Get your maps ready because PHA is heading back across the country with PHA on the Road: PH Patients and Families Education Forums this June. The 2011 “road trip” will make stops in four new cities: Seattle (June 4), Pittsburgh (June 11), St. Louis (June 11) and Minneapolis (June 18). Details on p.40.

PHA on the Road is a program of FREE full-day regional patient and caregiver education forums based on the idea that YOU, the patient, deserve the best information and support available. The forums will feature interactive presentations, sessions and exhibits exploring the symptoms, diagnosis and treatment of pulmonary hypertension. Additional sessions will discuss the practical challenges of living with PH, coping with the disease and handling lifestyle issues such as healthy eating and exercising.

PHA on the Road will also provide unique networking opportunities for attendees to connect with others in their local regions. As a small group that faces common challenges, PH community members are constantly looking for more opportunities for face-to-face interactions with each other. One goal of PHA on the Road is to help combat feelings of isolation by bringing the PH community together in areas close to home. Each forum will provide pre-forum support group sessions for newly diagnosed patients, veteran patients, caregivers and parents of children with pulmonary hypertension.

Not only do attendees get to interact with other patients and caregivers at PHA on the Road, but they can connect and learn from local medical professionals as well. Each regional forum will feature experienced PH medical experts from the local regions as speakers and presenters.

PHA is excited to welcome Dr. Paul Fairman from Virginia Commonwealth University as the Chair of the 2011 PHA on the Road program. Dr. Fairman
Hope is the thing with feathers, that perches in the soul, and sings the tune without the words, and never stops at all.  
~ Emily Dickinson

The truth is, at times, this journey must feel slow-moving to those living with pulmonary hypertension, and can be, without a doubt, deeply frustrating for all of us who have been affected by this disease. We talk about progress and the ultimate goal, a cure, a lot. However, for many of us, the following question lingers in the backdrop, “How close are we, really?”

In this spirit of questioning, I decided to examine our research efforts to date. For example, how many distinct research efforts has PHA supported? And, how have we done in communicating our need for PH research funding to the federal government and our private donors? And, finally, what would it take for us to conduct research at the level needed to further improve and ultimately end the journey with PH?

When I recently broached these questions with Dr. John Newman, Chair of PHA’s Scientific Leadership Council, without a pause, he said, “Each grant is a molecule in a wave of pulmonary hypertension research moving us forward.”

In a snapshot, this is what PHA has done to advance the field since support for research was incorporated into its organizational mission in 2000:

• Committed more than $10 million to four PH research grant programs in partnership with the National Heart, Lung, and Blood Institute (NHLBI), the American Heart Association, the American Thoracic Society and Pfizer Inc.;
• Engaged promising researchers across the U.S.

through our partnerships with these highly credible organizations;
• Awarded grants to more than 44 promising researchers in the PH field; and
• Was instrumental in advocating for the increase in NHLBI’s PH-focused funding from $12,147,753 in 1999 to $41,400,320 in 2009.

Dr. Newman described these efforts perfectly: this field is moving like a powerful wave, and every piece of science builds our momentum. We have good reasons to talk about progress in terms of numbers of grants funded, numbers of new investigators engaged in PH research, and the overall level of government and private funding now devoted to PH research. However, the answer to the more compelling question, “What would it take to discover the cure?” is more elusive. Research is expensive and each trial yields different pieces of the puzzle that inform previous and concurrent discoveries. In a simplified nutshell, more is needed.

Simply stated, the formula for continued progress seems to be: a strong, centralized voice for our cause (We have that!), visionary leadership and talented organizational skills to coalesce our efforts (PHA serves in this role!), state-of-the-art scientific brainpower (Yep, we have that, too!), broad support at government and private levels to fund PH research (We have made tremendous progress, but this is the area in which we must continue to engage our efforts!), and finally, hope that “…never stops at all.” (We definitely have that!)

To learn more about the scope of current research endeavors, please visit www.PHAssociation.org/Research
mentors are patients and caregivers from all over the world, standing by to help patients, caregivers and parents through one-on-one, email-based support. Liz Brigham is one of those mentors, and she shares a little about herself now.

What’s your PH story?
I was diagnosed with PH in June 2004, though I had been symptomatic for at least a couple of years before that. Like so many other PH patients, I was first misdiagnosed by an assortment of primary care doctors who told me I had asthma, job stress, allergies, etc. I finally decided that I knew something was wrong and I was not going to accept job stress as the answer any longer. I did some of my own research on the Internet (scary) and found that my symptoms matched this disease called pulmonary hypertension. After rounds with a few local doctors, I was actually referred to the Mayo Clinic in Rochester, Minnesota, where this diagnosis was confirmed and my journey began.

After I was diagnosed with PH, I was scared and depressed because what I had read about PH seemed pretty bleak. I remember not wanting to plant any perennial flowers in my garden that spring as I was sure I would not be around to see them bloom the following year. I learned that there were support groups in the area, but I decided that those must be depressing pity parties. Boy, was I ever wrong about that!

My attitude changed once I drew up enough courage to attend one support group meeting. Gosh, these folks were not sitting around feeling sorry for themselves. Instead, most of them were living active and meaningful lives, which included friends, family, work, pets, vacations, hobbies, etc. — all the things that bring value to our lives.

So my life with PH changed once I was willing to get over myself and really understand that my life was not PH — PH was just one of the many facets of my life. I soon became a support group leader, later a Patient-to-Patient Support Line volunteer, and finally a PHA Mentor. It is possible to get over one’s own petty self-absorption pretty quickly when trying to listen to and assist other patients — some of whom have so much more to deal with than I had.

Why should someone email a PHA Mentor?
There are a million reasons to email a PHA Mentor. To name just a few:

• Mentors are PH patient and caregivers who have volunteered to help and who feel they have something of value to offer others;
• PHA Mentors have “been there, done that,” and have years of experience and knowledge to share;
• Should a PHA Mentor not know the answer to a PH-related question, you can be sure they will check into it and get back to the mentee;
• PHA Mentors have many sources for PH-related information that the newly diagnosed patient might not yet know about;
• Sending an email is quick, easy, and you can do it whenever’s most convenient for you.

What’s your best advice for others living with PH?
Just that: LIVE! We can still carry on very meaningful and productive lives with PH. Those of us who have been diagnosed with PH have the opportunity to take a good hard look at the “whys” of our lives and how we want to really live. For me, this disease has been a gift of sorts. I have been given the opportunity to look deeply at my life and make something out of it. A beautiful song by an artist named Sarah Brightman called “I’ve Been This Way Before” has a line that says, “Some folks never see the light until the day they die.” As a PH patient, I’ve been blessed with the opportunity to try to see the light while I can still touch the lives of others in some meaningful way.

What does being a PHA Mentor mean to you?
It means so much to me to be able to help alleviate another patient or caregiver’s fear and confusion — especially when that patient or family member is newly diagnosed. PH is unbelievably complicated, and if I can help someone sort out some of their confusion, I am blessed. It takes courage to reach out for help and if I can be on the other end for another patient, my life is made richer.

Email Liz at Liz@PHAMentors.org, or connect with another PHA Mentor by gender, age, associated disease, or topic of interest at www.PHAssociation.org/Mentors
We are hope.

What does it mean to have pulmonary hypertension? I’m sure we all remember what it felt like when we were given our diagnosis. After weeks, or sometimes months of tests and doctors, as we sit in a small enclosed hospital room, we are finally told what is causing our shortness of breath, chest pain and fatigue. “You have pulmonary hypertension.”

Well, what the heck is that?!? I had never heard of this disease before, I had no idea what it was, or how much my life would change after that moment. Every day we are faced with challenges now, stairs seem to loom in front of us, we have to ask our friends to wait up at the mall, and maybe we are saying no to going out because we just don’t feel up to it. Floods of meds and new ways of life pour down over us, and we become nurses and experts in PH ourselves. We have to, and we do so with the bravest faces.

So what does it REALLY mean to have pulmonary hypertension? Well, “Pulmonary hypertension is high blood pressure in the arteries of the lungs that can lead to heart failure.” Jeeze, how scary does that sound? And there are websites out there with wrong or out-dated information that are WAY scarier than that! But that still doesn’t explain what it means to have pulmonary hypertension.

Having PH makes you a warrior, a rock amongst the waves. You are a strong individual, who despite being dealt a bad hand, has come through it and still finds a way to smile every day for just being here. People will put you down, people will leave, and others will tell you there’s something wrong with you, that you are inadequate in some way. NO, you aren’t. You are more than adequate. You are over-adequate. We put up with incredible struggles daily just doing regular things.

I have had some people approach me asking what my Flolan™ pump is, or what that plastic looking stuff is on my chest. I always explain it to them, as patiently as possible (but it’s become a pretty monotone, emotionless statement). “I have pulmonary hypertension; it’s a rare incurable disease. I have extra tissue in my pulmonary arteries so my heart has to work super hard to pump out blood. I’ve got a permanent IV in my chest that delivers meds to me 24/7 and without it I might not be alive today.” Most people respond with “Wow, I don’t know how you go through all that … I could never do that.” I just smile and say thank you, I’m making it through.

We are strong. We are much stronger than those who put us down, and we are plenty strong to kick this disease.

Hope is so important along with our strength. I know there was a time when I didn’t have hope, and it’s not a good place to be. Why act like you are dead when you aren’t, you know? We are amazing people, amazing young adults. Don’t forget that. We’re dealing with this illness in the prime of our lives. Some of us are just starting families, or just settling into careers, or starting school, excited for our future. We have all these dreams and ambitions, and then BAM, we have pulmonary hypertension. And that threatens to drain us of our dreams and goals … but we can’t let it, and we don’t.

We keep on fighting, because we have hope, and we are strong! And look at us! Many of us have surpassed our “life expectancy” rates by quite a bit! This is incredible, and it only makes every moment of life better, every bit of food taste fuller, and every sunset more beautiful. So yeah, I know how much having PH stinks, just plain out STINKS. But we should remember every day that there is hope, that we ARE the hope, and the strength, and that as PH warriors, we will get through this.

By Jenny Janzer
PH Patient

“A Breath of Fresh Air” is a new Pathlight section devoted to young adult issues. To learn more about Generation Hope, PHA’s group for patients in their late teens, 20s and 30s, visit www.PHAssociation.org/Patients/YoungAdults

This article by Jenny Janzer was first published as part of the Generation Hope blog. To read more blog entries, visit www.PHAssociation.org/GenerationHope/Blog
International Faces of PH: Shakeela Naz from Pakistan

My name is Shakeela Naz. I am a 23-year-old software engineer, and I live in Rawalpindi, Pakistan. I was born with Atrial Septal Defect (ASD) and skeletal anomalies in my left arm and both hands due to Holt-Oram Syndrome (which was inherited from my mother). At age 4, my ASD was repaired via an open-heart surgery. Life went smoothly afterwards, and I lived perfectly healthy for the next 14 years.

Because of my history, my parents were always very observant about any unusual shortness of breath, signs of turning blue, etc. So in 2003 when I started to get out of breath on my way home from school, I was taken for a checkup and was diagnosed via echocardiogram with right-heart enlargement. I was put on medication to reduce symptoms and monitored every four-to-six months. Still, I was easily able to climb three floors in a single go, without pausing for even a moment. I was a hyperactive and “always ready to help anyone” type of individual, and this did not change. Then pulmonary hypertension entered my life.

In December 2007 I started getting immensely tired and out of breath again. I was unable to walk even at a normal pace and ended up going suddenly unconscious right in the exam hall, just after I had handed over my final exam paper. By the time I was taken to the hospital, I was fully conscious and just feeling a bit weak. My blood pressure, sugar level and pulse rate were all found to be normal — everything seemed okay. Doctors advised holter monitoring, head-up tilt, and echocardiogram. All the test results were normal except the echocardiogram, which stated “severe pulmonary hypertension” in addition to the past diagnosis. Just last year I also got another tag on me, called Eisenmenger’s Syndrome.

Initially, PH gave me a really tough time. Life seemed to turn upside down. It was very hard to sit back and watch others play sports while I had to quit anything that could potentially exhaust me, and I had to get lots of rest. I stood in the middle: my dreams and aims on one hand and hard realities and fears on the other. Luckily, from the very beginning, I was interested in my studies more than anything else and this was something I could continue well by compromising other activities. I was still left with at least something of my interests: studying and teaching. It was a tradeoff; adapting to new circumstances in life involves a couple of tradeoffs — very much analogous to what we software engineers do with our software systems.

But PH has also had positive impacts. I realized that being intelligent and hardworking is not everything; one has to be good at management skills as well. Now that I have to spare even more time for myself, I am learning to manage things better. PH is teaching me one trait that I hadn’t previously learned, despite years of trying: patience. PH also made me proud of my sincere friends who always stayed there, even when I was engrossed by PH: not a single one left because of my disease.

Friends, family members, doctors — everything does play a vital role in getting you through, but positive thinking matters the most. You remain alive and perfect as long as you think that you are. Somebody said, “When you think everything is over, you got yourself a new start ... !”

Despite all this disease stuff, I have been able to manage my studies well. When mild symptoms appeared, I was a tenth grade student. It was in the fourth semester of my B.S. in Software Engineering when my symptoms got intense, and by the end of sixth semester, I was completely lost — I was unable to walk even a few steps and fainted twice in university. Still I’m proud to say I completed my B.S. successfully, and was among the top 10 students of my class. This achievement was possible through staying positive, receiving immense moral support from my friends, parents and teachers, giving my full effort and leaving the rest to God Almighty. Now I am a regular student of M.S. Software Engineering, and I look forward to contributing something valuable to my field. My health has improved greatly, and most of the time people can’t tell that I have some health issues.

Coming back to normal life took time, patience, and a strong support system consisting of my parents, friends and great doctors. I love each one of them!

Sometimes I just wonder what life has got next for me. I think it’s time for a cure now!

By Shakeela Naz
PH Patient

Interested in learning more about PH patients outside the U.S.? Visit www.PHAssociation.org/PHInternational/Faces to meet more International Faces of PH.
Helping Your Child Cope with Your Illness

If you have PH and you are a parent, talking to your children about your illness may be one of the most challenging emotional issues you will face with this disease. How and what you tell your child depends largely on their age and ability to understand and cope with information. In addition, since how PH affects you will most likely change over time, what information you give your children may need to change over time as well.

Written from the perspective of an educator, parent, and PH patient, this article is meant to serve only as a general guide and as a way to give you ideas on how to start the conversation. It is suggested that you also consult with child development experts who know your child and your family, such as your pediatrician and/or a teacher or school guidance counselor.

Infants and Toddlers

If you are going through an intense diagnostic or treatment process, be aware that even at this young age children may be aware that something is amiss. Be prepared for the possibility of changes in your young child’s behavior, such as disruptions in sleep patterns and increased behavioral issues such as tantrums or aggression. These are ways that very small children let us know that they are aware something is different in their world, even when they cannot understand or express it. Stay calm, stick to your routine, and be as nurturing and patient as possible. Remember, when it comes to a baby or toddler’s behavior, most often “this too shall pass.”

