We must accept finite disappointment, but never lose infinite hope.
— Dr. Martin Luther King, Jr.

As we look back on 2012 and forward to 2013, we take inspiration from Dr. King’s words. Without exception, when someone is diagnosed with pulmonary hypertension, they experience significant disappointment along with many other challenging emotions. But as we have seen time and again, when they discover PHA, they often gain infinite hope.

Every year at PHA takes on a special meaning, and 2012 was no different. Our accomplishments were many and — to name just a few — included: 1,531 registrants for our 10th International PH Conference and Scientific Sessions; attaining sufficient support to begin funding pediatric research for the first time in 2013; and being recognized for outstanding leadership and representation of our members in education and advocacy by the National Organization for Rare Disorders.

But our work will never be done until we achieve our ultimate goal — a cure for pulmonary hypertension. We want a cure for patients like Jeannette Morrill, Nicole Cooper and Sean Wyman whose stories we share in the following pages, as well as for patients everywhere living with this disease. Their courage gives us hope.

Discovering a cure is critically important to those who provide care, too — both family members and medical professionals — who give tirelessly of themselves for their loved ones and patients. Jennifer Davis and Nancy Leaman are two of those caregivers working so hard to make life better for their mothers. And Drs. Julio Sandoval and Raymond Benza and nurse practitioner Mary Bartlett are three of the many medical professionals who enhance the lives of those living with pulmonary hypertension with exemplary clinical care. Their determination gives us hope.

Whether our connection is frequent or occasional, active or more quiet, virtual or in person, you make PHA what it is and inspire us to offer the programs and services reflected in the pages of this report. In a very real sense, you are PHA. You give us hope, and together our hope is infinite.

Wishing you the best in 2013,

Val

Rino

PHA’s Mission

Our mission is to find ways to prevent and cure pulmonary hypertension, and to provide hope for the pulmonary hypertension community through support, education, advocacy and awareness.
Pulmonary hypertension patients and their families continuously amaze and inspire us with their hope, determination and relentless perseverance. At PHA, we are honored to work with patients and their families to help shape and provide services that allow them to connect with one another, learn about the disease and continue fighting toward a cure. In this report, we are pleased to highlight just a few of the many patients and caregivers who benefit from the programs PHA offers.

Jeannette Morrill
PH Patient, Shirley Mills, Maine

In 1976, Jeannette received the diagnosis that would change her life: she had pulmonary hypertension. It would be another 20 years before she would meet other PH patients. “I joined the Pulmonary Hypertension Association and connected with others who dealt with the same issues I did on a daily basis,” Jeannette says. “I don’t think I realized how isolated I had felt all those years until I finally talked with someone else who had PH.”

When Jeannette found PHA, it was a lifeline. Over the years, she has become increasingly involved in PHA, helping other patients find hope and support. Jeannette is a leader for two PHA support groups in Maine. Across the country, PHA’s support group network now numbers more than 240 groups.

Jeannette works to advocate for PH research and education through the 435 Campaign, PHA’s grassroots advocacy network. At the end of 2011, Jeannette shared her story and urged Members of Congress to support the Tom Lantos PH Research and Education Act, the only PH-specific bill in Congress, during PHA’s annual Congressional Luncheon in Washington, D.C. She also hosts a golf tournament and PH forum every fall as part of PHA’s Special Events program to raise awareness of PH and funds for research.

At PHA’s 10th International PH Conference and Scientific Sessions in June 2012, PHA honored Jeannette with the Outstanding PH Citizen award. PHA’s Conference had 1,531 people registered, making it the largest PH Conference to date, and included representatives from 29 countries. More than 50 sessions from Conference were recorded and are being made available on PHA Classroom, PHA’s vibrant e-learning center for patients and families.

In preparation for Conference, PH advocates like Jeannette joined together and sent 1,280 letters to Congress in support of the Tom Lantos PH Research and Education Act as part of PHA’s Conference Advocacy Challenge.

