

PULMONARY HYPERTENSION ASSOCIATION
EMPOWERING
HEROES
2015 ANNUAL REPORT

Opening the Door to PHA's 25th Year



Dear PHriends,

Opportunity and risk. That is the fulcrum on which we balance PHA's fight against pulmonary hypertension.

At PHA we talk about reasonable risk and the heroes who take those risks for the betterment of our entire community.

These risks are the things we MUST do if we are truly committed to better and longer lives for PH patients. Our community is full of people who stand up, recognize the risks and help us to move forward. You will read about many of these risks and these heroes in this annual report.

For instance, an early risk came in 1992 when one of our first heroes – Ed Simpson – proposed that PHA organize an International Conference to bring together PH patients, their families and physicians. At the time, PHA's entire treasury was \$858.31. A Conference would be a huge risk. Yet, when he proposed the idea in 1992 at PHA's first annual meeting, with a total attendance of 10, the small group agreed. In 1994, PHA's first International Conference was held in Stone Mountain, Ga. Today, our Conference has grown to become the largest PH meeting in the world, drawing attendees from more than 30 nations and inspiring the collaboration and energy that drives us forward.

Another risk came in 2000, when yet another PH hero – Dr. Bruce Brundage – along with Gentiva's Craig Mears and I met under a potted palm at a hotel in Chicago. Out of that meeting came the risk for PHA to create and publish *Advances in Pulmonary Hypertension*, the world's first medical journal focused entirely on PH. We had no idea whether the medical community could generate enough information to keep the journal going beyond its first year, or whether we could afford to sustain the publication. But we knew if we could do it, we would accelerate progress in the field. The budget for the first year of the journal was about 150 percent of PHA's entire budget the year before. PHA's Board of Trustees approved it and the risk paid off. PHA's medical journal has been publishing quarterly since 2002 and reaches more than 40,000 cardiologists, pulmonologists and rheumatologists with each issue.

There have been many more essential risks and many more heroes committed to taking those risks during PHA's first 25 years, and you will read about some of them in this annual report. As we look back at our last 25 years – and 2015, in particular, in this report – we recognize all the risks and heroes who brought us to where we are today. We also look forward, recognizing that as a larger organization, we have the opportunity for even greater success as we move into 2016, PHA's 25th anniversary year, and beyond.

Our future path in the fight against PH is bright. It includes PHA's accreditation program for PH Care Centers and its related registry. Creating standards for PH Care Centers in this rapidly growing field and tying that to data collection will create the opportunity for medical practices to understand what works better and what doesn't. With 29 centers accredited since the end of 2014 and another 50 in line for accreditation review, we are on track to have accredited 90 PH Care Centers in 2016. This risk and the heroes who are helping us forge these new paths will set new and higher standards for PH treatment, and those standards will translate to extended and better life. This risk – both financially and organizationally – is one that cannot be ignored.

As you read this annual report, I hope you will recognize the outcome of the risks PHA has taken and the heroes who stood up and committed to taking those risks for the betterment of the entire community. You are one of those heroes. We are grateful to count you in our community of hope, and we ask for your help as we move into 2016. Please help bring us into the future with the financial strength that will allow us to continue to take essential risks for you and all whose lives are touched by PH.

Sincerely,



Rino Aldrighetti
President & CEO





Empowering Patients and Families

EMPOWERING HEROES IN THE COMMUNITY THROUGH CONNECTION AND SUPPORT

PHA's network of in-person and online support keeps our community connected to each other and the resources found within our community of hope.

Support Groups

In January 1991, PHA founders Pat Paton, Judy Simpson, Dorothy Olson and Teresa Knazik met in Indiantown, Fla., to form what they thought would be a local and, the first, PH support group. After that initial meeting, other support groups began to form. Everyday heroes attended groups far from their homes and then organized new ones closer to where they lived, filling in the map. Today, this network has grown to more than 250 groups meeting in 49 states and Puerto Rico. These groups are led by 345 patients, caregivers and healthcare professionals who volunteered precious time and energy to set up and coordinate nearly 1,000 meetings across the country in 2015.

In 2015, to further empower these heroes, PHA hosted five in-person regional leader training summits and leader networking events in Seattle, Philadelphia, Atlanta, Phoenix and St. Louis. Additionally, each month, dozens of leaders came together for PHA-hosted trainings conducted online and via phone.

“These functions are inspiring and put leaders into hyper drive! The information and experiences we garner from these functions are lasting and help give us a focus on PHA as a whole.”

PHA support groups have become a backbone in the fight against this disease, offering patient support and education, awareness-building activities, advocacy and funding for research and patient-serving programs.

PHriends

One day, a young woman received devastating news from her doctor — she had PH and she should put her affairs in order. As she stood in the hospital elevator with her father, she looked through a brochure that he had picked up in the doctor's office. It included the phone number for PHA's Patient-to-Patient Support Line. They called from the parking lot and reached the volunteer on duty, Dorothy Olson. The young woman asked if her chances were as slim as her doctor indicated. Dorothy said:

“I have lived with this disease for 20 years, and I'm still going. With research and new treatments, our chances are getting better each year.”

Just as Dorothy provided a lifeline for this young woman, PHA PHriends are experienced PH patients and caregivers available to offer hope and support throughout the PH journey. PHriends volunteer on the Patient-to-Patient Support Line, as PH Email Mentors and as Daily Support Chat Hosts. In 2015, the Daily Support Chats averaged 400 new registrations per quarter, the Patient-to-Patient Support Line received more than 2,400 calls and PHA's Email Mentors received more than 350 contacts from community members. To help support children living with PH and their families, we welcomed new parent mentors into the PHriends program in 2015.

myPHA

A personal connection is at the heart of everything PHA does. When PHA began, co-founder Pat Paton called PHA's first 350 members individually. A community emerged from this personal contact, and while PHA has grown to more than 16,000 members and supporters in 2015, a continuing goal is to maintain these personal connections. We meet this challenge in many ways, with the newest being myPHA.

