moment to recognize how far we have come as a publication and an organization. From 50 copies in May 1990, *Pathlight* prints approximately 10,000 copies per issue today, distributed in the U.S. and 47 countries internationally. As Teresa Knazik expressed, *Pathlight* served as a “patient support group” as it began to connect patients, caregivers and medical professionals. Today these same populations can connect face-to-face through more than 215 support groups in 49 states and Puerto Rico with new groups forming all the time. When *Pathlight* first arrived at medical facilities in 1990, only a handful of doctors had knowledge of PH, and those medical professionals worked in relative isolation. Today thousands of physicians, nurses and allied health professionals work in the field of PH, connecting with each other through PHA’s member groups PH Clinicians and Researchers and PH Resource Network and through the programs of PHA’s Medical Education Fund.

This January PHA proudly launched our redesigned website [www.PHAssociation.org](http://www.PHAssociation.org), reaching more patients, caregivers and medical professionals than ever before. PHA’s website allows our community of hope to connect with resources, information and support at any time and from anywhere.

Whether it is through the printed pages of *Pathlight*, the electronic pages of PHA’s website or our growing programs for the PH community, PHA continues to advocate and support patients on the same grassroots level as we did in the early years when we were an entirely volunteer-run organization. As we have grown, we have stayed true to our roots and the vision and ingenuity of our founders: We continue to work every day to end the isolation that PH patients face, and find a cure for pulmonary hypertension. Just imagine what we can do in the next 20 years.

To learn more about PHA’s history, visit [www.PHAssociation.org/AboutPHA](http://www.PHAssociation.org/AboutPHA). To view past issues of Pathlight, visit [www.PHAssociation.org/Pathlight](http://www.PHAssociation.org/Pathlight).

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*By Megan Mallory*  
*PHA Publications Manager*
Building Medical Education in PH

A Partnership Initiative to Advance Medical Understanding of Pulmonary Hypertension

Pulmonary Hypertension 2010: Learning With the Stars
The Lindner Center for Research & Education and The Heart and Vascular Center at The Christ Hospital
April 9, 2010
Covington, Ky.
Email: gail.welsch@thechristhospital.com
Call: 513-585-1924

The Alfred P. Fishman Conference: Right Ventricular Structure and Function in Health and Disease
The University of Pennsylvania School of Medicine
April 9 – 10, 2010
Philadelphia, Penn.
Email: aspence@upenn.edu

4th Annual Pulmonary Hypertension Symposium: Updates on Classification and Therapies
Yale School of Medicine
June 3, 2010
East Haddam, Conn.

Monthly e-Learning Events
www.PHAssociation.org/Classroom

Attend PH educational events from the comfort of your own home or office. Events include online Q&A chats, conference call discussions, and webinar presentations.

Upcoming Events

April
PH Treatments & What’s on the Horizon
May
Newly Diagnosed? What You Need to Know
May
Working with PH
June
My Loved One Has PH
July
Lobby Locally! Visit Your Members of Congress without Leaving Your State

Newly Posted Archive Recordings

* Tour PHA’s New Website with Webmaster Diane: Finding all your old favorites & learning what’s new
* Lifestyle Modifications for Improved Quality of Life
* PHA’s 9th International PH Conference: What to Expect
* Exercise Tips for Staying Healthy
* State of PHA — An Annual Update from PHA President Rino Aldrighetti
* Traveling to Conference

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

PHA’s monthly e-Learning Event series is made possible through an unrestricted educational grant from Pfizer Inc.

Say Thanks with PHA Cards and Save 25%

Cover Art by PH Patient, Kathy Levitt
(Visit PHA’s website to see the cards in color.)
Cards are blank inside and come in packs of 10.

Only PHA Members are eligible for this special, limited-time offer. Order now through July 1 at the PHA Online Store, www.PHAssociation.org/Store or give us a call at 301-565-3004.

Not a member? Visit www.PHAssociation.org/Join
to become a member of PHA today!

Now Only $9 ($12 after July 1)
INTERVIEW WITH PH PATIENT

KATY DOAK

Where do you live?
I live in Sandy, Utah.

How old are you?
I am 11 years old.

When were you diagnosed?
I was diagnosed July 1, 2003.

When did you first start having symptoms of PH?
I first started having symptoms when I was 2 or 3.

What were your symptoms?
Around age 2 or 3, I started fainting, so my parents took me to the doctor to get me checked out.

Do you do summer activities (like go to camp)?
I don’t go to camp, but my parents like to take my family on vacation.

Have you ever felt unable to do something because of PH?
Yes, I do miss out on some things, like playing summer sports.