Preschoolers

Preschoolers are self-centered, concrete thinkers. Children at this age may ask questions about your oxygen or medication supplies that they can see, but the inner workings of PH will be well beyond them. Be honest, but don’t give any more information than the child needs to know or wants to ask. Simple answers like, “That helps Daddy breathe well at night” will most likely suffice small curiosity. If, however, you have a “But WHY?” stage on your hands, continue to stick to simple answers: “Because the doctor says it helps,” “Because we do things to keep our bodies healthy and this is one thing I do,” etc.

If there is a chance you could become too ill to care for your preschooler for a while, or may have to go to the hospital for a stay, children at this age want to know one thing: “Who will take care of me?” Don’t take it personally if they aren’t overly concerned about your own well-being at that moment — that’s not how their little minds are wired to work just yet. Think through this question ahead of time and come up with a list of special people who will be there for your child if this kind of situation arises. Share the list of people with other caregivers and teachers so that your child receives a consistent message. Children at this age thrive on predictability, a sense of security, and routine. In so much as is possible, make sure these things are in place in case of a crisis.

Another thing to be aware of is that your preschool child may process their understanding of your illness through play. They may act out “doctor” with more sophistication than their peers if they are aware of pumps and cannulas. While this may be a bit unsettling for you, understand that it is a child’s natural way of processing and exploring information and is most likely healthy. However, any fear or uncertainty they have may also be displayed in their play. Just be on the lookout for signs that your child is worried or unsettled about what they have learned about your illness and don’t hesitate to contact your pediatrician for advice on how to best support them at this stage.

Elementary Age

Children at this age are still concrete thinkers, but they are able to visualize on a more abstract level as well. You may want to use a doll or a bear to show where the heart and lungs are so that they can see where the sick part is in the body. Again, as with younger children, keep your conversations brief and concrete. Answer questions very honestly, but don’t provide more information than the child asks or can handle.

You may need to be prepared for questions
about your mortality ("Are you going to die?"), if PH is contagious ("Can I or my friends or other family catch it?") and feelings of guilt ("Did Mommy get sick because I was naughty?"). Think through how you will answer these questions for your child if they come up.

As with preschoolers, look for changes in behavior that signal your child is having difficulty understanding or coping. Depending on how you feel about sharing information on your illness, talking to school personnel may be a very good idea. Classroom teachers appreciate this kind of information so that they can be sensitive to the child’s needs during the day. School counselors may be available to help your child process difficult feelings. Taking a team approach with the school may be the best way to support your child.

Adolescents and Teenagers

By adolescence, kids understand significantly more. It is okay to ask more leading questions at this stage to encourage conversation with a teen who may be a reluctant communicator. Remember that we live in the age of the Internet, so if you don’t talk about it, the computer very well might! Be sure you are steering your teen to the right information.

Because they are better able to understand and talk about your condition, it could be tempting to lean on your child as your primary source of emotional support, but this is probably not the best approach. This is not to say that you shouldn’t talk about your feelings together, but avoid asking your teenager to assume an adult role. Encourage your child to keep up with as many normal social activities as possible, and keep the lines of communication open and balanced.

Ask your child if they want to talk to a counselor or another trusted adult about their feelings. Know that teenagers’ friends are central in their worlds right now and they may choose to lean on them instead of you. Sharing with your teen’s friends’ parents may help so that other adults can be ready to offer assistance and guidance if necessary.

When All Is Said and Done

Above all, with children of any age, reassure your child that you love them unconditionally and that getting sick is something that happens sometimes, even when we don’t really understand why. If your family has a faith or spirituality you wish to impart to your children, be sure to weave that into these conversations. Offer your child an open line of communication. Be on the lookout for signs that they need extra support, and use your community resources as much as necessary.

To read this article in its entirety, visit our website at www.PHAssociation.org/HelpYourChildCope

By Colleen Brunetti, MEd
PH Patient

PHA Online Communities: PHFriends Ready to Connect with You Right Now
www.PHAssociation.org/ConnectOnline

You are not alone. PHA has active online communities that you can connect with right now online. When you do, you will meet PH patients and family members experiencing the same issues as you. You’ll soon find fast “PHriends” — even though you’ve never physically met. We have different communities depending on your connection to PH and your preference for online communication.

Check them out and connect with the online support groups that are right for you:

» Discussion Board
» Daily Online Support Group Chats
» Facebook
» Ning Teen Social Network
» Patient and Caregiver Mentors

» Email Groups
• Parents
• Caregivers
• Young Adults (Generation Hope)
• Associated Diseases (PH Plus)
• Transplant
• International
• Prayer
• Other groups to get involved in various programs
Caregiver Shout-Out!

PH patient Delia Rivera honors her husband and caregiver Michael Rivera.

I would like to honor Michael Rivera. Not only is he my caregiver, but my husband. I was diagnosed in 2000, and for 11 years, he has been the one by my side through thick and thin. He has never missed an appointment. He always talks to doctors and nurses about any concerns or suggestions he might have. He’s never complained about having to do everything there is to do. He always keeps positive thoughts in my mind and tells me I have a bright future … that there’s nothing I can’t do.

I believe in my heart that all caregivers should be honored because they’re the ones that really keep us going. The doctors treat us but our caregivers are by our sides day after day, so I take my hat off to all the caregivers out there.

The “Caregiver Shout-Out” honors family members and friends in the PH community who provide patients with daily encouragement and support. For a chance to express gratitude to a loved one in Pathlight, tell us about a family member or friend whose support has made a difference in your life. Please include both your names, your relationship, a paragraph about why you’re thankful for your caregiver and, if you can, a photo of the two of you together. Email submissions to Caregiver@PHAssociation.org.

“I believe in my heart that all caregivers should be honored because they’re the ones that really keep us going.”

Your Voice Matters: Caregiver Survey Results Are In

This winter we asked our caregivers in the PH community to tell us about their experiences and needs. The response was tremendous, and we thank you! In the coming months, keep your eyes and ears open for upcoming PHA programs and resources based on your feedback.

One request that came up over and over again was an email group for caregivers. In the survey, 64 percent of caregivers said they want to connect by email. As Nancy Leaman, a caregiver and survey responder, says, “Connect with other caregivers so you don’t feel alone. It is so overwhelming.”

And since there’s no time like the present, join our PHA Caregiver email group and become a part of the conversation: www.PHAssociation.org/EmailGroups#Caregiver

Caregivers can also get one-on-one support from our mentors! See page 3 for our Mentor Spotlight, or check out www.PHAssociation.org/Mentors

Family members and friends, you are not alone.

Email a caregiver mentor for support.

Patient and caregiver mentors are ready to help at www.PHAssociation.org/Mentors
Insurance Peace of Mind:  
A Patient’s Perspective on Making Insurance Work for You

When diagnosed with PAH, who would have thought the hardest part would not necessarily be the daily challenges of the disease, but instead the unexpected battlefront of insurance?

I was diagnosed with PH about seven years ago at age 25. I had open heart surgery a month after diagnosis and only six months before my wedding. Before that, I had been an active, healthy individual with little experience working with healthcare insurers. Luckily, I had purchased a great individual preferred provider organization (PPO) plan straight out of college; the majority of my diagnostic tests were covered and I could go to the specialists I needed — and whom I credit with saving my life.

The first few months post-surgery remain fuzzy, but my doctor’s team helped get my insurance to cover my Tracleer™ and other medications. Then came the Viagra™ and the headaches, not as a side effect of the drug, but from trying to get it covered through insurance! Several years later I ran into similar issues when my insurance company tried to drop coverage of the Tracleer™.

Seven years and nearly 10 prescription drugs later, I’ve been successful in getting all of my medications covered and have determined how to best deal with common coverage barriers:

Do it when you feel well. I know, who wants to ruin a day when you feel great by calling an insurance company? But choosing days when you feel healthy and strong will increase your ability to make your case. It will also help you stay calm and focused when challenged.

Write down the names and dates of everyone you talk to. Call centers, faulty information in computers, disagreeable customer service representatives — they all have an impact on how quickly your issue gets resolved. By writing down the names and dates of those you speak to, you create a greater sense of responsibility on the other end and have reinforcement for future conversations.

Keep them on the phone until you have a resolution. Yes, it’s painful and challenging, especially when you work, but by keeping an insurance company on the phone, you are ensuring that someone is paying attention to your issue.

Keep an organized paper trail. This is especially important when it comes to medical bills. Write down names, dates and action items on a sticky note and attach to the disputed medical bill. Or, just write on the bill itself. And staple or clip your bills and explanation of benefits (EOBs) together with your notes. That way, when the second or third wave of inaccurate bills or insurance denials comes in, you have all the facts right at your fingertips when starting to make calls.

You’ll also want to put memos on your checks or electronic payments so you know which dates of service (DOS) payments they were meant for. Often a hospital or doctor’s office will simply apply your latest payment to the most outstanding bill. This can be an organizational nightmare when you have one or more disputed payments pending. When new bills include DOS I know I’ve already paid for, I review the DOS notes in my online checking payments, make notes on the bill and then call the hospital or doctor’s office. By reviewing the dates and payments with the person in charge of billing at the hospital or doctor’s office, they can adjust how payments are applied in their system so your next bill will correctly reflect your intended payments.

Get your human resources (HR) department involved. If your insurance is through your workplace, your HR department is another option for reinforcements. Like a doctor’s office, they have special contacts they can reach, and they know what your medical plan covers.

Consider secondary insurance. Secondary insurance (through work or a spouse’s workplace) can cover up to 90 percent of out-of-pocket costs left after primary insurance pays its piece. While the cost of an additional monthly premium may seem high, compare the cost of secondary insurance to the out-of-pocket amount you’re paying for doctor visits, medications and medical tests. You may be surprised at the result.

Ask for help. Some days, you just can’t do it anymore. It feels like the insurance companies have won and you just want to give up. Don’t! This is the time to ask for help. Whether it’s from a spouse who can contact their HR group, or a parent, sibling, child or a doctor who can work out next steps with an insurance company, sometimes just a short break can give you the stamina to pick up the ball next time around.

Most importantly, maintain a close and open relationship with your doctor and medical team. Your doctor is usually your biggest health advocate (other than you) and has a vested interest in seeing you get the medication and treatments you need. Often a doctor or administrator can reach people an individual cannot. They can approve or confirm things first hand, and they can often help you identify the best way to achieve success.

By Jennifer Tahmoush, PH Patient

By Jennifer Tahmoush, PH Patient
My Doctor Wants to Hear from Me: Advice from an “Empowered Patient”

Dr. Deborah Levine encourages pulmonary hypertension patients to think of themselves as partners in their healthcare, active participants who stay educated, empowered, and work with their healthcare professionals to make collaborative decisions about their treatment.

In a recent PHA webinar, “The Empowered Patient: Nurturing Partnerships to Get the Best Care Possible,” Dr. Levine, Director of the PH Clinic at the University of Texas at San Antonio, emphasized that open communication with one’s medical team is extremely important for everyone, but especially important for those of us with PH. The fear, anxiety, and uncertainty so common among newly diagnosed PH patients can make communication and understanding especially difficult. Education takes away much of that fear, anxiety and uncertainty.

Here are just a few of Dr. Levine’s tips for becoming an empowered patient:

- **Know what you want to accomplish during a doctor’s visit.** Gather questions prior to the appointment, on a pad, notebook or smart phone. Leave space between questions to take notes at the visit. Don’t be afraid to tell your doctor if you don’t understand an answer or explanation.

- **Keep an up-to-date medication list with you at all times.** Also keep a copy of all your medical records, and make sure that you have records transferred to new physicians.

- **Educate your medical team.** Print PHA materials about PH for non-PH medical teams.

- **Bring a friend or family member along to office visits,** especially early in your treatment. An extra pair of eyes and ears can capture things that the patient alone might miss.

- **Learn the routine at your doctor’s office and hospital,** including who to talk to about a variety of topics, such as insurance, new symptoms, medication problems and others. Bring all insurance info to every appointment, and a good book or iPod in case you have to wait.

- **After your appointment, follow through.** Review your notes with your family member or caregiver, and make sure you understand everything. Feel free to call back if you have any more questions. Update your medication list immediately if there are any changes. Call for test results, and don’t be afraid to ask for another opinion if you aren’t comfortable with your current clinic.

- **Know that your doctor wants to hear from you.** Everything is of interest! Write down the day and time when you feel a little lightheaded, and take these notes with you to your appointment. If your lips turn blue, make a phone call. Nothing is too small to note. Dr. Levine emphasized that patients should report on any and all symptoms that came along. Comprehensive notes give doctors a broader, more holistic view of your health.

- **Believe in yourself.** No one knows your body better than you.

To watch the full recording of Dr. Levine’s “Empowered Patient” webinar, visit PHA’s website at [www.PHAssociation.org/Classroom/EmpoweredPatient](http://www.PHAssociation.org/Classroom/EmpoweredPatient)

By Ellen Harris

**PH and... Brochures: Information About Associated PH**

PHA’s **PH and...** brochures explore the connection between PH and the following: Hereditary Hemorrhagic Telangectasia (HHT), HIV, Liver Disease, Methamphetamine Use, Scleroderma and Sickle Cell Disease.

Brochures are available for both patients and medical professionals. For brochures for patients, visit [www.PHAssociation.org/Patients/AssociatedDiseases](http://www.PHAssociation.org/Patients/AssociatedDiseases).

Brochures for medical professionals can be found at [www.PHAssociation.org/Medical/AssociatedDiseases](http://www.PHAssociation.org/Medical/AssociatedDiseases).

Patients, tell your medical professionals about this resource!

For more information about these brochures, contact PHA’s office at 301-565-3004.
ASK A PH SPECIALIST

Q: What is a six-minute-walk distance (6MWD) or six-minute-walk test (6MWT)? Why is my doctor asking me to do one?

A: The first part of this question is easy. Unlike most tests we order in medicine, the six-minute-walk test is exactly what it sounds like. The patient is asked to walk at a “comfortable” pace for a six-minute period of time and the distance covered is measured. Practically speaking, this is usually done in the clinic in a long hallway with known distances marked off in intervals (though variations on this theme are possible). The patient simply walks back and forth while being timed. Why your healthcare provider wants this information is more involved, but in essence, the 6MWT is a measurement of your ability to exercise. Although it is not as fancy or high tech as most of the tests ordered at your doctor’s office, it actually provides very useful clinical information, is fairly easy to perform and is inexpensive. Both absolute values (how far you can walk) and changes in values (how far you walk now compared to some time in the past) are useful to your provider. A number of studies in pulmonary hypertension have confirmed that 6MWD can help predict how you are doing clinically, and this distance, as well as the trend, will factor into what therapies you may be started on and how they are adjusted over time. I am not implying, however, that the 6MWT should be treated as a race and you should dive for the finish line each time. Rather, we want to get an idea of what you can do comfortably and how this is changing with your treatment. An improving 6MWD would imply your therapy is on the right track and, conversely, a worse distance might indicate a need for a more aggressive approach. Similarly, a low initial 6MWD might make your healthcare provider consider more aggressive therapy as your initial treatment.