PHA Goes on the Road to Connect and Educate Patients and Families

In addition to PHA’s biennial Conference, PHA also hosts PHA on the Road: PH Patients and Families Education Forums, free day-long regional forums sponsored by the PHA Medical Education Fund. In 2012, PHA visited New Brunswick, N.J., and the Chicago, Ill., area. Each forum had more than 200 registrants. As Carmen Lozada-Bruno, a PH patient at the New Jersey PHA on the Road forum, explains, “This was an informative session, an awesome and phenomenal experience. I’m so glad that I had another opportunity to meet other people with PH like me and to know that I’m not alone. I’m a PH warrior.” In 2012, PHA collaborated with the medical institutions where PHA on the Road speakers work to pitch PH-related stories to the media and further raise PH awareness.

“I’m a PH warrior.”

– Carmen Lozada-Bruno
Nicole Cooper
PH Patient, Windsor, Md.

Nicole (pictured above, left) was diagnosed with PH in 2009. She discovered PHA in 2010 and, since that time, has become a leader in the PH community, inspiring others with her dedication to PH awareness-raising. She is a member of PHA’s 435 Campaign, and in August 2012, she visited Sen. John Sarbanes (D-MD) to thank him for his support of the Tom Lantos PH Research and Education Act. “People probably think, ‘What difference can I make?’ Listen, I’m one person,” Nicole says. “I’ve been in that congressional office, and I’ve gotten a Member of Congress to co-sponsor after my meeting. If you get to one person, you make a difference.”

In addition to her advocacy efforts, Nicole spreads PH awareness as a PHA Special Events organizer. In 2012 Nicole’s 2nd Annual Vision of Hope Gala brought patients, caregivers and medical professionals together for an evening of dancing, entertainment and education. In preparation for the Gala and as a member of the PHAware Campaign, PHA’s grassroots campaign to raise PH awareness in the media, Nicole contacted local media outlets to spread the word about her gala and her fight with PH.

Nicole is also a support group leader for the Charm City Exhalers in Baltimore, Md., and she received the 2012 Outstanding Support Group Leader award at PHA’s 10th International PH Conference. She believes PH is an illness that you have; it does not define who you are, and “every day you open your eyes is a day of endless opportunities to spread awareness about PH.”

Like Nicole, support group leaders across the country are hosting creative meetings to bring patients and families together. A few of the unique topics that groups featured in 2012 were laughter yoga, identity theft, guided relaxation, and bonding and self-expression through art.

Phone Support for Patients

For patients who cannot attend in-person support group meetings, PHA offers monthly telephone support groups. “I live in a small town far from the support meetings. I’m so happy to be on this phone, talking to people who have PH,” says one telephone support group caller. “Thanks to PHA, this is the first time I have spoken to others with PH since I was diagnosed in 2008. I was just so happy to meet others who have it and understand symptoms and treatment.”

Patients and family members can also call the Patient-to-Patient Support Line (800-748-7274), which connects them with trained, long-term PH survivors.

New Edition of PHA’s Survival Guide

In 2012, PHA debuted the fifth edition of Pulmonary Hypertension: A Patient’s Survival Guide, PHA’s comprehensive resource for patients and caregivers. More than half of the chapters were updated for this release, including topics like drug treatments, diet, traveling, exercise, emergencies, depression, pediatric PH, insurance and a comprehensive listing of resources. Editions of the Survival Guide have been translated into five languages so far — Spanish, Korean, Farsi, Chinese and Japanese.

Pathlight: Connections in Print

Pathlight, the official newsletter of the PH community, reached more than 8,500 people in 2012 both in the U.S. and abroad. 2012 marked 22 years since Pathlight first began connecting patients, families and medical professionals through stories, news and information.
Jennifer Davis
PH Caregiver, Newport News, Va.