What has changed in your life since you were diagnosed with PH?
I feel like I’m not a “normal kid” sometimes. I miss a lot of school, and I can’t run as far as the other kids in my grade.

What is a message you’d like to pass on to other kids with PH?
I want them to remember to keep their heads up high and not to give up hope.

Interview conducted by Mira Kruger
PHA Pathlight Volunteer
Meera Salamah is many things besides a PH patient on a Flolan™ pump. She’s an exceptional student. She’s a loving daughter to parents Nita and Alex and sister to younger brother Zane. She’s also a self-professed “tree hugger.” The 14-year-old’s scientific mind, big heart, and budding environmentalism are just a few of the reasons she and her family were flown, all expenses paid, to the Hawaiian rainforest last year. When Meera was offered a wish from the Make a Wish Foundation in 2007, she answered without reservation, “I would like to go to the rainforest and plant a tree.” Everyone standing around in her hospital room that day was shocked to hear Meera, just 11 at the time, pass up the opportunity to meet a celebrity or travel to Disney World. But Meera looks back on the decision without regret: “I was really excited. … I love to make things better than I found them. Trees provide oxygen, which helps us all breathe easier.”

“Breathing easy” hasn’t come naturally to Meera for some time. Her journey with PH began at the age of eight when her mother noticed she was having trouble keeping up with other girls on her soccer team. The day that Meera was finally diagnosed with PH following a right-heart catheterization, her mother Nita remembers, “I couldn’t sleep the whole night. I stayed up trying to learn everything I could, and everything I read was devastating.”

Although overwhelmed by emotion, Nita and her husband went straight to work, coordinating with Meera’s teachers to accommodate her health needs at school and working with the doctors to find a treatment that would lower Meera’s dangerously high pulmonary pressures. After three months on Tracleer™ with no improvement, the doctor offered the family two options: Meera needed to begin on intravenous prostacyclin (Flolan™) or travel to New York City where she could take her chances on the orally administered study drug sildenafil. While the expense of monthly trips from Dallas to New York was high, Nita says, “We did what we had to do. We just needed to get Meera better.” The family was relieved when sildenafil agreed with Meera, who began to show signs of real improvement. Within two years, Meera was doing much better on combination therapy, and ready to begin the sixth grade.

In the fall of 2007 Meera’s health began to deteriorate. During one hospitalization, with Nita by her side, Meera went into cardiac arrest. As the nurses rushed around her and the doctors did chest compressions on Meera for over an hour, Nita stood at her daughter’s bedside. “I was praying loudly so Meera could hear me,” she remembers. When Alex arrived at the hospital, a doctor took them both aside and told them there was a good chance Meera wasn’t going to make it. Remembering this moment more than two years later, Nita’s voice still breaks. Then she recalls the moment when — after hours of uncertainty, followed by fear that Meera had survived the cardiac arrest only to be at severe risk of brain damage due to complications with her breathing tube — Meera took a Magna Doodle® from the bedside table and began writing messages to her parents and nurses. “It was nothing but a miracle,” Nita says.

But Meera’s health troubles continued. That year she went on to experience another cardiac arrest, a stretch on life support, gastrointestinal problems, a ruptured appendix, and six months in the hospital in New York. After many months and a lot of hard work in a rehab facility following her release from the hospital, Meera was finally able to return to Texas to wrap up the sixth grade. Despite having missed nearly the entire school year, she aced all of her finals and even placed into honors classes for the following fall. She was also able to attend PHA’s 8th International PH Conference in Houston that June, where she proudly walked in the Fashion Show, sporting her new Flolan™ pump and a light pink ball gown.

In March 2009, the Salamah family finally had the opportunity to travel to Maui to make Meera’s wish come true. While Meera enjoyed the trip considerably, she sees her wish as part of a larger story. The rainforest is home to millions of plants and animals, one of which — she is quick to point out — could potentially hold the cure for PH. Meera hopes to become a cardiologist so she can use her compassion to help other people. It looks like she’s got quite the head start.

By Emma Bonanomi
PHA Patient Outreach and Services Manager
MIRACLE CHILD
A Poem by Becca Atherton

I am a miracle child
Struggling the first months of my life
Given a 13 percent chance of survival to the age of five
Struggling for years …
Today I am 17
I am a miracle child

Life-saving battle scars adorn my body
Changing my shirt, I see the bright pink scar running down my chest
Always a reminder of my yearning for life
I am a miracle child

Fear is part of me
I am afraid when my heart skips a beat
I fear being in the hospital
Alone …
In pain …
Not knowing …
I cry at the very thought
I fear dying
I am a miracle child

I know I am not like most
Valuing life
I celebrate the morning
I appreciate those who love me
And know
Everyday truly is a gift
I am a miracle child

Being a miracle child
Is …
Frightening,
Is …
Celebrating,
Is …
Accepting,
Is …
Appreciating
Is …
Struggling
Is …
My life
I am a miracle child.