This is not to say the 6MWD is a perfect measurement or that it is the only data point your provider is looking at. It is a piece of information to be considered in the context of the whole patient. The current assessment of 6MWD does not account for such things as patient height or age. What is a reasonable distance to walk for someone who is 70 years old and 5’2” is not necessarily the same as for someone who is 25 years old and 6’5,” and this is a weakness of the study. There is a push to measure “adjusted” 6MWD, however. Also, 6MWD may not be as good an indicator of PH severity in patients who have limited ambulation for other reasons such as joint pain. This is particularly relevant to patients with connective tissue disease associated PH such as those with systemic sclerosis. Still, multiple studies have confirmed the utility of 6MWD in PH and it is the primary endpoint of a number of therapeutic trials in PH. The test has also proven useful in the assessment of other diseases such as chronic obstructive lung disease (COPD) and interstitial lung disease.

Other means of assessing exercise ability are sometimes considered in the PH patient. Cardiopulmonary exercise testing (CPET) is a more formal means of measuring your ability to exert yourself. This can be done on a treadmill or an exercise bike and can more accurately measure such things as your heart rate, heart rhythm, oxygenation, oxygen extraction, etc. However, it is considerably more expensive than a 6MWD and has not been as routinely used in predicting disease severity or therapeutic response in PH. Still, there are certain scenarios where a CPET provides useful information. Another interesting area of study is the use of exercise catheterization. This involves exercising (usually either on an upright or recumbent bicycle or while doing arm exercises such as straight arm raises) with a pulmonary artery catheter in place. As an area of investigation, there remains controversy regarding how useful this test is, in part because there is a fair amount of variation in pulmonary artery pressure with exercise in people without PH. In fact, the previous definition of exercise induced PH was removed from the most recent WHO consensus definition of PH due in part to this controversy.

There are clinicians and investigators (myself included) who still find the test useful in some situations, however, and there is a need for future studies in this area.

Answer provided by Todd M. Bull, MD, FACP, Associate Professor of Medicine, Division of Pulmonary Sciences and Critical Care Medicine, University of Colorado Health Sciences Center

References:

Each Issue Pathlight features a question from our PH community and its answer from a PH specialist. Send us your questions, keeping in mind doctors can only address general topics that are not specific to individuals. Send submissions to AskADoc@PHAssociation.org or call 301-565-3004 x770.
PH Resource Network Symposium 2011: 
Allied Health Professionals, Join Us for PH Education and Networking

With 2011 now upon us, it is time to start thinking about the upcoming 2011 PH Resource Network Symposium, *Inspiring Hope: New Directions in PAH*. This unique educational, networking and advocacy event will take place September 22-24 at the Hyatt Regency Crystal City in Arlington, Virginia, just outside of Washington, D.C.

Attending the PH Resource Network Symposium is a great opportunity for everyone from professionals new to pulmonary hypertension to the seasoned veteran. At the Symposium, attendees will have the opportunity to learn about the latest advances and treatment of pulmonary hypertension along with a chance to network with PH-treating healthcare professionals from across the country.

Over the years attending this symposium, we have taken away a wealth of knowledge that has helped to improve our practices on a daily basis. The contacts we have made have given us a vast array of resources to tap into. Continuing from our previous theme, *Empowering the Interdisciplinary Team*, we are proud to offer teaching through multi-disciplinary panels, sessions for pediatric practitioners, and sessions led by pharmacists. Further, we are excited that for the first time at Symposium, we will be offering CME credits for physician assistants.

Do not let this opportunity pass you by. This is the time to learn and grow as PH medical professionals. Come join us at the 2011 PH Resource Network Symposium, *Inspiring Hope: New Directions in PAH* in September. Registration is now open. Spread the word!

We look forward to seeing you there!

**FREE Registration Available!**

Thanks to an unrestricted educational grant from Actelion Pharmaceuticals US Inc., the first 300 PH-treating allied health professionals (non-corporate) will register for FREE*

*A $50 deposit is required to reserve a space and will be refunded after Symposium. However, cancellations after September 16 and “no shows” are not eligible for refunds. In order to receive free registration, attendee must be an active, paid member of PH Resource Network. To check the status of your PH Resource Network membership, Sign In to the PHA website or email PHRN@PHAssociation.org. To join or renew your membership online, visit www.PHAssociation.org/PHResourceNetwork/Join

Lisa Taylor, BA, RN
The Christ Hospital
Cincinnati, Ohio

Melisa Wilson, APRN, BC
Orlando Heart Center
Orlando, Fla.

Symposium Committee Co-Chairs

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**2011 PH Resource Network Symposium**

**Inspiring Hope: New Directions in PAH**

**September 22 – 24, 2011**

**Hyatt Regency Crystal City — Arlington, Va.**

Educational sessions will include:

- Virtual heart catheterization lab
- Echo interpretation
- Complex PH case studies
- Medication safety
- Managing PH emergencies
- Transitions between inpatient and outpatient care
- Pulmonary function testing
- Many more!

View a full list of topics and speakers and register for Symposium at [www.PHAssociation.org/PHRN/Symposium](http://www.PHAssociation.org/PHRN/Symposium)

Questions? Contact PHA at Symposium@PHAssociation.org or 301-565-3004 x761.
Call for Abstracts for the 2011 PH Resource Network Symposium

Want to highlight research that your institution is working on? The 2011 PH Resource Network Symposium Poster Hall provides the perfect opportunity.

Abstracts by allied health professionals in all areas of practice related to pulmonary hypertension are invited for submission for poster presentation. While not required, PHA encourages the submission of original abstracts. Abstracts also do not need to be fully executed in practice. Abstracts may include, but are not limited to, the following:

- Guidelines for specific clinical situations, implementation of a process to improve patient outcomes or innovative use of technology in clinical practice;
- Development or implementation of a performance improvement program;
- Patient safety initiatives;
- Patient satisfaction improvement initiatives;
- Identification and implementation of PH allied health educational needs;
- PH nursing orientation programs, role implementation or development of practice guidelines.

Submission Deadline: June 1, 2011
Notification Date: June 30, 2011

The first author will be notified via email regarding the presentation of the abstract. Text of accepted abstracts will be printed in the program book.

Abstract resources and submission guidelines are available at www.PHAssociation.org/PHRN/Symposium/Abstracts

Represent Your Patients on Capitol Hill!
Participate in the PH Resource Network Symposium Advocacy Day

I really feel good at the end of the day that we did something that will make a difference for our patients.
~ Jennifer, Advocacy Day 2009

Why participate in the 2011 PH Resource Network Advocacy Day on Thursday September 22?

- Members of Congress need to hear your perspective. You know many stories about the impact of PH and why finding a cure matters.
- It’s advocacy made easy. Lunch, transportation and training are provided.
- It’s fun. Mingle with old friends and make new ones.
- It works! Every PH advocacy day builds support for PH legislation in Congress. By joining the 2011 Advocacy Day team, you will make a difference in the fight against PH.

✓ Check the “Advocacy Day” box on your registration form, and we’ll see you September 22!

“Advocacy day exceeded my expectations. The [legislative staff members] were very friendly and easy to speak with.”
~ From an Advocacy Day 2009 evaluation
Tips for Traveling with Oxygen

Traveling with oxygen may seem intimidating; however, with a little planning, it can be done easily and safely.

1. Talk with your oxygen supplier about how much back-up oxygen you’ll need. The oxygen supplier can help arrange for oxygen from another source at your destination if you can’t bring your concentrator with you.

2. If you are using your own oxygen system, obtain the number of an oxygen supplier at your destination, just in case you have a malfunction. Always carry a hard copy of your oxygen prescription with you.

3. If you’re planning to fly, be aware that not all airlines offer or allow supplemental oxygen on board. For information about airline oxygen policies, contact the airline directly, as policies change frequently.

4. Notify your airline as soon as possible that you will be flying with oxygen; the airline will require documentation from your doctor regarding your need for oxygen.

5. If using a portable oxygen concentrator, you will need sufficient battery power to cover pre-flight and post-flight time.

6. Be aware that separate oxygen arrangements may need to be made for connecting flights.

7. Speak with your physician about how much supplemental oxygen you will need during your flight. You may need more oxygen at higher elevations.

8. Have a plan in place for how you will get from your car to the gate at the airport and from the gate to your destination.

9. Call 911 if you experience an emergency situation, such as running out of oxygen or a portable concentrator malfunction.

10. Make your arrangements well in advance to avoid extra stress!

By Mary Bartlett, FNP; Karen Younggren, RRT; Alan Lurie, RRT; Patricia Stephens, CNSS; Glenna Traiger, RN, MSN; Bradford Jones, RN, BSN; Louise Durst, RN

Welcome, Candice Abate, Vice President, Medical Services and Patient Education!

As Vice President, Medical Services & Patient Education for PHA, Candice is responsible for the advancement of program development for both medical professionals and patients. She oversees the following departments: Medical Services, Meetings and Conference Planning, and Web Services. Candice is a key liaison among medical professionals, patients and staff in the promotion of PHA activities, including the coordination of live and online educational events and the promotion of scientific research. As a member of the management team, she is also working on a variety of projects to further advance the reach and impact of PHA. Candice can be reached at Candice@PHAssociation.org or 301-565-3004 x778. ♦
Meet Dr. Myung Park: Helping to Shape the Future of PH Education

Dr. Myung Park is the Director of the Pulmonary Vascular Diseases Program at the University of Maryland School of Medicine. She is a member of PHA’s Scientific Leadership Council (SLC), the guiding medical body for PHA’s clinical and research activities, and she serves as the chair of the Medically Led Sessions Committee for PHA’s 10th International PH Conference and Scientific Sessions taking place in June 2012. Dr. Park recently took time to talk about her involvement in the fight against pulmonary hypertension.

You specialize in cardiology. What initially sparked your interest in PH?

My interest in PH started during my residency. This was at a time when we were just learning about PH, including the use of calcium channel blockers. I saw many patients, usually young women, suffering from this devastating illness when there were no PAH-specific treatments. Several years later, when epoprostenol was approved, it was truly miraculous to see the difference this treatment made in helping people recover and get better. As I realized the impact appropriate treatments and care have in fighting this condition, and that PAH was not well known or recognized, I became dedicated to help those who were diagnosed with PH.

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

Truly, the past decade has brought forth incredible advances in PH treatments. We have gone from having no effective drug in the mid 1990s to having nine FDA approved medications in the U.S. We are also more knowledgeable about how to use these drugs and on which patients, what our goals of treatment are, and how and when to use combination regimen. Many aspects of these questions still remain unanswered and are being actively investigated through clinical trials. But when I look back 15 years, I am awed at all the progress.

What is the most important piece of advice you give your PH patients?

Be your own advocate. This is, of course, best done by reading and educating yourself about PH, asking questions and working with your healthcare team to work toward the common goal of getting the best and most appropriate treatment for yourself.

How did you become involved with PHA?

I became involved with PHA in an effort to help my patients obtain information on PH. I realized early on that PHA is a wonderful resource for people searching to educate themselves about PH or wanting to meet others with whom they can share their experiences or ask questions. I wanted to get involved with this wonderful organization and do my part in “spreading the word” and helping to educate patients and healthcare providers.

What are your plans and goals for the Medically Led Sessions at the 2012 Conference?

We have assembled a wonderful group of PH specialists that is working with me and PHA staff to set the agenda for the upcoming 2012 Conference. Our goals are to help patients and their families better understand the process of PH, learn about the medicines (the when, why, and how) and consider what the future of PH will look like. We also plan to have sessions focusing on how to live with PH by discussing topics such as nutrition, exercise and alternative medicines. It is shaping up to be a wonderful meeting, and we are all very excited.

What advice do you have for new practitioners entering the field of PH?

This is a field with a very promising future, where new therapies and innovations will be making their mark. We need young, dedicated physicians who appreciate and understand the complexity of PH and are willing to contribute and make a difference.

Anything else you’d like to add?

I feel very honored to be in a field where I have the opportunity to be part of this journey of discovery. In my practice, I have met some truly amazing people with incredible faith, strength and love. I have learned much from my patients whose lives I have had the privilege to be part of all these years. I look forward to the next chapter in our journey of discovery together.

Interview conducted by John Krizel, PHA Medical Outreach Program Associate
Genetic Changes in PH: A New Angle

It is well known that genetics plays an important role in some forms of pulmonary hypertension. Some people with pulmonary arterial hypertension (PAH) have a family history of the disease. They inherit a genetic change (mutation) from one of their parents and this greatly increases their risk of developing PAH. Genetic changes are also identified in 10-40 percent of patients with sporadic idiopathic PAH. The main gene associated with PAH is called BMPR2; more information can be found on the PHA website, www.PHAssociation.org/AboutPH/Genetics

But many questions remain unanswered. Thankfully, not everyone who inherits a BMPR2 mutation will develop PAH. Why is this? What determines who in the family will get PAH? And if your PH is not caused by a mutation, does this mean genetics isn’t important?

Previous Research

PH develops when the cells that form the blood vessels of the lung become abnormal and restrict the flow of blood through the lungs. There is growing evidence that in some cases, these cells may have genetic changes that contribute to their abnormal behavior. The balance between cell growth and cell death is critical for our bodies to stay healthy. Genetic changes can disrupt this balance by making a cell grow faster than usual or allowing it to survive when it is instructed to die. Most cells of the body are genetically programmed to die off at a certain rate to make room for fresh new cells, and if they don’t do so, then cells can accumulate faster than they die off. This makes the vessel wall become thicker and the lumen (hollow bore) becomes narrower. Previous work by PH researchers has shown evidence for genetic changes in endothelial cells, the cells that line the inner side of the vessels where the blood flows through. This type of genetic change could be a trigger for PH that starts the disease process, or it could occur at a later stage and might contribute to it getting worse.

Current Research

New genetic technologies now enable us to easily search across all of the genetic material in a cell to look for changes. We are using these techniques to study the cells obtained from the lung vessels of PAH patients who had a lung transplant. In our initial study, we found a surprisingly high frequency of genetic changes in PAH lung cells. The genetic material in each of our cells is like a giant reference book divided up into 23 volumes. In four of the nine cases we studied, a large genetic change was seen, equivalent to one whole volume disappearing from the bookshelf. In a fifth case, a smaller change was seen, similar to losing several chapters from one of the books. These changes were only present in a proportion of the lung cells and were not seen in other tissues such as the person’s blood. This means that the changes were not inherited and cannot be passed on to their children.

Significance of the Results

• This is the first study to look for large-scale changes across all the genetic material in the cells from lungs of patients with PAH.

• Our initial results suggest these changes are quite frequent and are found in several different types of PAH, not just the familial and idiopathic forms. So genetics might play a bigger role than we previously thought. The difference is that this type of change occurs just in the lungs and is not inherited.

• In one case, we found both a BMPR2 mutation that was inherited and then a second change in the lung cells that was not inherited. This could explain why not everyone who inherits a mutation gets PH — perhaps additional changes are needed in the lung to trigger the disease.

Much further work is needed to understand these newly discovered changes, understand how and when they occur and determine what role they might play in PH. My thanks to all of you who volunteer to participate in PH research studies.