Despite living with the recent loss of her husband from cancer, an undiagnosed autoimmune disease, and raising two small children on her own, Jennifer has gone above and beyond to care for her mother, Linda. Since her mother’s PH diagnosis, Jennifer has assumed the role of caregiver by learning all she can about PH and helping Linda stay calm during E.R. visits. Jennifer quit her job and moved to help care for Linda as her PH worsened. “I hate how she and all my children have to go through this with me, but I thank God I am here with them,” Linda says. “I think Jennifer is wonderful, and she does everything she can to help me.”

At PHA, we are increasingly paying attention to the needs of caregivers like Jennifer so that we can help and support them in their challenging role. PHA hosts two monthly telephone support groups — one for caregivers and one for parents of children with PH. “It’s another way to know other families ... there’s just something more reassuring about having a phone conversation, getting to know people, knowing you’re not the only one going through this. Sometimes you get to feeling that there’s not a whole lot of hope out there, but there is,” says Jody Petry, parent of a PH patient.

Nancy Leaman
PH Caregiver, Meriden, Conn.

Nancy Leaman is a caregiver for her mother Linda, who was diagnosed with PH in 2008. Nancy balances graduate school with being her mother’s sole caregiver, and she has found comfort in connecting with other caregivers on PHA’s caregiver email group as she welcomes new members and supports the friends she has made through the difficult situations they share with the group. “Through this group, I’ve made some very special connections and friendships,” Nancy wrote to a recent new member. “I hope you’ll find the same feeling of home here. Though none of us choose to have PH in our lives, we do, and this group ensures that we don’t have to face it alone.”

Nancy has also found comfort in writing about her experiences for the spring 2012 Pathlight, PHA’s quarterly newsletter, where she encouraged other caregivers to acknowledge their own need for support. Her article reached approximately 8,500 mailboxes.

Nancy also has been instrumental in reaching out to other caregivers as part of the caregiver telephone support group. She was one of two presenters on the caregiver webinar on creativity as a form of healing and support in May 2012. Nancy told the group about how writing is therapeutic in her journey. Recordings of all of PHA’s webinars are available on PHA Classroom.

Resources for Families

In 2012, PHA created the PH Handbook for Families. This packet is geared to kids and teens with PH and includes activity sheets related to PH, information on age-appropriate PHA resources, and booklets about the disease — “Kids Get PH, Too” and “Doing My Part: Getting the Word Out About Pulmonary Hypertension.”
Sean Wyman  
PH Patient, Bloomington, Calif.

Sean is a 10-year survivor of PH, having received his diagnosis in 2002 at the age of 19. He is also a first-year medical student. Sean works with PHA’s various online communities to bring hope and support to other young PH patients. He serves on the advisory board for Generation Hope, PHA’s online community for patients in their late teens, 20s and 30s. He also serves as a PH Email Mentor. PHA’s email mentors are patients and caregivers who communicate with other patients and caregivers, offering support on topics ranging from day-to-day struggles to finding a doctor you can trust.

At PHA’s 10th International PH Conference in 2012, Sean met teen PH patient Shannon O’Donnell, and they developed an ongoing mentorship. Sean encourages Shannon to pursue her interest in medicine and take it at her own pace. He is also a source of support when others at her local high school don’t understand her situation and unique challenges.

“The most important thing is to make a connection with someone who’s experienced life with PH. Some look at it as a horrible disease — I look at it as a way to be philanthropic, a lifelong learner and, of course, a lifelong PHriend.”

– Sean Wyman

Sean (left) receives the Outstanding Young PH Citizen award at PHA’s 10th International PH Conference.

Online Resources: Connection and Education at the Click of a Mouse

Developed in 2012 and launched at PHA’s 10th International PH Conference and Scientific Sessions, PHA’s Empowered Patient Online Toolkit gives patients like Jeannette, Nicole and Sean more control over their complex medical information. The Online Toolkit is designed to make it easy for patients to track their medical history, medications and side effects, physician information, questions for upcoming appointments, insurance information and more. The Online Toolkit is available on PHA’s website, www.PHAssociation.org, along with countless other resources.