Launched in 2015, myPHA is an online community where PH patients and caregivers can find connection, support and information. The site is customized to the individual interests of those using it. That means that a parent of a child with PH can automatically be connected to a specific private group and resources for that part of our community. A patient with PH related to scleroderma will have the door opened to resources meeting his or her situation and interests. The site launched on April 10, 2015, with the goal of having 1,000 members in 12 months. This goal was easily met in the first six months, and we expect myPHA to continue to grow into 2016 and beyond.

Recently, Pat Paton wrote:

“Our goal when we began PHA a quarter century ago was to be effective in changing the history of this disease. We knew that the only way to succeed was to build a single and strong community where people could share their common interests and work together for a better future. I am thrilled that as PHA has grown, it has found ways to continue with those values.”

Lantos Service Awards

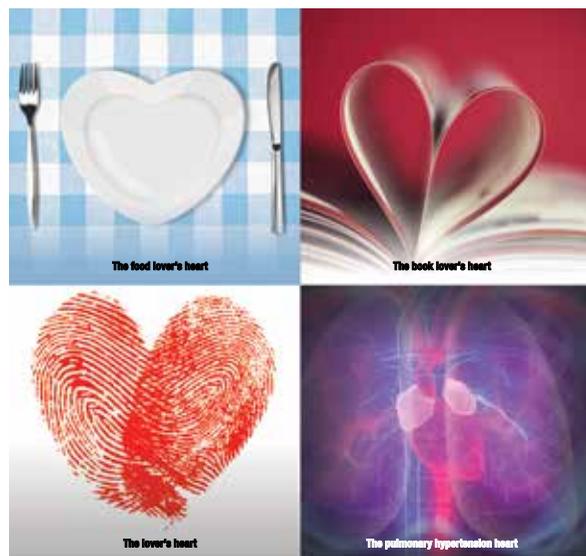
In 2015, PHA received 33 applications for our *Tom Lantos Innovation in Community Service Awards* program – the most applications received in one cycle since the program began in 2010. Sponsored by Gilead Sciences, this program provides funding of up to \$5,000 each to recipients to act on original ideas to advance the PH cause. PHA was able to fund 12 projects in 2015, including both domestic and international projects.

Give a Chance on Life for People with PH, by Oxana Kulish, Lviv, Ukraine.

"The main goal of this project is to overcome existing informational barriers in early diagnosis, prevention and treatment of PH by implementing an information campaign in the Ukraine," says Oxana. The project will include billboards, social media campaigns and flash mobs to get the word out about PH.

EMPOWERING HEROES THROUGH AWARENESS AND OUTREACH

Part of PHA's mission is to bring awareness of the disease to individuals who have never heard of PH before. In 2015, PHA made unprecedented gains in public awareness.



Pulmonary hypertension puts unbearable stress on the heart. We're putting our heart into finding a cure.

Often misdiagnosed - as asthma, for example - Pulmonary Hypertension (PH) can cause death from heart failure. There is no cure. But at the Pulmonary Hypertension Association, we're giving hope to PH patients and caregivers. Learn how you can help at www.PHAssociation.org



Heart2CurePH

While PHA has always done a great job of building PH awareness within our community, we are now embracing the opportunity to build external awareness, combining the power of our community's social media reach with newspapers and magazines, TV and radio, and billboards.

In November 2015, PHA launched a new public awareness campaign – Heart2CurePH (#Heart2CurePH). Through it, we are building the support of the American people for a disease that will be better and more broadly known. Watch for the growing impact of this program in PHA's 25th anniversary year.

This campaign has its roots in community members like Diane Ramirez, a patient in North Carolina, who used the power of her story to generate an article in the *New York Times* several years ago. Through media awareness, so many PHA community members over the years have helped to lay the groundwork for what is now Heart2CurePH.



The Pacing Parson

Over the years, medical professionals and community members alike have completed tasks of athletic endurance in the name of PH awareness. In 2009, teen Matthew Moniz and a team of climbers climbed 14 of Colorado's 14,000-foot peaks in 14 days to raise awareness and honor Matt's friend and PH patient Ian Hess. In 2010, two PH-treating physicians and a nurse practitioner set out to climb Mount Kilimanjaro to try to understand some of the struggles their patients face every day. In 2014, Dr. Patty George and Team PHenomenal Hope, a team of ultra-endurance athletes, participated in Race Across America. Continuing this tradition of raising PH awareness through extraordinary acts, in 2015 Don Stevenson, AKA "the Pacing Parson," walked 3,000 miles across America for PHA and PH patients everywhere.

Don helped put PHA on the map in 2015 through TV, radio and news reports (nearly 100 media stories). The Pacing Parson earned his nickname after many years of completing long-distance walks for health-related causes. Just shy of his 80th birthday, Don was resigned to retiring from the charity walks but, after losing a friend to PH, headed cross-country on foot in June 2015 from Washington State to PHA's national office in Silver Spring, Md. "Every charity walk I've done, I have a goal in mind. Regardless if my body says stop, my mind says, no. I'm the boss, and I keep going," Don told a reporter at WDIO (ABC-Duluth, Minn.).

CTEPH and Accurate Diagnosis

Sarah White Brackett is one of the heroes of our community. Misdiagnosed with PAH in 2011, it took four years for her to be correctly diagnosed with chronic thromboembolic pulmonary hypertension (CTEPH) and ultimately identified as a candidate for pulmonary thromboendarterectomy (PTE), a potentially curative procedure for patients with CTEPH. Recent data from the PAH QuERI study indicates that Sarah is not alone, reporting that at least 10 percent of patients treated for PAH have never had a right heart catheterization (RHC) and that only 57 percent have had the possibility of CTEPH appropriately ruled out.