Where to Find this Article


By Micheala Aldred, PhD, Genomic Medicine Institute, Cleveland Clinic, Cleveland, Ohio.
Nicole Cooper was diagnosed with PH in December 2009. Just over one year later, she’s running a rapidly growing support group in the Baltimore area and planning a gala in November. She is also one of the newest members of the 435 Campaign, PHA’s grassroots advocacy network. She feels she’s come a long way since the shock and depression she felt shortly after she was diagnosed.

“I was sitting in the doctor’s office and all I could hear was, ‘You’re gonna die. You’re gonna die. You’re gonna die,’” she says. “I knew my life had done a 180. I couldn’t walk the same, work out the same, or go on a plane. I was really scared.”

After reading about pulmonary hypertension on PHA’s website and asking her doctors questions, she felt that she wasn’t getting all of the answers she needed, so she attended her first support group meeting. “I needed to be around more patients,” she says. “At the support group, I saw patients who looked like me and I had so many questions!” Shortly after her first support group meeting in April, Nicole decided to start her own group a little closer to her home. That was how she met Joyce Gore.

Joyce and her husband Vernon moved to the Baltimore area from Arizona in 2010 to be closer to doctors who were more knowledgeable about PH, and they immediately began attending Nicole’s support group. Joyce went through three doctors and three misdiagnoses before she was referred to the University of California, San Diego Medical Center for a right heart catheterization. After returning to her home in Arizona with a PH diagnosis, Joyce says she continued to go through a series of medical mishaps due to medical professionals who did not fully understand PH. “If I wasn’t knowledgeable, I could have died. I decided it’s my disease, so I should know everything I can about it,” she says.

Joyce realized that through knowledge and advocacy, she’s able to help herself and help others. She, like Nicole, is a new 435 Campaign member.

Nicole and Joyce both found information on PHA’s website about advocating for initiatives that would lead to more research and public awareness of PH. “We talked about advocacy and attending the 2010 Congressional Luncheon in our support group,” Joyce says. “I told Nicole that I was going and Nicole said, ‘Well, then I’m going too!’” Both women attended the Luncheon and met with several congressional staff members to share their PH journeys and what a typical day is like for the average pulmonary hypertension patient. “I think God kept me here to do this. I love talking to officials; I’m not scared about it. They put on their britches the same way we do!” Joyce says.

This year, Joyce has reached out to Senator Barbara Mikulski and plans to reach out to her other two Members of Congress to talk to them about pulmonary hypertension and the need for more research and a cure. Both Nicole and Joyce believe in getting family and friends involved in everything they do for the PH community, including advocacy. “Your family and friends are interested — they care about you!” Nicole says.

Both women have made it a habit to talk about pulmonary hypertension with everyone they meet, whether it’s in the street, in the grocery store, or in congressional offices. As Joyce explains, “I’m in a wheelchair, my body is weak, but I pray. My spirit is strong and I will shout it from the rooftops to explain to people what it is like to be short of breath.”

To learn more about getting involved with legislative advocacy like Nicole and Joyce, contact Elisabeth, PHA’s Grassroots Campaigns Associate, at 301-565-3004 x753 or Elisabeth@PHAssociation.org.

By Elisabeth Williams
PHA Grassroots Campaigns Associate
On February 13, 2008, my baby girl Katie Grace was diagnosed with pulmonary hypertension. Like any family that has received this diagnosis, ours went into a tailspin of “what, why, where, and how.” Because we had never heard of pulmonary hypertension, and the news we received sounded so grim, we started to look for others who had been down this road. It was hard to find other families who knew what we were going through, but when we got to Stanford our doctor set us up with another family whose daughter had PH. That family brought Katie Grace a gift: a backpack shaped like a bear, even though it was before she started on IV treatment and needed the pack. After she started on IV medication, they also gave us a bag to carry her pump in, but it was black canvas and not practical for children.

So began the search for a bag that would make it easy for a five-year-old to play and look like other children.

As luck would have it, one of my neighbors met a retired school teacher named Mary who made school bags and purses. After Mary heard about Katie Grace’s pump, she couldn’t wait to meet us and make a bag for her. Once we met, we knew it was going to be more than “just a bag.” Katie Grace brought Mary the “Build-A-Bear” bear she had made and we found a bear-sized backpack. One thing led to another, and soon we had the idea of making a pump for the bear. At that point, Mary and I agreed instantly that all PH kids should have one.

Mary and I were paying for all of the materials ourselves, but she’s retired and we’re a family of four with one income, and this was hard on both of our budgets. So just like the good luck I had in meeting Mary, an issue of Pathlight arrived which included an article about the opportunity to apply for a Tom Lantos Innovation in Community Service Award. Although I had never applied for a grant before, my friends all encouraged me to do so and I did.

When I learned that I was awarded a grant, we got to work right away. Our first thought was to make as many as we could before PHA’s 2010 International PH Conference in California. It was so wonderful to be able to hand a “PHurry PHriend” to the kids at Conference and to send out more afterward. I love hearing stories of how the kids take them to all their doctors’ appointments, and I learned that one girl even named hers “Katie Grace.”

A PHurry PHriend is more than just a bear with a backpack. Each bear has IV cords and a pump … just like our kids. This gives the child comfort and a way to tell others about their disease and the pump without embarrassment. We send a letter from our family to each family that receives a PHurry PHriend, providing them with information and offering the hope and encouragement that life will go on even with PH. We have already sent out more than 60 PHurry PHriends. It has been a joy.

Life as a caregiver can be hectic and there are times I find myself running a little late in producing our PHurry PHriends, but if your child needs one, please send your name and address to me at groebs4@live.com and we will send you your free PHurry PHriend thanks to PHA and Gilead’s sponsorship of the Lantos grants program.

To learn more about the Lantos grants program, visit www.PHAssociation.org/LantosAwards.

By Kathy Groebner
Mom to PH Patient Katie Grace
A Big Birthday Raises a Big Total for PH

“Getting to be 80 was a big deal for me.”

Seventeen years ago, Al Abram of Pompano Beach, Florida, was diagnosed with scleroderma. Ever since that diagnosis, Al and his wife, Dorothy, have been passionate fundraisers and awareness raisers for scleroderma research. When Al was also diagnosed with pulmonary hypertension three years ago, they decided to put all their fundraising efforts towards PHA. “We’ve been very, very thankful for PHA and the research you’ve done,” Dorothy says.

After his PH diagnosis, Al wasn’t sure he would have many more birthdays to celebrate. So when the big 8-0 drew near, he and Dorothy decided to host a “big, bang-up party” in celebration. They mailed out invitations far and wide, and noted that in lieu of presents, Al would be honored if the guests could make gifts in his honor to PHA.

“I’ve always felt that most senior citizens don’t need much that we don’t already have — and the few things we do need, we can take care of for ourselves,” Al says. “I wrote on the invitation that I didn’t want presents, but that the overall idea was to send a few bucks to PHA. And boy, did our friends and family come through in a very big way.”

When the party day came on January 9, 2011, more than 160 guests were there to celebrate with Al and Dorothy, representing family, friends, and even local politicians (who helped Al and Dorothy secure three proclamations to mark the occasion). “We’ve built friendships with a lot of people over the years, and it was amazing to see them come together for Al,” Dorothy says. “We’re very grateful for all of our friends and family.”

Leading up to and after the party, friends and family came together to donate more than $4,500 to PHA in Al’s honor. “Our goal was $4,000 and I’m glad we exceeded that amount,” Dorothy says. “We’ve also heard from folks that they want to keep giving to PHA in Al’s honor — and we hope it keeps coming!”

For more information about how you can incorporate fundraising into your next celebration through PHA’s In Honor of Our Lives program, contact Jennifer Kaminski at Jennifer@PHAAssociation.org or call 301-565-3004 x756.

By Jennifer Kaminski
PHA Development Associate

Al’s not the only one putting off presents for the greater good. PH patient Sharyn Fox of Cincinnati, Ohio, also celebrated a big birthday recently — her 70th — and she asked friends and family to make gifts to PHA instead of giving her presents. To learn more about In Honor of Our Lives and how you can include PHA at your party, visit www.PHAAssociation.org/Fundraise/AtCelebrations

Congratulations, PHers!

You lent your lips to save lives, and now the worldwide PH community has landed a Guinness World Record for most lip prints collected. More importantly, you raised awareness of PH among hundreds of your neighbors, classmates, colleagues and complete strangers. Don’t let those lips sit idle now that the record’s been reached — keep sharing your story!

Visit www.PuckerUp4PH.com/blog for the latest news and recaps from the campaign.
Put Your Time, Talent and Treasure to Work for the PH Community

PH patients 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 fundraising programs described below or by supporting PHA with your “treasure” by making a donation, including us in your estate plans, or becoming a member.

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<td><strong>ONLINE</strong> <strong>Online</strong> Raise awareness and funds when you invite your friends and family to support you by making 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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<td><strong>AT WORK</strong> <strong>At Work</strong> Motivate your coworkers to support PHA by holding a fundraiser at your workplace. The tools and tips included in PHA’s Our Workplace Has a Heart Kit make planning a workplace fundraiser easy and fun! 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 each of your gifts to PHA. <a href="http://www.PHAssociation.org/Fundraise/AtWork">www.PHAssociation.org/Fundraise/AtWork</a></td>
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<td><strong>AT A CELEBRATION</strong> <strong>At a Celebration</strong> 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>
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<td><strong>AT SPECIAL EVENTS</strong> <strong>At Special Events</strong> From fun walks to golf tournaments to galas — to [insert 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.PHAssociation.org/SpecialEvents">www.PHAssociation.org/SpecialEvents</a></td>
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<td><strong>GENERAL DONATIONS</strong> <strong>General Donations</strong> 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>
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<td><strong>SUSTAINERS CIRCLE</strong> <strong>Sustainers Circle</strong> 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>
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<td><strong>LEGACY * OF HOPE SOCIETY</strong> <strong>Legacy of Hope Society</strong> 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>
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<td>** Jennifer Kaminski: 301-565-3004 x756, <a href="mailto:Jennifer@PHAssociation.org">Jennifer@PHAssociation.org</a></td>
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<td>*** Jess McKearin: 301-565-3004 x765, <a href="mailto:JessicaM@PHAssociation.org">JessicaM@PHAssociation.org</a></td>
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International Highlights: What’s Going on Around the World?

Did you know that there are more than 50 PH associations operating worldwide? Just a few decades ago, the resources, support, and encouragement that these groups offer today just didn’t exist! Here’s a round-up of some highlights from our friends overseas, pointing yet again to the incredible energy of our global PH community!

- **In Austria**… PH was in the bright lights for 24 days, projected on one of Vienna’s most famous coffee shops, the Landtmann Café. Media coverage of the display coupled with the bustling tourist season maximized its impact.

- **In Belgium**… PH Belgium will celebrate its 10 year anniversary this spring! The group is planning an international nursing day on May 12, as well as programming for new and youth patients.

- **In Bulgaria**… Representatives of the national PH group were invited to present at the 12th National Cardiology Conference.

- **In the Czech Republic**… PHers enjoyed a “Rehabilitation Retreat,” which featured modified activities and medically led educational programming. PH patients also met in Slovakia and Slovenia, alongside medical professionals and specialists in both countries.

- **In France**… About 180 patients, family members, and medical professionals attended the First PH Patient Congress in Lyon. PH awareness also took to the seas thanks to HTAP France and PHA Europe’s support of an annual transatlantic sailing race that will cover 2,800 nautical miles and help the six-person crew understand the relationship between man and nature.

- **In Germany**… PHev Germany, which celebrated its 13th National Patient Meeting, awarded journalist Bert Ostberg for his documentary on PH. The film features a young, wheelchair-bound PH patient and his journey to rehabilitation.

- **In Israel**… PHers are busy planning their Annual Patient Conference and their first Symposium for allied healthcare professionals, slated for spring or fall 2011.

- **In Italy**… A new documentary of video interviews of patients is underway, and leaders have been busy representing those voices at a PH Conference at the University of Bologna.

- **In Japan**… PHA Japan will soon publish a new Japanese translation of *Pulmonary Hypertension: A Patient’s Survival Guide*. This will be the third Japanese edition published. *We wish our friends in Japan Godspeed in their recovery.*

- **In Norway**… An elite basketball team in Norway, whose captain is the son of PHA Norway President Hall Skåra, helped raise PH awareness by puckering up for PH. Members of PHA Norway also enjoyed the group’s first face-to-face meeting and several patients were the first PHers to attend a clinic specializing in training and diet tailored to lung patients, previously geared toward COPD patients.

- **In Poland**… PHers in Poland will join the nation in the “Day of the Heart,” a big event in Poland and an important step toward organizing the first national PH Day in the country.

- **In Spain**… The National PH Association of Spain, ANHP, represented PHers at the Spanish Society of Cardiology Cardiovascular Disease Conference, and joined the Spanish Heart Foundation in a 100 km journey to Santiago de Compostela to honor cardiac patients.

- **In Switzerland**… The Second PH Children’s Meeting was held in Zurich; children and families were educated on PH and entertained by the hospital clown, Dr. Kiko.

- **In Turkey**… Association leaders distributed educational material and networked at the Turkish Cardiology Association Congress. They also presented on their association at the Turkish Respiratory Society Congress. The group is proud to unveil a new 24-hour patient helpline.

The news featured in this issue’s round-up is only the beginning! For more news from around the world, visit [www.PHAssociation.org/PHInternational](http://www.PHAssociation.org/PHInternational).

By Christine Dickler
PHA Associate Director of International Services
Twenty years ago, four women decided it was time PH patients had something to look forward to, a future.

Thirty years ago, three PH patients—Dorothy Olson, Teresa Knazik and Pat Paton—sat down with Pat’s sister, Judy Simpson, to change the collective futures of everyone living with PH. Their efforts grew to become the membership organization today known as the Pulmonary Hypertension Association. Today, the three surviving founders—Dorothy, Pat and Judy—often reflect on those early days, when there were almost no resources dedicated to supporting PH patients.

To read how Dorothy, Pat and Judy’s grassroots efforts to combat PH were only just beginning, visit PHAssociation.org/Give/Founders.

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

Fishing for Success: Diane Ramirez’s Strategy for Raising Awareness

Diane Ramirez, PH patient and long-time advocate, knows about raising awareness. In January she was the subject of a New York Times feature on rare diseases (www.PHAssociation.org/NewYorkTimes), and she will be featured in an upcoming issue of Health Monitor. In 2009-2010, Diane organized the support group members in her area of North Carolina and visited all Congressional Members in her state. As a result, North Carolina had the most Tom Lantos PH Research and Education Act co-sponsors of any state.

When Diane thinks about her success, she laughs and says, “When [my fiancé] fishes, he has 10 lines in the water and he waits for one to bite. He tells me, ‘You may not like fishing, but what you do with advocacy is like fishing!'” She explains, “At any given time I have several emails or calls out. I’m constantly reaching out and then I just wait to hear a response from someone.” Diane’s success is no accident and her strategy is simple. Here’s her advice:

» “Look everywhere for an opportunity.”
  • Diane looks for local or regional publications that cover pulmonary or cardiovascular diseases and/or patient stories. “Look at the publications for an editor and their contact information,” she suggests.
  • One way to get some quick face-to-face time with your Members of Congress is to check the community calendars for any upcoming events in your area.