In 2012, the transplant section of PHA’s website underwent a redesign. The new design makes it easier for PH patients and their families to gather information about transplant, including details about the evaluation and procedure and how to prepare financially. The section also features links to PHA Classroom webinar recordings about transplant and PHA’s transplant email group. In 2012, PHA’s transplant email group greatly expanded and now includes more than 60 people.

For patients and families who want regular PH community updates sent to their email Inboxes, PHA offers PHANews, our biweekly e-newsletter with information on the latest news and events in the PH community.

Resources for Coping with PH

In 2012, PHA launched a series of coping resources to help both patients and caregivers deal with the emotional, social and spiritual sides of living with a chronic illness. With input from a host of medical professionals, including physicians, social workers and other health professionals, PHA developed coping guides for five defined populations: newly diagnosed patients, long-term survivors, parents, caregivers and teens. These are available on our website and by request from PHA’s office. One community member says, “These resources present issues I deal with daily in a realistic way and provide me with strategies for coping!”
Putting Medical Professionals First

Treating pulmonary hypertension is a team effort, involving patients, caregivers and healthcare professionals. PHA feels privileged to work with and support the dynamic and dedicated professionals who treat and care for PH patients and search for a cure to this devastating disease.

PHA’s Research Grant Program: Hope for the Future

PHA continues to move PH research forward. Through partnerships with the National Heart, Lung, and Blood Institute, the American Thoracic Society (ATS), the American Heart Association and Pfizer, PHA has committed more than $12 million and supported the work of 49 individuals to advance research in the field since the inception of PHA’s research grant program in 2000.

In 2012, the Robyn Barst Pediatric PH Research and Mentoring Fund reached its first goal of achieving $1,000,000 in funding. This is the world’s first pediatric pulmonary hypertension research program. The first awards will be made in 2013.

Also in 2012, PHA launched the PHA and ATS Foundation Fellow Career Development Awards. These awards are designed to support the research of MD and PhD fellows undergoing training in PAH-directed research. The goal is to support the research efforts of fellows during the latter part of their training (typically after their second year of training) in order to enhance their educational experience, advance discovery, and promote careers in academia. Each year, two $50,000 awards will be offered for one year each.

Sometimes it’s PH: An Early Diagnosis Campaign

In 2012, PHA launched Sometimes it’s PH: An Early Diagnosis Campaign, a bold multi-year initiative to reduce the time from onset of symptoms to diagnosis of PH. This campaign is built on the idea that doctors are taught to associate common symptoms with common ailments with this saying, “When you hear hoof beats, think horses, not zebras.” Pulmonary hypertension is a medical zebra.

To promote the campaign, PHA launched a new website: www.SometimesItsPH.org. As PHA works with medical professionals to decrease the time between symptom onset and diagnosis, patients are also gearing up by sharing their personal diagnosis stories on the campaign website and sporting zebra stripes. Many of PHA’s 2012 special events organizers incorporated the zebra theme and early diagnosis information into their events.

Mary Bartlett, NP
Winthrop Pulmonary Associates, Mineola, N.Y.

Mary is one of the many healthcare professionals dedicated to helping PH patients and their families. In 2012, Mary received PHA’s Outstanding Allied Health Professional award at PHA’s 10th International PH Conference. Mary has been involved with PHA since 2004. She is an active member of the PH Professional Network (PHPN), PHA’s membership network for PH-treating nurses and other healthcare professionals. Mary spearheaded the effort to strengthen the PHPN Mentor Program, which partners experienced PH professionals with new practitioners in the field or professionals taking on new challenges. She has also been instrumental in planning for PHA’s biennial PH Professional Network Symposium.