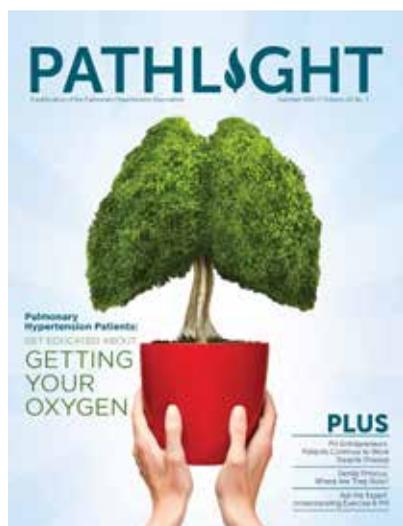
Today Sarah enjoys a much higher quality of life, and no longer needs PH medications or oxygen. Testimonies like Sarah's, coupled with correlating data collected by PHA's Subcommittee on Early Diagnosis for the CTEPH Patient in 2015, have helped PHA recognize that focusing on early diagnosis isn't enough; the conversation needs to be about accurate diagnosis.

To that end, 2015 marked the beginning of an effort to ensure that all patients in the PH community have not only had their diagnosis confirmed by right heart catheterization, but have also had the possibility of operable CTEPH ruled out. This educational effort, titled No Right Heart Catheterization, No V/Q Scan, No Diagnosis, hopes to encourage our community members to be informed consumers in their own healthcare, empowering them to talk with members of their medical team about whether or not they've received a complete diagnostic workup.

In addition to this more internally facing effort, at the end of 2014 PHA launched the first CTEPH Awareness Day, a now annual event geared toward increasing broader awareness of CTEPH. Having a commemorative day during PH Awareness Month has not only helped us to reach patients with a history of blood clots, but has better positioned PHA to engage with the organizations who support those patients, connecting us with another layer of medical professionals who are learning about CTEPH, PAH and the importance of early diagnosis. Nov. 17, 2015, marked our second celebration of this CTEPH Awareness Day and included patient Q&As with experts in both English and in Spanish, a number of educational events hosted by PTE centers and PHA chapter offices across the U.S. and the first PTE patient reunion, hosted by the University of California, San Diego. Attendees at all events were encouraged to **BUST CTEPH** through *Better Understanding, Screening, and Treatment* of this rare form of pulmonary hypertension.

EMPOWERING HEROES THROUGH EDUCATION AND INFORMATION

PHA puts PH education and resources in the hands of those who need it most – our patients and their families.



New Pathlight magazine

Pathlight has been part of PHA's history since the beginning. As PHA enters its 25th year, we think back to *Pathlight's* first editor, Teresa Knazik, the first issue of the newsletter and the 50 people to whom that Xeroxed publication was sent in 1990. In the third issue, the founders laid out their goals for PHA – to organize support groups, make *Pathlight* accessible to everyone, help families cope, educate the public about PH, promote awareness among the medical community, encourage research and form a "collective voice." We still stand by these principles today.

In honor of *Pathlight's* 25th anniversary, this quarterly print publication debuted as a new, streamlined magazine in summer 2015. The redesign process involved feedback from the entire community through an online survey and in-person and phone-based focus groups.

The new magazine focuses on giving the community even more of what they want: inspiring stories, tips for living with the disease, research news and ways to fight back.



"Although I haven't read all of *Pathlight* yet, what I did read has brought me closer to accepting my diagnosis. I've denied it for three years. I can say I have PAH but can zap it right back out of my thoughts again. I've done the same with my diabetes for 20+ years. The new *Pathlight* is worth looking forward to, and I know I will. Keep up the great work!" – Kathy Glass

PHANews.org

In 1999, Sally Maddox was a new Board member whose responsibility was to create educational opportunities for PH patients and their families. Sally developed the concept of PHANews as a biweekly e-newsletter that would share information in an easy-to-digest way. In 2015, this publication grew to more than 10,000 subscribers and began emailing on a weekly basis. With this growth, PHA began to look at how PHANews could be more valuable for its readers. In November 2015, PHANews launched as a new, easy-to-use website at PHANews.org. This site provides the latest in pulmonary hypertension and PHA news and is easily accessible on any mobile device. Once a week, the latest news from the website emails to community members.

PHA Classroom

Throughout the years, many medical professionals have echoed one doctor's comment:

"PH patients know more about their disease than we've seen in any other field. This is a huge advantage in treatment."

PHA Classroom is a cornerstone of that knowledge. Our video and audio learning center for patients and caregivers grew to more than 200 units of education and a dozen learning guides during 2015. Many more visitors are using it, as demonstrated by a 157 percent growth in viewers over the past two years. We have resources for all ages; for instance, in 2015 PHA partnered with the Nora Thelma Boström Foundation to create a webinar focusing on the care of an infant or toddler with PH.

In late 2015, in preparation for PHA's 25th Anniversary, *PHA Classroom* was fully redesigned to make it even easier to access and use the wealth of information on this site. This redesigned educational website offers content tailored to the viewers and their interests.

Taking PH Education on the Road

In 2015, *PHA on the Road: PH Patients and Families Education Forums* visited Atlanta, Philadelphia, Phoenix and St. Louis, registering more than 800 total attendees for the forums. This program began seven years ago, after PHA realized that attendees at PHA's Biennial International Conferences were mostly those who were better able to travel, which meant many patients and caregivers were unable to take advantage of the education and networking opportunities that Conference provides. These regional "mini conferences" are one solution to meet that challenge, and interest in *PHA on the Road* programs has grown every year.

"As a result of what I have learned at *PHA on the Road*, a change I plan to make in my life is to never let my health issues deter me from living life to the fullest, even if it is at a slower pace! This is fine with me and learning to make the adjustments to accomplish this goal will help me to cope with my health much better." - *PHA on the Road* Attendee



Global Education

The linguistic demographics of the U.S. have changed greatly in the almost 25 years that PHA has existed. PHA strives to keep up with those changes in order to make sure that every person affected by PH has the education and support that he or she needs. To that end, PHA worked with the Sociedad Latina de Hipertensión Pulmonar to launch the 2015 Spanish-language edition of its reference guide for PH patients, caregivers and medical professionals, *Pulmonary Hypertension: A Patient's Survival Guide*, which is also available in six other languages.