» “I spoke with someone who got thousands of emails a day. I don’t want to take the chance that my email will get buried in an inbox!”
  • Diane likes to pick up the phone to pitch her story to reporters. If you email or leave a phone message, but haven’t heard back yet, give them a follow-up call.

» “What’s more important, my comfort or getting this information out?” Diane’s tips for calming your nerves before interviews or Congressional appointments:
  • Be professional, clear and concise. Visit PHA’s website for quick PH talking points: www.PHAssociation.org/MediaGuide/InterviewTips
  • Sometimes legislative staffers are shocked to hear what you go through daily as a PH patient. Use props (medicine bottles, a pump, etc.), use whatever you need to get your message across.
  • “For the longest time, I felt like I was on an island. I think about that patient who is still out there who thinks they are all by themselves. I make a decision right then to calm down. Remember: you are there to raise awareness,” says Diane.

For more tips, contact Elisabeth Williams at 301-565-3004 x753 or visit www.PHAssociation.org/GetInvolved.
This past November, PH patient Ellen Harris brought the PH community one step closer to being added to the 88 other disease states listed in the Social Security Administration’s (SSA) Compassionate Allowance program. Armed with a moving personal story, Ellen delivered a poignant testimony that culminated in PHA’s recommendation to include “Pulmonary Arterial Hypertension (PAH) — with NYHA/WHO class IV symptoms and/or severely reduced exercise capacity” as a compassionate allowance.

The Compassionate Allowance program is designed to use objective information to identify diseases and other medical conditions that invariably qualify an individual as disabled. This allows the SSA to more quickly provide benefits to the most obviously disabled individuals. Ellen’s testimony was part of PHA’s ongoing efforts to help qualified PH patients receive Social Security Disability benefits as quickly as possible.

PHA continues to work closely with the SSA to advocate for policy that meets the needs of the PH community. Learn more at www.PHAssociation.org/Patients/Insurance/Disability or call PHA at 301-565-3004 x773.

Ellen Harris in her own words...

“I was pleased to have the opportunity to testify, because I know how hard it can be to receive Social Security benefits, due to my own condition, but also due to friends and family who clearly are unable to work and yet cannot seem to convey this to the Social Security Administration.

It was a little shocking, and a little amusing, when the room gasped when I talked about how much my medicine costs each year. Due to the TV lights, I couldn’t see the audience, but the whole room gasping let me know that someone was actually out there! I think they got the point that PH can be incredibly expensive to treat.”

How to File a Department of Insurance Complaint

1. Gather the appropriate information. Be prepared with:
   • a copy of your insurance card;
   • pages of the summary plan description or benefit booklet regarding coverage of denied services;
   • your medical information from your physician and pertinent labs, tests and hospitalization records;
   • any appeal information;
   • denial letter(s);
   • notes on any calls you have had with your insurance company; and
   • anything else you feel is important.

2. Find and contact your state Department of Insurance. Find your DOI online or call PHA at 301-565-3004 x773 and we’ll help you find the appropriate contact information. You can call your DOI (recommended if the appointment date for the denied service or treatment will happen soon), write, or submit an online complaint. If you have specific questions, include them in the complaint letter; the DOI will investigate and find answers.

3. Follow up. After you file a complaint, the DOI should send you an acknowledgement that it has received the complaint, a summary of the complaint and a time frame for when they expect to resolve the issue. If this is too long for you, call them and let them know why.

Read more at www.PHAssociation.org/Patients/Insurance/Complaints/DeptOfInsurance or call 301-565-3004 x773 for a more detailed print version of this information.
PHA’s Statement of Principles on Healthcare Reform outlines our commitment to advocating for healthcare policies that meet the needs of the PH community. In 2010, a variety of legislative and regulatory changes, including the Affordable Care Act (ACA), brought us closer to a healthcare system that meets these needs.

As Congress and policymakers continue to implement the ACA and other healthcare legislation over the next few years, PHA continues to urge adoption of the following recommendations (in bold) which are central to improving the quality of care for our patients:

- **Ensure that every American has healthcare that is universal, continuous (portable), affordable, sustainable, and accessible.**
  - Under the ACA, health plans cannot limit or deny benefits or deny coverage for a child younger than age 19 (effective September 23, 2010) or adults (effective 2014) simply because the person has a “pre-existing condition” — that is, a health problem that developed before the individual applied to join the plan.
  - The ACA also prohibits waiting periods of greater than 90 days for private insurance coverage to begin (effective 2014).

- **Eliminate pre-existing condition coverage exclusions and waiting periods in all health insurance plans.**
  - The ACA prohibits health plans from putting a “lifetime” dollar limit on most benefits you receive (effective September 23, 2010). The ACA also restricts and phases out the “annual” dollar limits a health plan can place on most of your benefits — and does away with these limits entirely in 2014.

- **Remove lifetime caps on health insurance benefits.**
  - Legislation was introduced in the 111th Congress to make this policy change. Despite significant bipartisan support it failed to advance. The issue will be revisited in the 112th Congress and PHA will continue to support it actively.

- **Eliminate the two-year waiting period for Medicare coverage of patients deemed disabled by the Social Security Administration.**
  - The 111th Congress also passed legislation that enables patients with rare diseases to be compensated for participating in a clinical trial (up to $2,000) without this income counting against their eligibility for means-tested programs such as Medicaid and Social Security Disability.

- **Streamline access to specialists, including out-of-network specialists at nationally renowned centers of excellence.**
  - The ACA provides a guaranteed external appeals process for beneficiaries in all health insurance plans. Denial of coverage for specialists and out-of-network providers can be reviewed by a third-party under this process. The legislation also provides grants to the states to create consumer assistance units to help beneficiaries with coverage related problems.

- **Establish a patient-centered system of care coordination (medical home or other) for patients with chronic illnesses.**
  - The ACA provides states the option of enrolling Medicaid beneficiaries with chronic conditions into a health home. Health homes would be composed of a team of health professionals and would provide a comprehensive set of medical services, including care coordination.
  - The ACA also establishes a new provider model known as Accountable Care Organizations (ACO) for Medicare patients. ACOs will accept responsibility for the cost and quality of care delivered to a specific population of Medicare patients. Physician practices that can be organized as patient-centered medical homes are the most likely candidates for ACO designation.
  - The bill also establishes the Center for Medicare and Medicaid Innovation which is charged with developing additional innovative delivery arrangements to improve quality and reduce the cost of care. Successful models, including medical homes, can be expanded nationally.

- **Create incentives for expanded coverage of clinical trials investigating new treatments for chronic and life-threatening diseases.**
  - The ACA requires insurance coverage of routine patient care costs associated with clinical trials.
  - The 111th Congress also passed legislation that enables patients with rare diseases to be compensated for participating in a clinical trial (up to $2,000) without this income counting against their eligibility for means-tested programs such as Medicaid and Social Security Disability.

CONTINUED ON NEXT PAGE
• Aggressively fund biomedical research at the National Institutes of Health (NIH) and disease prevention programs at the Centers for Disease Control and Prevention.

  » The ACA established the new “Cures Acceleration Network” at the NIH. This program is designed to speed the translation of basic biomedical research discoveries into new treatments and cures for deadly diseases.

  » In addition, the law creates a new “Prevention and Public Health Fund” designed to expand and sustain the necessary infrastructure to prevent disease, detect it early and manage conditions before they become severe. This new initiative will increase the national investment in prevention and public health, improve health and enhance healthcare quality. To date, $500 million has been released to support prevention, training and wellness projects across the nation.

• Fund, establish, and administer a system of electronic medical records and other health information technologies aimed at improving quality, reducing medical errors, increasing administrative efficiencies and reducing costs.

  » This was accomplished as part of the American Recovery and Reinvestment Act, more commonly known as the “stimulus bill.” $20 billion was provided to support the transition to a standardized electronic medical record system by healthcare providers.

• Streamline the Social Security Disability application process, and expand the Compassionate Allowances disability program for individuals with severe, life-threatening illnesses.

  » PHA continues to actively collaborate with the Social Security Administration to update its PH-related disability language and include PH in their Compassionate Allowances list. (See p.23)

PHA is encouraging policymakers to act aggressively in the 112th Congress, continuing efforts to reform our nation’s healthcare system and meet the needs of PH patients. If you have any questions or require further information, contact Katie Kroner, Director of Advocacy and Awareness, at 301-565-3004 x749 or visit www.PHAssociation.org/Patients/Insurance/HealthcarePrinciples.

What to Expect in 2011

• Continued closure of the Medicare Part D coverage gap. Medicare beneficiaries who reach the coverage gap will receive a 50 percent discount when buying Medicare Part D covered brand-name prescription drugs. Over the next 10 years, seniors will receive additional savings on brand-name and generic drugs until the coverage gap is closed in 2020.

• Free preventive care for Medicare beneficiaries. Certain free preventive services, such as annual wellness visits and personalized prevention plans, will be available for people on Medicare.

• Reduction in healthcare premiums. At least 85 percent of all premium dollars collected by insurance companies for large employer plans and 80 percent of premium dollars collected from plans sold to individuals and small employers must be spent on healthcare services and improvement. If insurance companies do not meet these goals, they must provide rebates to consumers.

• Improvement of healthcare quality and efficiency. A new Center for Medicare & Medicaid Innovation will begin testing new ways of delivering care to patients. As of January 1, the Department of Health and Human Services will have a strategy for this new center.

• Improvement of care for Medicare beneficiaries after they leave the hospital. The Community Care Transitions Program will help high-risk Medicare beneficiaries who are hospitalized avoid unnecessary readmissions by coordinating care and connecting patients to services in their communities.

• Improved access to services at home and in the community. The new Community First Choice Option will allow states to offer home and community based services to disabled individuals through Medicaid rather than institutional care in nursing homes.

• Visit www.PHAssociation.org/Insurance/HealthcareReform or call 301-565-3004 x773 for more information about healthcare reform.
Spring to Action: Urge Members of Congress to Co-sponsor PH Research Act

It’s a new year, a new spring and a new Congress. The 112th Congress recently introduced the 2011 version of the Tom Lantos Pulmonary Hypertension Research and Education Act. Now that the bill has been introduced, it’s time for the entire PH community to spring into advocacy and reach out to every Member of Congress.

The bill will:

• Increase awareness among medical professionals about PH in order to decrease misdiagnosis and save lives.
• Increase awareness among the general public about PH so that individuals living with PH get more support from their local communities and those who have PH symptoms seek medical care.

Why should you share your story with your Member of Congress?

• “Members of Congress don’t know about this bill. They probably won’t know unless they are on [the relevant] committee. It’s important for us to let them know about it.” ~ Merle Reeseman, PH patient
• “Because of the continual misdiagnosis or non-diagnosis of the disease, people are dying unnecessarily. I know it is only through awareness and education that we will see a change and, hopefully, a cure in my lifetime.” ~ Carol Lindstrom, PH patient
• “Your stories are the reason we will ultimately pass your legislation. This is a democracy. Tell your stories!” ~ Rep. Lois Capps

How can I spring into action?

Consider one of these ways to secure your two senators’ and one representative’s co-sponsorship:

• Call! Participate in PHA’s National Call-In Day on April 26, 2011. PHA provides a sample script to make your calls easy: www.PHAssociation.org/Advocacy/Alerts
• Visit! A visit with your Members of Congress at their office in your area is one of the most effective ways to secure their co-sponsorship. To learn more, visit www.PHAssociation.org/Advocacy/ConnectLocally
• Connect! After you call or email your Members of Congress, urge your loved ones to do the same. If you use Facebook or Twitter, post a link to PHA’s Advocacy Action Alerts page.

Get more tips on advocating for PH research. Contact Elisabeth at 301-565-3004 x753 or Elisabeth@PHAssociation.org or visit www.PHAssociation.org/Advocacy

PH Community Joins Effort to Keep Transplants Funded in Arizona

Last October, Arizona implemented budget cuts and stopped financing certain transplant operations under the state’s version of Medicaid. Consequently, 98 beneficiaries who had been previously told they were approved for transplantation were removed from the waiting list. Two of those beneficiaries have since passed away due to health complications.

PHA joined a national effort to encourage the Arizona legislature to repeal these cuts and insure that Medicaid recipients who need them have access to the life-saving transplants. We reached out to the media and contacted Arizona legislators. PH associations around the world wrote letters. As we go to press, Arizona’s governor has proposed creating an “uncompensated care fund” to help the uninsured and underinsured who need life-saving medical care. However, in the same proposal she recommended cutting 280,000 people from Medicaid. PHA continues to look for ways to make a difference in Arizona.
Why Support the NIH?

The National Institutes of Health (NIH) is a federal agency dedicated to funding medical research and discoveries that improve health and save lives. Much like PHA, the NIH started small — as a one-room laboratory back in 1887. Today, it includes 27 institutes and centers that each champion a particular research agenda.

The NIH, particularly the National Heart, Lung, and Blood Institute, pays for research about pulmonary hypertension that no one else does. This research includes recent studies on the benefit of blood-thinners for patients with PH and sickle cell disease, the causes of PH in individuals with HIV, and how PH patients can benefit most from aerobic exercise.

PH patient Rhonda Bye recently participated in the PH and aerobic exercise trial. She says, “Because of my increased level of exercise, today I am more active, have more energy, more stamina, and much more confidence in my ability to do things as simple as shopping or as challenging as travel … If we want to see alternative, novel, free or low-cost treatment options developed, we need to advocate for and support federal funding for PH medical research.”

You can help! The NIH depends on concerned citizens like us to tell Congress how important their work is. By speaking out, we help ensure that Congress prioritizes research on PH and other life-threatening conditions in the federal budget. Look for opportunities to take action at www.PHAssociation.org/Advocacy/Alerts or call Katie at 301-565-3004 x749.

50 State Media Challenge: Be First to Get News Coverage in Your State!

For every pulmonary hypertension story that appears in the media, national awareness of PH grows. That’s why this year PHA is challenging everyone, in every state to build on the media successes of the past to ensure that people all over this country put a face to PH.

Sharing your story with the media helps save lives! The stories shared over the years by PH community members have raised PH awareness among thousands of people who have never heard of the disease. With each PH story that appears in the news, we have renewed hope that more misdiagnosed PH patients can become aware that they need to get a proper diagnosis.

Join PHA’s 50 State Media Challenge and be the first to get media coverage in your state! Some helpful tips to get you started:

1. Gather the contact information for reporters and editors at your local news and radio stations, newspapers and magazines. Look for contacts who would be interested in writing a personal story.
2. Ask PHA for press kits, which are packed with information about PH. These kits will help you answer questions about PH, while focusing on your story.
3. You are newsworthy! Prepare your story pitch by writing out some key points of your story and identifying the ones that might be most interesting or surprising to a reporter. For instance, the length of time it took you to get diagnosed or the cost of your medications.
4. Submit your pitch using the editor and reporter contact list you created in Step 1.
5. Follow up with media outlets with an email, letter or phone call and offer to answer any questions they may have about your story.
6. Share your success with PHA! The 50 State Media Challenge Success webpage will be continually updated to show all of the media successes our community achieves. Make sure your success is listed by contacting PHA.