Mary co-leads the Long Island (Nassau County) PH Support Group in New York, and she helps organize one of PHA’s longest running special events — the New York Fun Walk, which celebrated its eighth year in 2012 and has raised more than $300,000 for PH research since it began.
Expanding PH Education for Medical Professionals

In 2012, PHA launched a completely redesigned version of PHA Online University, www.PHAOnlineUniv.org, PHA’s premier website for medical professionals. The site offers courses, journal articles, live webinars and other practice-related resources for free. Additionally, PHA Online University is now optimized for mobile technology so that busy medical professionals can access the site through their tablets, smart phones or other devices. In the words of one site tester, “This is a fabulous site! It will enable medical professionals to get up to date on ‘the latest’ in PH research and treatment. I have never been on a website where I could move more freely and easily.” About a third of the visitors to this site are from outside the U.S.

In addition to PHA Online University, PHA offers live medical education programming for medical professionals. The PHA Preceptorship Program provides direct instruction on state-of-the-art PAH diagnosis and management to physicians and other health professionals who help care for patients with PAH, and the PHA On-Demand Program allows medical professionals to customize their own PH medical education program.

“I foresee a huge impact of this program on my practice.”
– Participant, Orlando, Fla., PHA Preceptorship Program

Julio Sandoval Zarate, MD
National Institute of Cardiology, Mexico

In 2012, Dr. Julio Sandoval (pictured above, left) became the first recipient of PHA’s International Physician Award at PHA’s 10th International PH Conference and Scientific Sessions. During Conference, Dr. Sandoval and others participated in the Second International Leaders’ Summit where PH community leaders from around the globe — representing 29 countries on six continents — came together to share friendship, knowledge and strategies.

Dr. Sandoval has served on PHA’s Scientific Leadership Council (SLC), a group of world-renowned PH physicians and researchers who oversee the development of the wide array of PHA’s medical programming. Dr. Sandoval is also a current member of PH Clinicians and Researchers, PHA’s membership network for physicians and researchers in the PH field.

Dr. Sandoval is active in the field of PH research and participated in a roundtable discussion about the importance of early PH diagnosis at the American Thoracic Society’s 2012 International Conference. The transcript of this conversation appeared in Advances in Pulmonary Hypertension, PHA’s quarterly medical journal. Advances reaches 40,000 medical professionals worldwide, and editions are now being produced for international audiences in India and Spanish-speaking countries.
Medical Professionals Actively Participate in PHA’s 10th International PH Conference and Scientific Sessions

During our 10th International PH Conference and Scientific Sessions in June 2012, PHA’s Research Room featured nine research teams from institutions all over the country and continued a tradition that started at the first International PH Conference in 1994.

The research teams studied subjects ranging from genetics of PH to the psychosocial impact of living with the disease and hosted 235 participants — more than ever before.

In addition to an expanded Research Room, Conference also boasted the largest number of scientific abstracts with more than 100 posters available for viewing. One of the many abstracts is pictured below.

PH Fundamentals, six sessions on basic PH education for medical professionals, proved incredibly popular in 2012 with more than 100 attendees at each session — some with standing room only.

PHA Speaks Out on Insurance Initiatives

In 2012, PHA’s SLC created an insurance subcommittee to continue to move PHA’s insurance initiatives forward. In the spring of 2012, several PHA leaders met with members of the Social Security Administration (SSA) to advocate for change in a federal policy to help very ill patients receive Social Security Disability benefits more quickly. “Washington policymaking takes time, and we did not expect a clear ‘yes’ or ‘no’ decision at this meeting. Yet our group was impressed with the empathy and desire for collaboration shown by the SSA,” Dr. Sean Studer, one of the participants, says. “The SSA officials’ interest in our issue energized us for continued work on this key matter.”

In 2012, Dr. Karen Fagan, chair-elect of PHA’s SLC, helped fight against a harmful policy for PH patients dependent on Alabama Medicaid. Under the proposed policy, patients would only be able to receive one brand name drug per month. Alabama has revoked the policy.

Raymond L. Benza, MD, FACC, FAHA
Allegheny General Hospital, Pittsburgh, Pa.