PHA has also boosted availability and production of its Spanish-language *Envelope of Hope* program and supporting materials, mailing out thousands across the country in this year alone, and has worked to ensure that its Early Diagnosis and CTEPH campaigns all at least have Spanish-friendly aspects.

PHA's efforts do not stay within the confines of our country boundaries. In 2015, PHA worked with PHA Europe to launch and co-host "Our PH Library," where all educational and support resources from around the world are hosted for association members and leaders to "check out" as well as translate and adapt according to their needs.

2015 saw the largest World PH Day yet on May 5 with 43 countries participating. PHA hosted social media and website content for the day with www.WorldPHDay.org, available in four languages.



EMPOWERING HEROES THROUGH TREATMENT ACCESS

Each year, PHA responds to approximately 200 direct requests for assistance with treatment access challenges. We also seek to support those living with PH and their families through education, policy advocacy and our unique specialty pharmacy feedback program.

Specialty Pharmacy Feedback Program

In January 2013, a PH patient posted to Facebook: "I was switched from CuraScript to [another specialty pharmacy] for my Adcirca because my insurance changed the first of the year. I ran out of my Adcirca Saturday. Four days without now ... I've been on the phone every day since last Monday with [the specialty pharmacy], and my PH doctor so this wouldn't happen. They said it would be here today, still nothing. I've called UPS and got the tracking number and status and it's saying it's on its way. Losing my patience! Has anyone ever heard of [this specialty pharmacy]?"

This came at the same time that Colleen Brunetti, PHA Board of Trustees member and co-founder of Generation Hope, was experiencing similar challenges with her specialty pharmacy.

The relationship between a pulmonary hypertension patient and his or her specialty pharmacy is a crucial one. When that relationship is working well, a PHer's specialty pharmacy serves as friend and partner, helping to navigate the plethora of barriers to effective treatment. However, when the patient-specialty pharmacy relationship becomes problematic due to complications with medication re-order, delivery or billing, patients' quality of life plummets. PHA realized that if these issues were ever going to improve, it would be because patients were speaking about them in a way that specialty pharmacies could understand.

PHA's Specialty Pharmacy Feedback Initiative pairs a feedback collection process open to patients, caregivers and medical professionals with the coordination of a Specialty Pharmacy Advisory Board open to all manufacturers and specialty pharmacies in the PH space, as well as selected community representatives. On average, this feedback system collects approximately 100 comments per month. These comments have allowed specialty pharmacies and manufacturers to identify areas for improvement and, just as importantly, to hear from patients about what is working well. To our knowledge, it is the only such independently managed program in the U.S.



In 2015, PHA received interest in the Specialty Pharmacy Feedback Initiative from several other health organizations. As a result, we began exploring the technology needed to allow feedback from multiple disease states to be managed from a single location, without losing the ability to protect proprietary information.

During the first quarter of 2014, **52 percent** of respondents through the specialty pharmacy feedback tools said they spent more than five minutes on the phone every month refilling their prescriptions for PH medications, a point of frustration particularly for those who cannot breathe efficiently enough to make long calls. During the first quarterly Advisory Board meeting, PHA impressed the need for shorter, more effective refill calls. In Q2 of 2015, **only 25 percent** of respondents said they experienced long call times with their specialty pharmacies.

Treatment Access Advocacy: Oxygen Access

Improved oxygen access is just one example of the many ways PHA's Treatment Access program works with regulators and lawmakers to advocate for improved access to treatment for PH patients.

In 2014 and 2015, PHA received a number of calls from Medicare recipients whose oxygen providers told them they no longer offered liquid oxygen or other oxygen delivery systems or services. PHA worked closely with the Center for Medicare and Medicaid services and COPD Foundation to resolve individual concerns and provide information about Medicare recipients' rights and responsibilities related to oxygen access. An adapted version of the guide is now available on PHA's website.

Insurance Education

PHA provides an online insurance guide, insurance webinars for both patients and medical professionals and related educational resources for those seeking to understand their insurance coverage or navigate challenges. One participant in a 2015 webinar on applying for Social Security Disability said of the session, "This has helped me more than anything else so far."

EMPOWERING HEROES THROUGH ADVOCACY

PHA empowers the community to advocate for every PH patient. If we stand as one united voice, we are unstoppable.

"I know this disease is rare, but sometimes it really does amaze you the connections you make with people because of PH."

– PHer Perry Mamigonian on meeting a legislative staffer who lost his father to PH 25 years ago



In 2015, PHA began expanding our legislative partnerships in selected areas, including treatment access. We joined several long-standing partners like the American Thoracic Society for their annual Hill days and increased our involvement with the Coalition for Accessible Treatment, Coalition for Clinical and Translational Science and Rare Disease Legislative Advocates. Through these partnerships, we advocated for increased funding from the National Institutes of Health (NIH), a more sustainable pay structure for Medicare physicians and lower co-insurance costs for those in need of complex medications.

We continued our focus on co-insurance costs and related legislation such as the *Patients Access to Treatments Act* throughout the year with Congressional outreach during National PH Call-In Day, our local legislative visit campaign in August, PH Professional Network Advocacy Day and our National PH Advocacy Day in the fall. As we go to print, the *Patients' Access to Treatments Act* has 95 co-sponsors.

"I need these drugs to survive, but I can't pay for them all myself. I get co-insurance assistance of \$20,000 a month. I still have to pay \$6,500-\$7,000 a month." – PHer Diane Adkins

We also addressed the needs of those living with PH and their families through conversations with federal agencies. We advocated for a patient meeting between the Food and Drug Administration and the transplant community. That meeting will take place in 2016. We assisted PHers in submitting and voting on research questions as part of the National Heart, Lung, and Blood Institute's strategic planning process. Thanks to the PH community, PH-related questions were in the top 5 percent of most-voted-for topics.

PHA has been expanding and adapting our legislative strategy for maximum impact, but the core of our efforts hasn't changed. As always, hearing directly from PHers about their legislative priorities and supporting individual advocates through the *435 Campaign* remain critical to our work. PHA introduced a new Advocacy Advisory Board and Advocacy Mentors Program in 2015.