For more tips and resources to help you jump into the 50 State Media Challenge, contact Elisabeth at 301-565-3004 x753 or Elisabeth@PHAssociation.org or visit www.PHAssociation.org/Awareness/50StateMediaChallenge.
Profile of a Support Group Leader: Meet Seattle/Des Moines Leader Yunena Morales

Seattle Support Group
Leader Yunena Morales’s PH diagnosis story might sound familiar to many readers: she had shortness of breath, fatigue and dizziness and doctors told her she had everything under the sun except pulmonary hypertension. Once she finally received an accurate diagnosis, she connected with the local PH support group in Seattle in 2010 and found hope, information and support. Now she is the leader of that support group, and she and her group are looking forward to a year filled with excitement, support and hope — and PHA on the Road. Seattle/Bellevue is the site of one of the four PHA on the Road forums this summer. Read on to learn more about Seattle’s support group leader and her support group.

Do you think the Seattle Support Group makes a difference for patients?
The group was a great help to me, especially as my road with pulmonary hypertension has been a very rocky and confusing one. The group helped me to retain my sanity. Other patients come consistently and also benefit in similar ways. Without this group, I know I would not be able to cope. I just could not do it alone. I believe it is the same for every one with pulmonary hypertension in the state.

Why did you want to lead a support group?
I had experience with groups and group dynamics, so I decided to take on the challenge. This has been very fulfilling for me, as I had always wanted to give back and this was a great opportunity to do just that. When the former leader, Ruth Pavek, passed away, I missed the support and togetherness of the group, missed learning something new each time, and missed everyone helping one another to cope with this disease. I also know that Ruth and her husband wanted the group to continue, and we are all happy that her legacy continues.

What is one of your favorite support group moments?
The first time the first patient showed up for the meeting I was very thrilled. One person is a whole universe for me, so I was very excited and it gave me great hope.

What are you looking forward to with your support group this year?
I am looking forward to seeing all support groups in Washington State unite to become a powerful agent of change when it comes to PH. I am hoping we can work in conjunction with other groups on our future goals and projects. We can join to share speakers and other resources.

PH patients have great talents, which we can use to help one another and help foster the growth of support groups. I have great plans for us to work together to build our PH support groups to raise awareness here in Washington state. I want to encourage all the patients in the Seattle area to come join us to achieve this together.

How do you feel about PHA on the Road in Seattle?
You cannot imagine how happy I am for this. It is a great opportunity to gather patients and professionals from the whole State of Washington to share and learn about the one big thing we have in common. It will also build the support group, which I really want to see grow. We can have more education for our patients here, which is the most important thing to me.

When we asked if there was anything else Yunena wanted to add, she sent us a long list of names of people to thank, including family, friends and medical professionals from the University of Washington Medical Center. Leaders in the PH community don’t do it alone!

For more information about this support group, visit www.PHAssociation.org/DesMoinesSeattleGroup. For more information about PHA on the Road, see p.40 of this issue of Pathlight or visit www.PHAssociation.org/OnTheRoad.

Interview conducted by Debbie Castro, PHA Director of Volunteer Services
Two Heads are Better Than One: PH Support Groups Bring Multiple Doctors to Speak at Meetings

“Maybe I should get a second opinion…” When it comes to serious medical concerns, often we aren’t content to hear only one person’s take, and that might be why medical panel meetings are gaining popularity among support groups.

Panel meetings consist of multiple medical professionals presenting on their areas of expertise. For PH support groups, meetings with panels of medical experts allow PH patients and their caregivers to hear different viewpoints, absorb information as these speakers address issues related to the disease and have an opportunity to have their questions answered.

Between November and February, groups in Hershey, Penn.; Ann Arbor, Mich.; and Fresno, Calif., arranged meetings with panels of medical experts.

Meetings with multiple speakers take extra time to plan and are usually treated as much larger events than a typical support group meeting. Both the Ann Arbor and Fresno groups scheduled their panel meeting for November as part of their November PH Awareness Month activities. Ann Arbor’s support group panel meeting has become an annual event.

What other benefits do medical panel meetings provide? In addition to bringing collective knowledge to the meeting, the presence of multiple medical experts also means members can break into small discussion groups with individual medical professionals, providing more time for each person to share their story and ask questions.

Medical panel meetings also tend to be especially popular and have the added benefit of attracting caregivers who want to come and learn from the medical professionals.

This past November, the Fresno, Calif., Support Group organized a panel meeting with two doctors, a registered nurse, a certified nurse practitioner, and a family nurse practitioner and the group had its largest turnout to date. Support Group Leader Perry Mamigonian observed that “these people really don’t get a chance to talk with medical professionals. It’s really beneficial to them.”

PHA appreciates the work of our Support Group Leaders in organizing meetings and events nationwide and we thank the medical professionals who donate their time and energy to educating patients.

Add Advocacy to Your Agenda Without Adding Work to Your Plate

“Just because they are Congressmen doesn’t mean they know about this bill… It’s important for us to let them know about it!”

~ Merle Reeseman, after Representative Jason Altmire spoke at her Support Group Meeting

Contact from a constituent like you is one of the only things that will motivate a Member of Congress to co-sponsor the Tom Lantos PH Research and Education Act. Support group leaders, here are a few easy ways to work with your support group and motivate our elected officials:

» Designate an advocacy coordinator for your support group
» Hold a support group meeting devoted to advocacy and raising awareness
» Invite your Members of Congress to a meeting
» Schedule a meeting at your Member of Congress’ local office for you and several support group members

For resources to get started, contact 301-565-3004 x753 or Elisabeth@PHAssociation.org or visit our Advocacy Action Center: www.PHAssociation.org/Advocacy/Alerts
Support Groups Get Creative with Meeting Topics

Dr. Thomas Slaughter, professor of anesthesiology at Wake Forest University, speaks to the Charlotte, N.C., Support Group about PH patients and surgery in January 2011.

PH patient and Sarasota (Fla.) Support Group Leader Gail Bucci (pictured standing) shares her PH journey as the guest speaker for a Port Charlotte (Fla.) Support Group meeting in February 2011.

The York, Penn., Support Group enjoys a special holiday dinner in January 2011 to kick off the new year.

Members of the Newport Beach (Calif.) Support Group gather inside for a meal before watching their community’s annual boat parade in December 2010.

Members of the Upstate South Carolina Support Group participate in chair yoga.
What Does It Take to Plan a Special Event?

The final installment in a four-part series: Running a smooth and sustainable event

In this series we’ve touched on many elements of planning a successful special event. It began with how to get started: selecting a time, date and location and establishing a plan of action. Then we discussed the major components of the planning process including volunteer recruitment, fundraising and publicity. Now that you’ve set the foundation for success, putting it all together for the big day will be the icing on the cake.

Communication is Key

Communication is crucial on the day of the event. While no one likes to think pessimistically, everyone should think realistically and recognize that even the smallest lapse in communication can turn a seemingly routine question or concern into a bigger dilemma. That’s why it’s important to exchange contact information ahead of time and ensure that all volunteers, committee members and speakers/presenters are reachable both prior to and during the event. Lead event organizers should be reachable by cell phone at all times during your fundraiser. For events where the venue/setting is more expansive, such as golf tournaments, it may be useful to have walkie-talkies for all organizers and volunteers.

Volunteers

Identify the primary volunteer positions beforehand. It’s also best to have in mind the people who will fill the most important roles like registration and any other position where money will be handled or exchanged. It’s crucial that you not only think of duties that particular volunteers should do but also those they shouldn’t do. For instance, you wouldn’t delegate a volunteer who lacks technological familiarity to set up the event’s audio/video (A/V) equipment. While this may seem obvious, if you don’t take the time to assess your volunteers’ skills, you may end up shifting people around at the last minute.

Here’s a general list of responsibilities that typically require volunteer assistance: Decorating/Set-up, Registration Table/Booth Staffing, Raffle and Silent Auctions, Directing Traffic/Parking, and Cleanup.

Presenters and Speakers

It’s likely that your event presenters and speakers are also volunteers donating their time. It’s important that you are adequately prepared for their participation. Check (and double check) all A/V equipment to ensure it is working properly. Make certain that all presenters and speakers are familiar with the event format and when they will be speaking. As with your other volunteers, be sure that they have all the materials they need and that they are properly thanked for their contributions to the event. Providing them with the necessary materials may mean that you offer a topic for their presentation. Thanking your speakers may consist of a small token of appreciation; presenting a certificate is a great way to publicly acknowledge them.

Other Essential Considerations

Several pieces of advice don’t fit neatly under one category but are nonetheless among the most important items to remember for the big day:

• Clearly indicate the event location and parking for attendees (if it’s not already evident).
• Be prepared to accept donations in a variety of forms. Many people will come to the event wanting to make a donation on the spot (or register on-site, if available). PHA provides forms for accepting cash, credit and check donations, and a Special Events staff member can explain this process to you.
• Acknowledge any sponsors or organizational partners. The generosity of companies and businesses likely made many aspects of your event a reality. It is important to not only thank them in print, but to also orally mention their contributions during the event.

Wrapping up and Looking Ahead

Once the event is over, meet with your committee to de-brief and discuss the highs, lows and improvements that could be made in the future. The sooner this is done, the better. This is also an appropriate time to compile a master list of thank yous to mail to volunteers or participants who invested effort or resources in the event.

Finally, and probably most importantly, take the time to relax, recuperate and acknowledge the tremendous gift you have given the PH community. Your efforts have been substantial and so too has your impact!

For everything Special Events, including all four installments in this series, visit www.PHAssociation.org/SpecialEvents. If you have specific questions on event planning, contact Jessica at JessicaM@PHAssociation.org or 301-565-3004 x765.
Kerri Rubio is one determined lady. Not only has she participated in the New York Fun Walk many times, but she recently organized a dinner fundraiser and, through those efforts, connected with a local radio fundraiser to further raise PH awareness and benefit PHA programs.

Kerri and her husband, Juan, are resolute that no other family should have to experience a loss as they have. Their 14-month-old daughter, Kayla, passed away in August 2008 after battling severe pulmonary hypertension. Just two months later, Kerri and Juan attended the 4th Annual New York Fun Walk to walk in Kayla’s memory and participate in the memorial balloon release. They’ve attended the walk every year since then.

Now they are turning their grief into further action. On October 9, Kerri and Juan organized a dinner fundraiser. They contacted their local businesses, who donated food and other items. They also held a raffle of donated items, and the event raised $3,000.

While planning this event, Kerri contacted a local oldies radio station, B103, on Long Island, N.Y. She was put in touch with Mickey B, a writer/singer/producer known as “The Prince of Rock n Roll.” When she told Mickey the story of Kayla’s battle with PH, he immediately wanted to help. Mickey was producing a charity event on November 6, the Thanksgiving Disco Fever Concert, with many artists from the ‘70s. Three other charities would be present and have the opportunity to raise money to benefit their organizations, and Mickey added PHA to the roster. On October 2, Mickey attended the New York Fun Walk to promote the event. He addressed the crowd and got everyone dancing; he even held an impromptu dance contest and gave away two tickets to the disco concert on the spot.

On the night of the concert Kerri and Juan set up a table with lots of information about pulmonary hypertension and a poster board that told Kayla’s story. Together with Juan and Kerri, my husband Ken, my friend Jean Steck and I worked the lobby as concert attendees arrived, selling tickets for a 50/50 raffle and telling all who’d listen about PH and our efforts to raise awareness and funds for research. We were thrilled when the winner of the raffle donated his winnings right back to PHA.

Kerri and Juan Rubio aren’t done and promise to continue their efforts in Kayla’s memory and on behalf of all families affected by pulmonary hypertension. We are so lucky to have them fighting with us.

By Joanne Sperando-Schmidt
PH Patient and New York Fun Walk Organizer

Stay Connected With PHA Between Events

Special event organizers enable us to get closer to a PH cure, one event at a time. Become part of a growing movement of volunteer event fundraisers by checking out these three emerging resources:

» Event-ful Times: a quarterly e-newsletter for the special events community with feature stories, tips and information on mentorship. Anyone and everyone can join our mailing list! Contact Jenna at Eventful@PHAssociation.org.

» Special Events Forum: an online (email) community where PHA’s volunteer special event organizers and those interested in event fundraising can share and receive planning tips, advice and encouragement. We’ll bring you the latest information on Special Events program developments and PHA, too! Contact Jessica at Events@PHAssociation.org.

» Special Events Mentorship Program: If you’re new to planning events and want extra advice from a seasoned PHA volunteer planner, you’re in luck! PHA offers a mentorship program specifically for our special event organizers. Meet a mentor at www.PHAssociation.org/SpecialEvents/Mentors
Inaugural Fundraisers Inspire Creativity within PHA’s Special Events

As PHA gears up for a busy spring events season this year, take a look back at a selection of some of our most notable inaugural special event fundraisers within the past six months. First-time event planners keep PHA’s Special Events program inspired with ideas as fresh as a spring bouquet! Thanks to each of these remarkable individuals and groups for their fundraising and awareness-raising contributions through their local communities. Become part of the growing trend of first-time event organizers by contacting Jessica McKearin, Associate Director of Special Events, at 301-565-3004 x765 or Events@PHAssociation.org.

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Event: Serendipity Silent Auction for PHA
Location: Easley, S.C.
Attendance: More than 125
Primary Organizers: Members of the Upstate South Carolina PH Support Group
Fun Fact: A proclamation declaring November 2010 as Pulmonary Hypertension Awareness Month was secured and then presented at the event!

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Event: Unmask PH: A Masquerade Ball
Location: Wilkes Barre, Penn.
Attendance: Approximately 125
Primary Organizers: Generation Hope member and PH patient Katie Tobias (pictured above, second from right, with PHA staff), along with her friend and former school teacher, Lisa Granahan
Fun Fact: At this masquerade-themed dinner, guests had the opportunity to design and decorate their own mask!

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Event: PHA Wine Tasting & Raffle House party
Location: Longmont, Colo.
Attendance: A small gathering of close family and friends for a cause
Primary Organizer: Sonia Brocko, aunt to pediatric PH patient Iain Hess (Sonia is pictured above, left.)
Fun Fact: Nearly 30 donated items were up for silent auction and raffle at this cozy fundraiser!

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Event: Fiesta de Amor con Próposito
Location: Brooklyn, N.Y.
Attendance: 70
Primary Organizers: The Trinity Lutheran Church congregation in support of a fellow member who lives with PH
Fun Fact: This event marks two firsts. PHA’s first special event of 2011 also doubles as one of our very first bilingual events!
## Special Events 2011

### Sat., April 16, 2011
3rd Annual Scramble for a Cure Golf Tournament  
WHERE: Angel Park Golf Club, Las Vegas, Nev.  
DETAILS: Jack Nino at 702-250-2214 or Jack.Nino@igt.com or [www.scramble4acure.com](http://www.scramble4acure.com)

### Sat., April 30, 2011
The Grape Escape 2011  
WHERE: St. Stephen’s Hall & Picnic Grounds, Richwoods, Mo.  
DETAILS: Jenny Bardenheier at jennbardenheier@yahoo.com

### May 2011
Summer event planners: Make sure you have all the supplies from PHA that you need! Handouts, displays and volunteer goodies are available. Email Events@PHAAssociation.org or call 301-565-3004 x765.