In 2012, Dr. Ray Benza received PHA’s Physician of the Year award in recognition of his dedication to the PH community through excellent clinical care, research, education and advocacy on behalf of PH patients.

Dr. Benza has literally scaled mountains for the benefit of the PH community, summitting Grand Teton in 2007 and Mt. Kilimanjaro in 2010. He regularly volunteers his time as a faculty presenter for PHA’s educational programs, and he is a past member of PHA’s Scientific Leadership Council.

In 2012, Dr. Benza worked with the United Network for Organ Sharing (UNOS) and the International Society for Heart Lung Transplantation (ISHLT) to help improve the outcomes for PH patients awaiting lung transplantation. This change and recognition of how the Lung Allocation Score for PH patients should be applied differently is a huge victory for PH. Dr. Benza referred to it as “one of the proudest accomplishments of my career.”
Standing Financially Strong

The financial support of individuals, foundations, organizations and corporations make it possible for PHA to carry out our mission: to fund research, to provide support and education, to raise awareness of PH and to advocate for health legislation that will improve lives. PHA is deeply grateful for the support of volunteers and donors and is proud to have met the BBB Wise Giving Alliance Standards for Charity Accountability. Additionally, for nine consecutive years, PHA has received the highest possible rating — 4 stars — for fiscal accountability and transparency from Charity Navigator, placing PHA in the top 1 percent of all rated charities.

Legacy of Hope Society

PHA’s Legacy of Hope Society honors those who have included PHA in their estate plans or whose legacies have been realized. Legacy donors make a special commitment to PHA, ensuring that our work will go on for all those whose lives are affected by PH.

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Abbey S. Meyers Leadership Award

The National Organization for Rare Disorders (NORD) awarded PHA the Abbey S. Meyers Leadership Award in 2012 for outstanding leadership and representation of our members in education and advocacy. In honoring PHA with this award, NORD highlighted many of PHA’s services, including: PHA on the Road: PH Patients and Families Education Forums, PHA’s International PH Conference and Scientific Sessions, PHA Classroom, PHA Online University, PHA Medical Education On-Demand Programs, Lobby Day visits to Capitol Hill, PHA’s growing research program, PHA’s Patient-to-Patient Support Line and PHA’s many global connections. PHA has been a member of NORD since 1993.

2012 Corporate Committee

PHA is able to meet the needs of our community in part thanks to the financial support of our various funders. We are grateful for the support of our 2012 Corporate Committee on a wide variety of awareness and educational projects and activities.

- Actelion Pharmaceuticals US, Inc.
- Bayer HealthCare
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- Gilead Sciences, Inc.
- GlaxoSmithKline
- Lung LLC
- Medtronic, Inc.
- Novartis Pharmaceuticals
- Pfizer, Inc.
- United Therapeutics Corporation
### 2011 PHA Revenue

- **Membership**: 1.2%
- **Individual Donations**: 3.6%
- **Individual Donations - Research**: 6.6%
- **Corporate Giving**: 29.9%
- **Medical Education**: 30.6%
- **Other Groups**: 2.1%
- **Foundations/Grants**: 2.7%
- **Workplace Giving**: 1.0%
- **Special Events**: 2.8%
- **Special Events - Research**: 6.3%
- **Symposium Revenue**: 7.5%
- **Investment Gains**: 5.6%

### 2011 PHA Expenses

- **Patient & Member Services**: 17.5%
- **Medical Services**: 16.4%
- **Web Services**: 3.4%
- **Print Services**: 2.9%
- **Symposium**: 7.4%
- **Advocacy and Awareness**: 4.9%
- **Medical Education**: 27.1%
- **Research**: 6.9%
- **Management & General**: 8.5%
- **Fundraising**: 5.1%
Putting Hope First: PHA Leadership as of December 2012

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PHA received a 2012 APEX Award of Publication Excellence for the creation and publication of our 2011 annual report.

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