In addition, a PH-specific bill remains a legislative priority. Reps. Kevin Brady (R-TX) and Lois Capps (D-CA) introduced the Pulmonary Hypertension Research and Diagnosis Act (H.R. 3520) in late September, just in time for 90 PH medical professionals to request co-sponsorship from their Members of Congress during the PH Professional Network Advocacy Day. A week later, the bill had added seven new co-sponsors as a direct result of PHers' advocacy efforts.



Empowering Medical Professionals

EMPOWERING HEROES IN THE COMMUNITY THROUGH CONNECTION AND SUPPORT

PHA's connection and networking opportunities for medical professionals facilitate collaboration and information sharing that lead to better care for patients.

Medical Membership Networks

In 1999, PHA began working with a small group of nurses and other PH-treating healthcare professionals who had begun hosting monthly phone calls in order to share information about treating this little-known disease. These initial phone calls led to the idea of creating a network to connect medical professionals who were working in the field and, from there, the concept of the PH Professional Network (PHPN) was born, officially launching at PHA's 2000 International PH Conference in Chicago. The success of PHPN was followed by similar interest and needs by physicians, and PH Clinicians and Researchers (PHCR) was created in 2003.

"In 1999 there were only a handful of PH coordinators working in isolation. We desperately wanted to connect to support one another, share our knowledge and, ultimately, improve patient care. PHPN, supported by PHA, became our path to fill that urgent need."

– Abby Poms, RRT, CCRP

In 2015, with interest in the pulmonary hypertension field continuing to grow with an increasing number of medications and prescribing providers, each of these groups also grew and they are helping PH-treating medical professionals share information, collaborate and ultimately provide better treatment for their patients. PHCR saw a membership growth of 19 percent and PHPN experienced an unprecedented growth of 50 percent.

LOOKING BACK

In 2003, PHA began to work with the leadership of PHPN to create the first PH Professional Network Symposium, which 60 healthcare professionals attended. Interest grew from PHPN members, and by the 2005 Symposium, attendance grew to 250. Interest, support, registration and programming have continued to grow since those first meetings.

PH Professional Network Symposium

From Sept. 17-19, 2015, 475 attendees gathered in Arlington, Va., for the 2015 PHPN Symposium, *Setting the Pace in the PH Race Through Education, Research and Advocacy*. Healthcare professionals and PHPN members from around the globe participated in networking and educational sessions ranging from the management of pediatric PH patients, to understanding complex hemodynamics, to how to successfully coordinate care among several medical disciplines.

EMPOWERING HEROES THROUGH AWARENESS AND OUTREACH

By raising the profile of this rare disease among healthcare professionals, PHA is reducing the time to accurate diagnosis and enhancing patients' lives.

The Early Diagnosis Campaign: *Sometimes It's PH*

Early and accurate diagnosis is crucial to the lives and health outcomes of PH patients. In its third year, PHA's Early Diagnosis Campaign, an evolving effort led by 48 members of PHA's medical community, has begun to see indications of improvement in terms of the average time to PH diagnosis. New patient data collected through PHA's *Envelope of Hope* program has helped gauge the positive impact of the campaign, while also helping to highlight the remaining challenges that still need to be overcome as we move toward the campaign's ultimate goal – reducing the time between symptom onset and accurate PH diagnosis. In 2015, the data showed 60 percent reported the time between symptom onset and diagnosis was 12 months or fewer.

In 2014, PHA began looking at emerging evidence that racial and ethnic minorities as well as the socioeconomically disadvantaged are disproportionately likely not only to receive a delayed diagnosis, but also to experience additional barriers to treatment. Out of that conversation, we formed a major new effort, the PH Care for All Initiative. In 2015, the initiative began research efforts to identify socioeconomic barriers to diagnosis and treatment of PH. This is a first step in addressing the identified issues. Dr. Vinicio de Jesus Perez of Stanford University, who co-chairs the committee along with Dr. Arunabh Talwar of NorthShore University Hospital, said of the initiative:

"I was surprised and gratified at the response to this new Initiative when we put the word out. In a matter of weeks, 25 leading medical professionals had volunteered to help PHA build this effort and have collaborated to put forth a research statement to address the most critical questions in this area. Our research has begun, and I know we will be making a big difference in helping many more people who live with this disease."

EMPOWERING HEROES THROUGH EDUCATION AND INFORMATION

In a disease as rare as PH, it is up to the stakeholders to ensure that the latest information reaches practitioners. Providing education for healthcare professionals is one of the best ways PHA can help spread knowledge about the treatment and care of PH.

PHA Medical Education On-Demand

PHA Medical Education On-Demand is a program that has consistently grown throughout the seven years of the PHA Medical Education Fund. Supported through unrestricted educational grants, several thousand healthcare professionals participated in locally requested *On-Demand* programs in 2015 on topics ranging from the screening, diagnosis and treatment of PH; to how to integrate guidelines and clinical trial evidence into practice; to PAH and connective tissue diseases; to cardiac imaging and others – 11 available topics in all. In 2015, 50 of these in-person events took place and PHA added two new talks to the curriculum as interest in *On-Demand* continues to grow.

LOOKING BACK

In 2005, PHA began organizing in-person medical education events for the first time. This initial program was very successful, and after several years, it was clear that there was more interest and need for this type of programming among the medical community. Today, PHA hosts 60 in-person medical education events each year through the *PHA Medical Education On-Demand* and *PHA Preceptorship* programs.

PHA Preceptorship

The *PHA Preceptorship* program offers day-long, direct instruction on state-of-the-art PH diagnosis and management for physicians and other healthcare professionals. Hosted by nationally recognized PH centers, these interactive preceptorships build links among community PH specialists, non-specialists and clinicians at established PH centers, creating new avenues for communication and care coordination of these complex patients.



“It’s rare for this type of medical education to come out of a patient association, but it is also very important. It has been a game changer in the field, and I’m proud to be working on this with PHA.”