### Sat., May 14, 2011
N.C. Cure PH Golf Tournament  
WHERE: Salem Glen Golf & Country Club, Clemmons, N.C.  
DETAILS: Cindy Pickles at 336-978-1668 or cpickles50@gmail.com or [www.firstgiving.com/phassociation/Event/CurePHGolfTournament](http://www.firstgiving.com/phassociation/Event/CurePHGolfTournament)

### June 2011
Mark your calendars! This month we’ll host another Special Events webinar, free and open to the entire community. Gear up for the Awareness Month event season with this webinar. For additional details or to register, visit [www.PHAssociation.org/Classroom](http://www.PHAssociation.org/Classroom)

### June 2011
Look for Eventful Times to arrive in your Inbox. Make sure you’re on the list to receive this PHA Special Events publication! Sign up at [www.PHAssociation.org/SpecialEvents/OrganizeAnEvent](http://www.PHAssociation.org/SpecialEvents/OrganizeAnEvent)  
Questions: Contact Jenna Roe at Eventful@PHAssociation.org

### Sat., June 4, 2011
2nd Annual Race 2 Cure PH: Taylor Caffrey Memorial 5K  
WHERE: Anaheim Hills, Calif.  
DETAILS: Shari Caffrey at 714-200-8322 or shari@TaylorsWish.org or [www.TaylorsWish.org](http://www.TaylorsWish.org)

### Sun., June 5, 2011
Power for PH: Inaugural New Jersey Fun Walk  
WHERE: Roosevelt Park, Edison, N.J.  
DETAILS: Christina Lapatka at 732-429-8326 or powerforph@gmail.com

### Sat., June 18, 2011
Miles for Mallory PHamily PHun Walk  
WHERE: Lake Hamet, Minneapolis, Minn.  
DETAILS: Kelley Skumautz at theskumikians@sbcglobal.net

### Sat., June 25, 2011
James A. Martin Memorial Walk for PH  
WHERE: San Dimas, Calif.  
DETAILS: Bernadette Gore at 626-914-4396 or bernielgore@yahoo.com

### Sat., June 25, 2011
Race Against PH — North Carolina  
WHERE: Durham, N.C.  
DETAILS: Anita Kiprovska at AKiprovska@unither.com or [www.fsseries.com/pha5k](http://www.fsseries.com/pha5k)

### Sat., June 25, 2011
Rolling PHor a Cure — Bunco Tournament  
WHERE: Ormond Beach, Fla.  
DETAILS: Amy Piazza at cureph@hotmail.com or 386-235-0884 or [www.firstgiving.com/rollingphoracure](http://www.firstgiving.com/rollingphoracure)

### Mon., June 27, 2011
2011 JFK Tower Golf Tournament  
WHERE: Hampshire Country Club, Mamaroneck, N.Y.  
DETAILS: Steve Abraham at 914-907-9935 or jfktowergolf@yahoo.com or [www.jfktowergolf.com](http://www.jfktowergolf.com)

### Mon., June 27, 2011
2011 Swing 4 the Cure: Wojo PH Golf Classic  
WHERE: Tustin Ranch, Calif.  
DETAILS: Betty Lou Wojciechowski at 949-215-1573 or bettylouwojo@hotmail.com or [www.swing4thecure.us](http://www.swing4thecure.us)

For more special events coverage, visit [www.PHAssociation.org/SpecialEvents](http://www.PHAssociation.org/SpecialEvents)
EDITOR’S CORNER

Welcome to another issue of Persistent Voices. Even though this summer marks 13 years for me as a PH patient, I never, ever tire of hearing someone else’s journey with this illness that binds us all together. The three stories we’re sharing today come from different viewpoints but the common word that kept popping up in my mind as I read all of them was “Resilience.” Dianna tells us the story of her daughter’s journey and illustrates the very difficult path walked by the parents of children with PH. Sixteen-year-old patient Nicole uses storytelling to express her feelings and shows wisdom and strength way beyond her years. And finally, Jeannette Morrill, a longtime PH patient (way to go, Jeannette!), weaves together her experience of being both hospitalized and meeting a newly diagnosed patient on the same day. I promise you’ll find these stories inspiring and insightful.

As always,
To the cure!
Joanne Sperando-Schmidt, Persistent Voices Editor

It must be extraordinarily difficult for the parents of PH children. Dianna McGlone shares her baby daughter’s journey from birth through diagnosis and describes life as it is today with her two-year-old patient. She reminds other parents to make memories every day and remember that we’re not alone: “You have PHriends now!”

— Joanne

Lily’s Story, as told by her mother Dianna McGlone, Columbus, Ohio

My daughter Lily was born on March 7, 2009, with a hole in her heart, and she has primary pulmonary hypertension. But the first time that PH was introduced to me, the doctors never actually said the words “pulmonary hypertension.” Instead, the cardiologist simply said that the pressures in Lily’s heart were high, and prescribed sildenafil (Revatio™) and furosemide (Lasix™) to treat the condition. She was just a couple of months old at the time.

Later it was decided that Lily would need open-heart surgery to repair the hole in her heart. Prior to the surgery the doctor told me that “if the pressures in her heart are too high, we can’t do surgery. It will kill her.” Again the term “pulmonary hypertension” was not mentioned. In the end, the doctors performed the surgery without getting a read of the pressures as her lung had collapsed, and she was placed on life support. Things had progressed from being a case of “oh, this is a routine surgery, she’ll be fine ...” to “hope for the best, prepare for the worst.”

Six months after surgery, Lily was still on sildenafil and furosemide and the “pressures” in her heart weren’t getting any better. It began to be something that the cardiologist mentioned to me at each appointment. At nine months, he told me he was referring her to — and finally here came those words — a “pulmonary hypertension” specialist. Yet it still didn’t seem like that big of a deal. I had been dealing with so many of Lily’s other problems that I didn’t do any research on her pressures. I just
faithfully gave Lily her medicines and waited to see what the doctor would say. She started seeing Dr. Daniels. He said that the pressures in her heart were high, but she was active and happy, so why mess with anything just yet.

Three months later, we had another appointment. This time the doctor talked about doing a heart catheterization and the possibility of stronger medicines. He talked about I.V.s, continuous infusion, and suddenly I went from not really worrying about her “high blood pressure” to being absolutely petrified. What WAS pulmonary hypertension? I did research until I nearly broke the keyboard. I read medical journals, hospital sites, anything that looked reputable. I found the PHA website. I went into the chat rooms, I told them I felt like it was a death sentence for my daughter, but the patients in the chat rooms reassured me they were still alive and kicking.

On November 5, 2010, Lily had the heart catheterization. The doctor explained it this way: “You have your regular blood pressure, and then you have your pulmonary blood pressure. The pulmonary blood pressure measures how hard your heart works to pump blood to your lungs. Your pulmonary pressure should be about a fifth, or 20 percent, of your regular blood pressure. Lily’s is 70 percent.” He said she reacted well to Nitric Oxide and thought she’d do well on a medicine called bosentan (Tracleer™).

In January 2011 we experienced another setback when Lily began to have some problems with breathing. She had a spell where she went blue for over a minute. The end result was that Lily had to be put on 24-hour oxygen. It’s been a bit of a challenge, but we have a very good preschool that works with us. It’s hard, as a parent, seeing these things happening to your child and being unable to help. Lily has quickly become used to her oxygen, though, and does not like to be unhooked from it. If she is, or her canula comes out of her nose, she will say “uh-oh” and make sure you fix it.

Now for once, Lily is on the growth chart. I really attribute this to the bosentan. She is now in the 25th percentile. We are also hopeful that she will soon lose her feeding tube permanently. She scored well on her developmental tests, and people are amazed to see her take off running with her oxygen cord trailing behind her. Lily is thriving and learning new words all the time. Her newest one is “Mess-in.” She is always eager to take her ‘Mess-in’ and will remind you if you are running a few minutes late on giving it to her.

Every day is a struggle. There are good days, and there are bad days. On the bad days, I can barely hold back tears. On the bad days, I grieve. I grieve for the loss of my daughter’s normal life. I grieve for the loss of the memories we will never get to make, because this disease will restrict her. On the good days, I make memories. I realize that every single second I have with my daughter is precious in a way that only other parents with a chronically ill child can understand. I slow-dance with her in the living room. I hold her while she has a bottle after I put her oxygen on her at night. I take hundreds of pictures. I love her like there is no tomorrow because I’m acutely aware of the fact that her tomorrows might be very limited.

If I could tell a parent of a child with PH anything, it would be: “Every single day, set out to make a good memory with your child. Hug them. Kiss them. Laugh with them. Strive to give them as much of a normal childhood as possible. Also, remember, you are NOT alone! You have PHriends now!”

“Lily is thriving and learning new words all the time. Her newest one is ‘Mess-in.’ She is always eager to take her ‘Mess-in’ and will remind you if you are running a few minutes late on giving it to her.”
Many PH patients find that writing and journaling are helpful coping mechanisms when dealing with their illness. Nicole Northrop was diagnosed one year ago and uses these outlets to help her on her journey with PH. While accepting the limitations that PH has created, she knows that so many others share her battle and has consciously made up her mind to adapt to the situation.

— Joanne

Nicole Northrop, Age 16, Longwood, Fla.

Alfie (pictured right) sits hiding by the window. She wishes that she could be out there, with her oxygen in her nose, without being ridiculed by the others. She is already different enough; she’s a dog, while most of the people out there are humans. She had reason to be teased before, but now that she’s more different, she feels isolated. There is nobody like her.

A girl comes into the room, about 9 or 10 years old. She sees Alfie with the oxygen in her nose, and Alfie sees the expression on her face turn into an expression of confusion, and also bewilderment. If her expression could speak words, Alfie was sure it would say, “Wow, you’re a freak.” Despite the hurt that she feels, Alfie just looks up at the girl and smiles. The girl needs to read from the dog’s expression, “Yeah, even though I look like a freak, I don’t care,” though Alfie does care very much.

This story sums up how I feel, especially when I have my oxygen in my nose around other people. (Alfie is my character who also has PH.) I also feel left out because I can’t participate in most of the activities that others can. I feel as if most people would think I was a freak. I don’t share my emotions easily so nobody knows how I feel.

I was diagnosed with PH on January 22, 2010. At the time I didn’t see how serious it was. I just sat there, curled up in a bit of a ball, and thought, “Ok, I’ll get through it.” Although I know now it’s more serious than I originally thought, I still will get through it, even if I do have this illness for the rest of my life.

I’ve been having symptoms of my PH, or at least my heart defect, for most of my life. My mom remembers me running down the hall and back, and I would be winded, just from doing that. Everyone would say it was asthma or that I wasn’t getting enough exercise, and we believed this for 15 years.

Then, one day in December 2009, I was with my old friend, and his mom was worried about me because I had gotten winded, my skin turned pale and my lips and fingernails had turned blue. I was convinced it was just asthma again, but I was wrong.

On January 21, 2010, my parents took me to the pediatrician for a checkup. My mom brought up the blue fingernails, and the doctor checked my oxygen saturation levels. He saw it was 79, and he thought that his machine was broken. He got a new machine and took it again. It was the same result. He then got some oxygen and I put it in my nose for a few minutes. He took it again, and there was no change. He then told me to go to a cardiologist as soon as possible.
Jeannette’s story really brings home the reality of how we PHers can help and support each other. A longterm, 35-year-survivor (!), Jeannette was in the hospital and in pain, but didn’t hesitate to help a newly diagnosed patient who was frightened and in need. She immediately saw the similarities in their diagnosis experiences and the differences. Jeannette knows that her new friend Braden will have access to multiple treatment options and support systems that didn’t exist in 1976 ... “and she will have me.” You don’t want to miss this story.

— Joanne

Déjà vu! By Jeannette Morrill, Shirley Mills, Maine

I woke up on October 9, 2010, and had to go straight back to bed. I just didn’t feel right. I was sweating, and had developed chest pain. My son, Ian, told me I was flushed and said, “We’re going to the hospital.” I was frustrated. I hadn’t been admitted to the hospital in more than 10 months. But I was scared, and I knew Ian was right.

The Emergency Room doctor felt I should go to a larger hospital, where physicians would know more about dealing with pulmonary hypertension and my treprostinil (Remodulin™) intravenous pump. I wanted to go to Maine Medical Center, several hours away in Portland, to see my PH specialist. The nurse agreed — and when my husband David arrived, he was adamant. So off I went.
I was seen by a cardiologist, who ordered a cardiac catheterization for Monday. I would be in the hospital over the weekend. Why was this happening to me now? I had support group and physician meetings and a trip to Rochester, N.Y., scheduled in just days. I did not have time to be sick! But I would soon find out why my life had taken this turn at just this time.

On Sunday, one of the nurses asked if I would see a young woman on the floor who had just been diagnosed with PH the day before. Even though my pain had become more intense, I told her absolutely. I could not even get up from bed, so I asked if she could come to me. And so I met Braden Buehler.

I saw myself in Braden — young, vibrant, full of life, a beautiful person. Seeing her troubled face, I remembered just how I had felt 35 years ago when I was first told I had PH and had only two years to live. Like me, Braden had become increasingly short of breath when doing simple tasks. She had just had her first baby. She told herself she needed to get back in shape, not work as hard, get more sleep. Then she fainted, was given an ECHO, and was sent straight to the hospital. I remembered making the same excuses, and how terrible it was at first to discover what was wrong.

I wondered, what should I say? The nurses had already told her some of my story to comfort her after she had read some of the old, horrible PH information on the Internet in her hospital room. It was difficult, while we talked, not to remember those scary times I have had. But I could tell her that I had been diagnosed at 23 and was now 58. I could see how much hope that gave her. We talked for a long time. Her husband met my own husband, David. He was able to share encouraging stories about taking care of someone with PH. When they left my room, they were smiling again.

Braden had one more test to take before she could go home. She had to go back to the cath lab and see if she was a responder to calcium channel blockers. And, she was! Her pulmonary pressure went back to normal during the test. When she told me, I was so thrilled for her. After reflecting on the news, I realized PH diagnosis and prognosis is changing for patients diagnosed early and who receive appropriate treatment.

Under the care of my own specialist, Dr. Joel Wirth, Braden is being treated with 120mg of nifedipine (Nifedical XL™). By December, her pressures dropped from the 80s back to normal range. How fantastic is that! She has her own graphic design business and is still working hard, and now she can keep up with her little boy.

And now, I have found a very dear friend in Braden. We talk often, and we have a very special bond. It is amazing to me that I should be hospitalized at this very time; as my own cath eventually showed, it was only rheumatoid arthritis in my chest wall, mimicking cardiac pain. I can’t explain it. It was meant to be.

Braden’s journey has shown me a new story is being written for PH. It is her chapter, but it gives me so much strength. Her prognosis is so promising! I see so many similarities, and hope for many differences. She will have treatment options I did not have. She will have access to support networks that did not exist in 1976. And she will have me.