Becca is 17 years old. She was born with tetralogy of fallot (TOF), pulmonary artresia, and pulmonary arterial hypertension. She wrote “Miracle Child” for a poetry contest at school.

PHENOMENAL YOUTH
PATHLIGHT SPRING 2010

WE WANT YOUR IDEAS!
This PHA surfer, the mascot for PHA’s 9th International PH Conference and Scientific Sessions, needs a name!

You could win… A PHA PRIZE PACK!

Just send us…
* Your Name
* Your Age (Must be 15 or younger to enter)
* Your City and State
* How you are connected to PH:
  * I am a patient.
  * I have a sibling with PH.
  * I have a relative with PH.
  * Other.
* Your name for the mascot

Email your suggestions to Conference@PHAssociation.org

or write to PHA Mascot Contest, 801 Roeder Road, Suite 1000, Silver Spring, MD 20910

Contest winner will be announced at Conference!
Dear PHA,

My name is Jenny Pannell. I am 12 years old. My grandpa passed away three years ago with pulmonary hypertension. I wanted to do something about it. My dad got online. I immediately wanted to join. I started selling bracelets, and they sold fast. As the weeks went by, I was tempted to get a dollar out of the envelope, but the little voice inside told me no because this money was for papa. My grandma and others told me that what I was doing was a good thing. I really missed my papa and I still do, but somehow being a part of PHA makes me feel better. I can’t really bring him back, but I can save other lives by raising money. Thank you for starting this organization. If we all try together, we can have confidence that one day we will find a cure!

Thanks,

Jenny

Here’s my $126 that I raised.
PHocus on Pediatrics at PHA’s International PH Conference

PHA’s 9th International PH Conference will offer a number of pediatric-specific programs, with programming tailored to the needs of adult caregivers, families, siblings and young PH patients themselves.

Friday morning features a Families of Children and Teens with PH Pre-Conference Meet-up Group to give families an opportunity to meet each other and for kids with PH to have a full weekend of fun together. Friday afternoon will feature two unique Patient/Family Led Breakout Sessions for Parenting a Child with PAH divided by age ranges 0–11 and 12+. Additionally, new support group meeting topics have been added, including Parents of PH Children Who Are Under 21, Teen PHers (12–18 years old) and My Parent/Sibling has PH (for kids under 21).

On Saturday and Sunday, the popular Ask the Pediatrician Medically Led Breakout Sessions return with two sessions just for parents and another session just for kids. Additionally, The Latest in Medical PH Therapies for Children and The Latest in Surgical PH Therapies for Children will offer comprehensive presentations for pediatric treatment.

Kids’ Cabana at Conference 2010

The Kids’ Cabana (Kids’ Room) will be open throughout Conference for patients and non-patient children ages 3–16 (parents must pick up their children for meals). A Kids’ Cabana T-shirt, arts and crafts, games and other fun activities, as well as an optional field trip, will be provided. There is no charge for children’s activities, but Conference registration and reservations are required for participation.

Deadline to register is June 1. Call 301-565-3004 x764 or email Kidsroom@PHAssociation.org with questions. There will be no on-site registration for the Kids’ Cabana optional field trip activities.

Help PHA-UK kiss PH ignorance goodbye in 2010 and set a world record by collecting more than 40,000 blue lip prints for the Guinness World Record! PHA-UK and 29 international PH groups ‘Kiss off’ the campaign on May 15, 2010, and the PuckerUp4PH campaign will run until the start of International PH Awareness Month in November 2010. For more information, visit www.puckerup4ph.com
Passages is PHA’s way of honoring those who have lost their battle with PH, as it has been since the very first Pathlight was published in May 1990. As we learn of patients’ passing, we inform the PH community. PHA extends sympathy to the families and friends of those who are gone but not forgotten; each Pathlight is dedicated to their memory.

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

Donations listed were received between December 1, 2009, and February 28, 2010. PHA is deeply grateful to the PH community for its extraordinary support.

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

In memory of

George B. Bereny
Marjorie Burnup
Anthony Casacalenda
Louise Coburn
Amalia Corona
Debbie Diana
Mary S. DuPre
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- **Organ Donor Awareness**  
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- **Organization Liaisons**  
  - National Institutes of Health: Judy Simpson, R.N., Ed.S., jsimpson@cox.net: 479-253-0082
  - American Thoracic Society: Public Advisory Roundtable  
    - Rino Aldrighetti, Rino@PHAssociation.org: 301-565-3004
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