– Vallerie McLaughlin, MD

PHA Online University

PHA Online University is an online hub for reliable and up-to-date information about PH for physicians, clinicians and allied health professionals. Medical professionals can earn free CME credits/CEUs; find valuable resources such as information on treatment, research programs, abstracts and presentations from past meetings; and access PHA’s medical journal, *Advances in Pulmonary Hypertension*. In 2015, *PHA Online University* created more than 30 new courses, hosted more than eight webinars, and received more than 160,000 unique website views. In 2015, for the first time ever, *PHA Online University* expanded to include Spanish-language courses to serve medical professionals in Spanish-language countries.

Advances in Pulmonary Hypertension

PHA published the first issue of *Advances in Pulmonary Hypertension*, the world’s first PH-specific medical journal, in 2002. In 2015, *Advances* continues to reach more than 40,000 cardiologists, pulmonologists and rheumatologists internationally each quarter with issues including the following topics:

- Prognostication and Risk Prediction for Pulmonary Hypertension
- Evaluation and Management of PH and Right Heart Dysfunction in the ICU
- New Treatments and Targets in Pulmonary Hypertension
- New Approaches for Managing Pulmonary Arterial Hypertension

As a resource that has been publishing continuously for 13 years, *Advances* is aiding in the proliferation of medical knowledge and expanding global PH education on a regular basis.





Empowering the Future of Our Community

As PHA enters our 25th year of building communities and better todays and tomorrows, this annual report celebrates the heroes – people like you – who make our advances in the fight against PH possible.

Jan. 12, 2016, will mark 25 years since Teresa Knazik, Dorothy Olson, Pat Paton and Judy Simpson sat around Pat's kitchen table in Indiantown, Fla., and formed the organization that would become PHA.

Since that time, PHA has built a strong community through which the impossible became possible. From a desire to end isolation in a disease with poor prognosis and no treatments, PHA has consistently taken larger and larger steps to change the trajectory of this disease. Today, we are the accrediting body for the field and are beginning to enroll patients in the related registry. This community that we've built together over the past quarter century is at the core of that success, and we ask you to continue your support as we move forward into the future and ensure the strength of our next 25 years.

PH Care Centers

Since 2000, the field has grown from 100 PH-treating physicians to more than 10,000 PH-treating physicians today. With such tremendous growth, and with a majority of those physicians each treating so few patients, it became apparent that standards needed to be developed to improve the overall quality of care in PH.

From a rough idea, the PH Care Centers (PHCC) Initiative grew to be a fully defined program of accreditation that launched in September 2014. The response to the program was robust, with nearly a dozen centers submitting an application before the end of the year. More than 30 additional centers have completed the complex application and are in various stages of the accreditation process.

“Patients can be assured that centers accredited by PHA are providing a superior level of comprehensive care that is evidence-based in diagnosis and treatment.” — PH Care Centers Patient Advisory Panel

Growing to 26 adult PHA-Accredited Centers of Comprehensive Care (CCCs) and three pediatric CCCs in the first half of 2015, the PHCC network provides patients and interested healthcare professionals alike access to a recognized network of specialists in this field who have demonstrated the ability to appropriately manage patients with pulmonary hypertension.

“PHCC is central to making progress in the research, educational and care-providing spheres of pulmonary hypertension.”

– Michael D. McGoan, MD

Pulmonary Hypertension Association Registry

As the PHCC accreditation program was being developed, an important question emerged – how can we know the program is truly improving quality of care and, equally important, how can we measure it? The answer was clear: we would need to gather data from the accredited centers into a registry.

The PHA Patient Registry (PHAR) will not only provide important metrics on PHCCs, but it will also accelerate the process toward the goal of improved patient care. Accredited centers will receive statistics on their practice patterns, with risk-adjusted comparisons to national averages. In addition, interested researchers with a question that can be answered by the registry will be able to submit their proposal to the registry to further the understanding of PH. PHAR will provide a robust, updated understanding of how PH affects patients' lives, tracking changes in several patient-reported outcomes long-term.

Six accredited clinical sites agreed to pilot the work of the registry committees and begin contribution to the registry, and in summer 2015, the first patient was enrolled in the program, with many more soon to follow. In PHA's 25th year in 2016, the sophistication and data in the registry will continue to grow.

PHA's Research Program

“By 1999, PHA had developed a strong enough community base that we thought we could begin to raise money for research. We met with Bruce Brundage, the only doctor on the Board of Trustees at the time, and he recommended that we start with a young researcher program. He told us that if we started there, we would be able to bring people in on the front end of their careers and they would stay in the field for the rest of their careers. I am so pleased to say that we have been able to do that.” – Judy Simpson

For more than a decade, research has been a key component of PHA's mission. Since adding on our fifth funding focus area and second NIH collaboration in 2014, PVDOMICS, the PHA Research Program continues to grow with the interest of both medical and patient constituents. Through collaborative granting opportunities, in 2015 PHA facilitated nearly \$1,500,000 towards PH research thanks to the generous contributions of patient, family and healthcare professional constituents through special events, corporate foundations and individual donations. The PHA Research Program

provides important funding to investigators interested in PH, keeping them in the field long term. For example, the NHLBI K08/K23 Supplemental Award program provides one new grant per year to investigators with a track record in PH interested in continuing their academic careers in PH. All of the 12 previous grantees have continued their academic careers and continue to specialize in PH.

To date, PHA has committed more than \$17,000,000 to PH research, including expanding and funding the world's first pediatric PH research program.

“PHA's community of patients, caregivers, medical professionals and industry representatives allows us to make connections between patients and the resources they need to fight this disease. As we grow in numbers and programs, we expand the possibilities for better, longer lives for all PH patients.” – Steve White

Looking Forward

We don't know when or where a cure for pulmonary hypertension will come, but at PHA we believe in empowering individuals and organizations around the world to be involved, as much or as little as health and interest allow, in the path to get us there. From our humble beginnings, PHA has grown and expanded in each of our 24 years. Today, PHA has more than 16,000 members and supporters around the world, and the number of global PH associations has gone from just one – PHA in 1991 – to more than 70 independent associations. Our grassroots and chapter event organizers have continued their hard work raising funds and awareness in this fight with more than 120 events in 2015. Through the efforts of our community all over the world, you are helping us empower the next generation of PH heroes.