My path has been so hard at times, but I know now that my journey matters. I have made a difference! My journey now is helping other patients. *
has been a part of PHA on the Road since the program’s inaugural year in 2009. He served on the planning committee in 2009, and participated on the committee and served as a presenter at the Baltimore/Washington, D.C., forum in 2010. Participation in PHA on the Road is free, but space is limited and registration is required. Registration for the event is available online at www.PHAssociation.org/OnTheRoad. For questions about PHA on the Road, email OnTheRoad@PHAssociation.org or call 301-565-3004 x768.

We look forward to seeing you “on the road” in Seattle, Pittsburgh, St. Louis and Minneapolis in June!

By Suzanne Flood, PHA Marketing & Communications Associate

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**PH Patients and Families Education Forums**

PHA on the Road provides FREE education to PH patients and families with interactive live presentations, education sessions, exhibits and more. Forum speakers and presenters are leading PH medical professionals in your local area. This is a FREE patient education forum, but space is limited and registration is required. We encourage early registration. Register online now at www.PHAssociation.org/OnTheRoad

**Seattle, Wash.**
**SATURDAY, JUNE 4, 2011**
8:30 a.m. – 4:30 p.m.
Hilton Bellevue
Bellevue, Wash.

**Pittsburgh, Penn.**
**SATURDAY, JUNE 11, 2011**
8:30 a.m. – 4:30 p.m.
Hyatt Regency
Pittsburgh International Airport
Pittsburgh, Penn.

**St. Louis, Mo.**
**SATURDAY, JUNE 11, 2011**
8:30 a.m. – 4:30 p.m.
Crowne Plaza St. Louis Downtown
St. Louis, Mo.

**Minneapolis, Minn.**
**SATURDAY, JUNE 18, 2011**
8:30 a.m. – 4:30 p.m.
Minneapolis Marriott Southwest
Minnetonka, Minn.

**Topics to Include:**
- How is PAH Diagnosed?
- Initial PAH Treatments
- Long-term PAH Management
- What Is on the Horizon for PAH? (Clinical Trials)
- Insurance Issues
- Eating Better
- PH and Connective Tissue Disease
- Transplant Options
- PAH in Pediatric Patients
- Traveling with PH
- Emergency Situations

**For more information, visit:** www.PHAssociation.org/OnTheRoad
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**PHA Offers Online Education Opportunities for All**

**PHA Classroom: Online Education for Patients and Caregivers**

PHA Classroom, a program of PHA’s Medical Education Fund, is a vibrant e-learning community where patients and caregivers can participate in e-learning through live webinar events and recorded events. This free resource allows members of the PH community to learn about the topics that are of interest to them, and with more than 80 recorded presentations available, patients and caregivers can participate in e-learning any time.

Choose from a wide variety of topics, including the range of presentations featured at PHA’s 9th International PH Conference & Scientific Sessions. Patients and caregivers who are interested in participating in a live Question and Answer session with medical providers can join one of the regularly scheduled interactive live e-learning events. With an Internet connection and a phone line, you can participate from anywhere.

Can’t make it to a live e-learning event? Recordings are posted on PHA Classroom soon after the event takes place. With the recently added “news feed” feature, you can stay informed about upcoming e-learning events. For more information and to register for upcoming events, visit [www.PHAssociation.org/Classroom](http://www.PHAssociation.org/Classroom) today!

**PHA Online University: Online Education for Medical Professionals**

PHA Online University is a cutting-edge source for free CME-accredited education and other resources about pulmonary hypertension for medical providers. The website provides medical professionals of various backgrounds and experience levels the opportunity to learn about PH by taking courses authored by the foremost experts in the field and earn free CME credit at the same time. Patients, we encourage you to spread the word to your healthcare providers about this valuable resource. Learn more at [www.PHAOnlineUniv.org](http://www.PHAOnlineUniv.org)

**Highlighted Courses:**

**Course:** PH in Systemic Sclerosis  
**Author:** Virginia D. Steen, MD, Georgetown University Medical Center, Washington, D.C.  
*Dr. Steen brings her experience working with scleroderma patients to this course which discusses predicting, diagnosing, confirming and treating PAH in systemic Sclerosis.*

**Course:** The Hemodynamic Parameters and Right Ventricular Failure in Pulmonary Arterial Hypertension  
**Author:** Arlene Schiro, RN, ACNS, BC, ACNP, Brigham and Women’s Hospital, Boston, Mass.  
*This course looks at how the two major diagnostic tools are used to assess RV function as well as how to apply the results from pulmonary artery catheterization to determine hemodynamics and describe RV failure in PH.*

**Upcoming Courses:**

**Course:** PH Associated with COPD  
**Authors:** Charles Burger, MD, and John Moss, MD, Mayo Clinic, Jacksonville, Fla.

**Course:** Right Heart Catheterization  
**Author:** Robert Frantz, MD, Mayo Clinic, Rochester, Minn.

**Course:** Scleroderma Features in PH Patients  
**Author:** Richard Silver, MD, Medical University of South Carolina, Charleston, S.C.

**Course:** Physical Assessment of PH Patients  
**Author:** Juliana Liu, ARNP, Stanford University, Stanford, Calif.

**Recordings of Recent E-Learning Events:**

- Pim-1: A New Hope for the Diagnosis and Treatment of PH  
- State of PH - An Annual Update from PHA President Rino Aldrichetti  
- PH Treatments: What’s on the Horizon?

**Upcoming Webinars:**

- **April** Telling Your Story: Explaining Your PH to Friends, Family and Coworkers  
- **May** Fighting the Cause Online: World Wide Awareness Through the Click of Your Mouse

Parents of children with PH, stay tuned for more information about an upcoming pediatric webinar series. Learn more at [www.PHAssociation.org/Parents/Support](http://www.PHAssociation.org/Parents/Support)
Enhance the impact of your center’s medical education program by partnering with PHA!

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

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

**Continuing Education**
PHA provides the opportunity for post-event discussion, follow-up events and a venue for sharing session content through our primary website ([www.PHAssociation.org](http://www.PHAssociation.org)) and the PHA Online University ([www.PHAOnlineUniv.org](http://www.PHAOnlineUniv.org)).

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**Largest Patient Gathering in California Bay Area Planned**

In 1999, members of the San Jose, Calif., PH Support Group decided to hold a regional conference. They established a committee and went to work, and as a result, the California PH Forum has been held biennially since its inception.

The 2011 California PH Forum will be a one-day Patient Education Seminar on June 25 in the San Francisco Bay Area. Guest speakers will include pulmonary arterial hypertension specialists. Learn more about the latest news and standards of care for PH as well as meet others in the community.

Want to participate in the Forum? Have questions? Email info@caphforum.com or visit [www.CAPHForum.com](http://www.CAPHForum.com) for details.

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- Advocacy Action Alerts
- Media Action Alerts
- PHA on the Road Alerts
- 2011 PH Resource Network Symposium Alerts
- Advances in PH medical journal
- Legacy eNewsletter
- D.C. Metro Volunteers

If you don’t have a website user account to sign into, you can sign up for email lists when you fill out the “New User Registration” form.
**INTERVIEW WITH PH PATIENT**

**CULLEN STEELE**

Where do you live?
I live in Kent, Washington.

How old are you?
I am 11 years old.

When were you diagnosed?
I was diagnosed in 2008. I was 8 years old.

When did you first start having symptoms of PH?
I started having symptoms when I was 5 years old, but we didn’t know yet that I had pulmonary hypertension until years later. I was diagnosed with Long QT Syndrome when I was 7, and pulmonary hypertension a year after that.

What were your symptoms?
I was playing soccer and having a hard time catching my breath. I used to be very athletic, but I noticed I was having a hard time keeping up with the other kids. I would get chest pains and feel dizzy, and sometimes I couldn’t sleep at night because I couldn’t breathe.

What activities do you like to do?
I love to play video games, and I also really like to cook, read, and play basketball at school during lunch time.

Have you ever felt unable to do something because of PH?
Sports and swimming are the two things that I miss the most. I really miss playing soccer, and I can’t swim anymore because I have a central line.

How has your life changed since you were diagnosed with PH?
My classmates are really good about treating me the same, but I sometimes feel different and left out when I can’t join them when they’re playing sports. I have to carry a backpack with my Flolan™ pump in it 24 hours a day. I sleep with it and bathe with it, and I wish I didn’t need it. I also take lots and lots of pills every day and have a lot of doctor’s appointments.

What is a message you’d like to pass on to other kids with PH?
Don’t worry, you are going to have family and friends to help you with this. It is scary when you are first diagnosed, but as time goes on, you learn more about your disease and the doctors find ways to help you feel better. Soon, things will become a little less scary.

Interview conducted by Mira Kruger
PHA Pathlight Volunteer

**TALK BACK!**

This is your space.
Send your cartoons, poems, drawings, jokes, questions, comments on articles or ideas for future articles to Michal. She can be reached by email at Michal@PHAssociation.org or call 301-565-3004 x800.
YOUTH TAKE ON PH

Support for the PH community comes in many forms, from many people. Patients, siblings, parents and friends all contribute to the fight to raise awareness and find a cure. Read on for some ways that young people are helping the cause. What can you do? Tell us by emailing Michal@PHAssociation.org.

Savanna (12 years old) is the older sister of a PH patient.

This year my soccer team puckered up 4 PH (see photo below). It was great to know that our team work was not only on the field. Some teammates and I also attend a club called c3. At the club, we talked about puckering up for PH and got 30 more puckers.

Last year for my birthday, I asked for donations for PHA and we raised more than $300. All of this also got in the newspaper and spread more awareness. This year for my birthday, my friends and I are planning to raise awareness for PH and ask for donations again. My friends Lexi and Kristen have joined with me on this. Kristen is in Girl Scouts and she went to her troop and got them to pucker up for PH. She also had some of her brother’s friends pucker up too. Lexie did a school report; she called and asked me all about PH and what it is like to have a sister with PH.

Cristiana’s family has lost three members to PH, including her father and grandfather.

I am in my high school Med-Sci group [Medical Science] and I actually love it! I had the idea to sell the periwinkle PHA “Empowered by Hope” bracelets [to raise money for PHA]. I presented it to the head of Med-Sci and another teacher and they both loved it! We made $150 by the second day and continued selling them until March. We allowed the students in Med-Sci to sell five bracelets at a time and for each set of five bracelets sold, they earn one hour of community service. I am the project manager, and we are selling the bracelets for $2 and handing out the small green PHA informational cards with each bracelet.

Camille, a PH patient, is currently attending college.

Two years ago I was approached by Children Special Services to participate in a study conducted by Michigan State’s first-year medical school students. The study entailed meeting with two first-year medical students about once every two months. We talked about my condition, how I live my life and my medical treatment. The two medical students were very nice and very interested in the treatment of PH and the lifestyle that comes with living with it. (Read the medical students’ story about this experience in the spring 2009 issue of Pathlight.)

This is something I still do today, and I love doing it. It helps me educate first-year med students and spread the word about PH in my own community. My hope is that one of the medical students may graduate from medical school and want to specialize in the treatment of PH and further the research for a cure.

Nicole is a 16-year-old PH patient.

Every year at school I am assigned a science project to do. I wanted to educate people about PH, so I did a project on it. The first part of the project was a background paper, which is basically a short research paper. I did that on PH, and I used PHA’s Pulmonary Hypertension: A Patient Survival Guide as a main source. The second part of the project is the actual experiment. It pertained to the effects of sleep (or lack thereof) on a chronically ill child. I would stay up late at night, and starting at midnight, would add 30-minute increments every night and wake up at 10:00 every morning. I did this for five days. When I woke up, I would check my blood pressure and oxygen saturation levels. My experiment came up inconclusive, as the data I collected was very erratic.
Website Resources for Parents of PH Patients

Parents of children with pulmonary hypertension face a number of unique challenges from identifying PH doctors who specifically treat children to dealing with schools and more. PHA’s website can help you navigate some of the challenges you may face.

Finding a pulmonary hypertension specialist is a priority for anyone diagnosed with PH. To find a list of those who specialize in pediatric pulmonary hypertension go to: www.PHAssociation.org/Pediatricians

When planning for school, you must balance the educational needs of your child with the restrictions their health may impose. Go to www.PHAssociation.org/Parents/School to learn about accommodations which may be helpful such as 504 Plans and Individual Education Plans. You can also download our School Resource Handbook. This helpful handbook includes a draft letter for your child’s school, an emergency information sheet and activity and medical information.

To connect with a community of parents just like you, check out www.PHAssociation.org/Parents/Support. Join a discussion with the PHA Parents Email Group to ask for advice, share your concerns, or just visit with other parents. A monthly support group conference call specifically for PH parents is held on the third Thursday of every month. Topics have included coping mechanisms, the transition from pediatric to adult care, and travel tips as well as other individual issues raised by participants. PHA’s Parent Mentors are a team of parents who are ready and eager to answer your questions by email. They can share their experiences of raising children with PH and help you find resources to ensure your son or daughter receives the best care possible.

Summer camps are a fun way for children to forget about PH and interact with other kids. But, as a parent, you want to ensure that your child is safe and healthy within this environment and that camp organizers are aware of any special needs that your child may have. Our camps section, www.PHAssociation.org/Parents/Camps, helps you to choose the camp that is right for your child.

PHA Classroom provides education on a huge variety of patient and caregiver issues. Live e-learning events are held regularly, and all events are recorded so if you miss one, check back to catch-up on the webinar. Just some of the topics available are “Making the Transition from Pediatric to Adult PH Programs” and “Caring for the Caregiver.” Upcoming events include “Pediatric Research Review,” “Emergency Preparedness for Children with PAH” and much more. See www.PHAssociation.org/Classroom/CaregiversAndParents for a list of all e-learning topics.

Kids and Teens! PH Kids, www.PHAssociation.org/PHKids, is a section of our website dedicated to kids dealing with PH. Here, kids can read about other children with PH, learn about their disease and get tips on school and sports. PHA Teens, http://phateens.ning.com, is a safe, secure teen social network where those aged 13-19 can compare notes with other PH teens.

By Sylvia Earley
PHA Communications & Development Coordinator

Cut out and keep our Quick Reference Parent Resource Guide

Find a Pediatric PH Specialist: www.PHAssociation.org/Pediatricians
Planning for School: www.PHAssociation.org/Parents/School
Finding Support and Connecting with Other Parents: www.PHAssociation.org/Parents/Support
Summer Camps: www.PHAssociation.org/Parents/Camps
PHA Classroom: www.PHAssociation.org/Classroom/CaregiversAndParents
Kids section: www.PHAssociation.org/PHKids
PHA Teens: http://phateens.ning.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 x756 or Jennifer@PHAssociation.org to have a recently deceased loved one’s name listed in Passages or to report errors or omissions.

For those for whom it would be helpful, PHA has developed a resource, Mourning a Loved One: A Guide to Grieving, which is available at www.PHAssociation.org/Caregivers/Bereavement. For more information, or to request a print version of this guide, please contact Bereavement@PHAssociation.org or 301-565-3004 x800. We welcome all loved ones to remain a part of our community for as long as it is beneficial.

PHA IS DEEPLY GRATEFUL TO THE PH COMMUNITY FOR ITS EXTRAORDINARY SUPPORT.

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