THE PULMONARY HYPERTENSION ASSOCIATION, INC.

STATEMENTS OF FINANCIAL POSITION

DECEMBER 31, 2014 AND 2013

	2014	2013
ASSETS		
CURRENT ASSETS		
Cash and cash equivalents	\$ 4,557,332	\$ 4,585,354
Contributions receivable	924,378	1,517,000
Prepaid expenses	128,033	92,109
Total current assets	5,609,743	6,194,463
RESTRICTED CASH	140,615	140,615
INVESTMENTS - at fair value	6,368,565	5,710,022
ENDOWED INVESTMENTS AND ACCUMULATED EARNINGS - at fair value	5,138,914	4,539,216
EQUIPMENT AND LEASEHOLD IMPROVEMENTS, NET OF ACCUMULATED DEPRECIATION	25,978	10,316
OTHER ASSETS	51,410	57,603
Total assets	\$ 17,335,225	\$ 16,652,235
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts payable	\$ 82,919	\$ 96,928
Accrued expenses	303,731	57,666
Grants payable - current portion	238,250	341,250
Total current liabilities	624,900	495,844
GRANTS PAYABLE - NON CURRENT PORTION	606,250	473,220
DEFERRED RENT	154,900	153,717
Total liabilities	1,386,050	1,122,781
NET ASSETS		
Unrestricted		
Available for operations	5,660,095	5,224,110
Designated for contingencies	250,000	250,000
Designated for equipment and leasehold improvements	25,978	10,316
Total unrestricted	5,936,073	5,484,426
Temporarily restricted	8,137,627	8,169,553
Permanently restricted	1,875,475	1,875,475
Total net assets	15,949,175	15,529,454
Total liabilities and net assets	\$ 17,335,225	\$ 16,652,235

THE PULMONARY HYPERTENSION ASSOCIATION, INC.

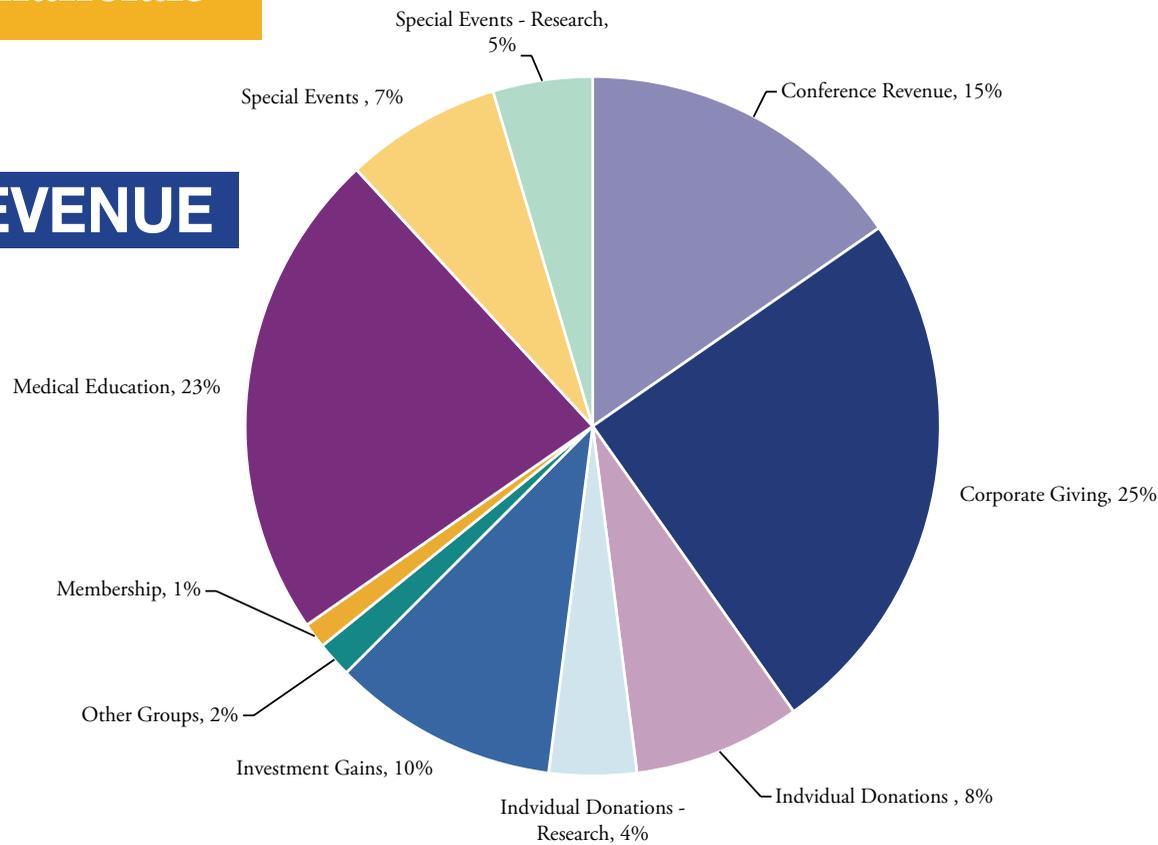
STATEMENTS OF ACTIVITIES

YEARS ENDED DECEMBER 31, 2014 AND 2013

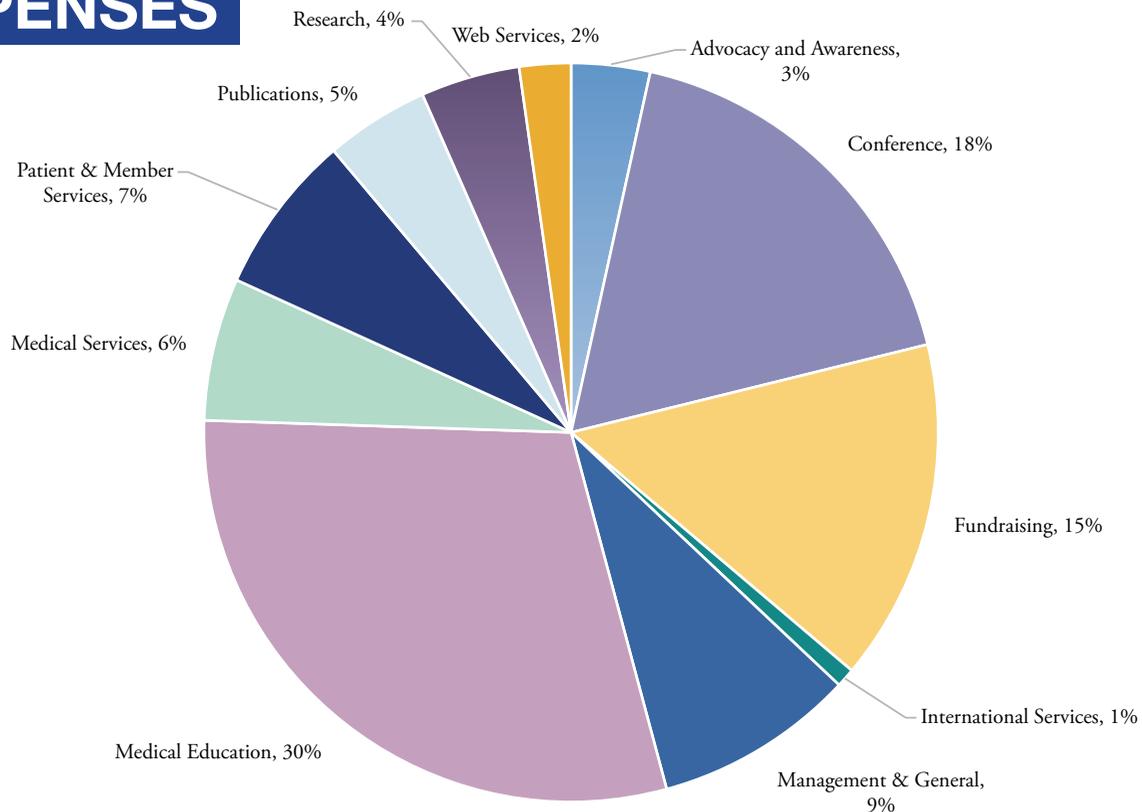
	2014				2013			
	Unrestricted	Temporarily Restricted	Permanently Restricted	Total	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
REVENUE AND SUPPORT								
Contributions	\$ 4,311,491	\$ 109,545	\$ -	\$ 4,421,036	\$ 4,765,038	\$ 3,145,874	\$ -	\$ 7,908,912
Contributions - research	-	3,895,526	-	3,895,526	-	845,222	-	845,222
In-kind donations	1,540	-	-	1,540	14,762	68,075	-	82,837
Conference	260,123	-	-	260,123	66,625	-	-	66,625
Grants	62,100	-	-	62,100	84,692	-	-	84,692
Membership dues	255,046	-	-	255,046	257,184	-	-	257,184
Merchandise sales	41,239	-	-	41,239	52,477	-	-	52,477
Investment income	750,586	313,952	-	1,064,538	579,919	510,896	-	1,090,815
Other	119,735	-	-	119,735	76	-	-	76
Releases from restrictions	4,350,949	(4,350,949)	-	-	2,352,532	(2,352,532)	-	-
Total revenue and support	10,152,809	(31,926)	-	10,120,883	8,171,305	2,217,535	-	10,388,840
EXPENSES								
Program services	7,392,138	-	-	7,392,138	6,768,488	-	-	6,768,488
Management and general	856,446	-	-	856,446	739,597	-	-	739,597
Fund raising	1,452,578	-	-	1,452,578	477,806	-	-	477,806
Total expenses	9,701,162	-	-	9,701,162	7,985,891	-	-	7,985,891
CHANGE IN NET ASSETS	451,647	(31,926)	-	419,721	185,414	2,217,535	-	2,402,949
NET ASSETS								
Beginning of year	5,484,426	8,169,553	1,875,475	15,529,454	5,299,012	5,952,018	1,875,475	13,126,505
End of year	\$ 5,936,073	\$ 8,137,627	\$ 1,875,475	\$ 15,949,175	\$ 5,484,426	\$ 8,169,553	\$ 1,875,475	\$ 15,529,454

Excerpts Only: Full audit available at www.PHAssociation.org/AboutPHA/Financials

REVENUE



EXPENSES



Thank You For Your Support

The financial support of individuals, foundations, organizations and corporations make it possible for PHA to fund research, provide support and education, raise awareness of PH and 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 and be recognized as a “top-rated nonprofit” by GreatNonprofits.

Additionally, for 12 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.

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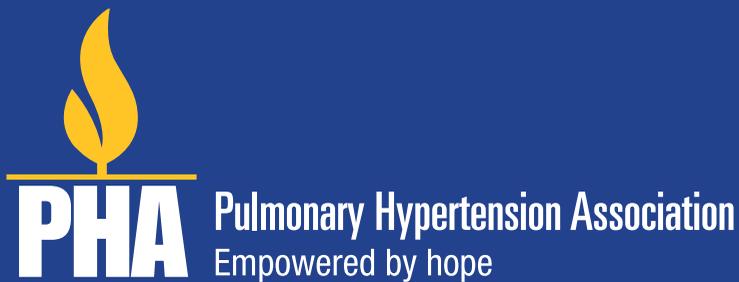
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801 Roeder Road, Ste. 1000
Silver Spring, MD 20910
Patient-to-Patient Support Line: 1-800-748-7274

www.PHAssociation.org
[#Heart2CurePH](https://twitter.com/Heart2CurePH)

The mission of the Pulmonary Hypertension Association is to extend and improve the lives of those affected by pulmonary hypertension.

PHA's vision is a world without PH, empowered by hope.