



Pulmonary Hypertension Association  
Empowered by hope

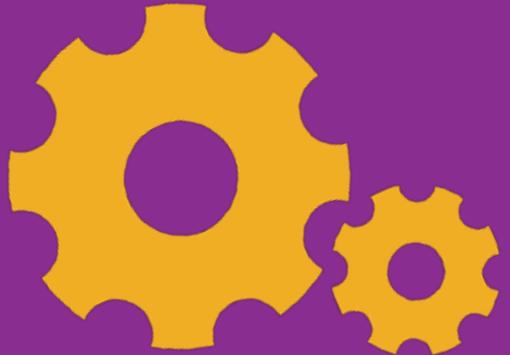


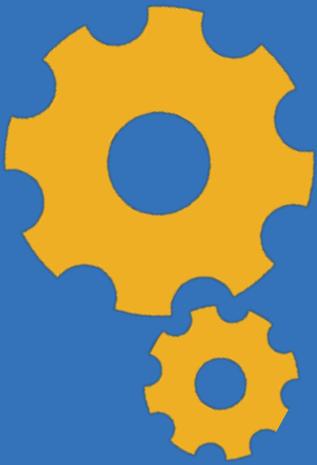
ANNUAL REPORT 2014

# hope

IN MOTION

THE POWER OF { - i n g }





Dear PHriend,

What a year.

2014 has been an extraordinary year for the PH community. I'm sure we've said it before, but this year it seems even more true. One of the most exciting things about being part of a community that is growing and changing as rapidly as the PHA is just how far we can go in one year.

- As 2013 came to a close, we were just beginning to lay out the structure for reviewing and evaluating PHA's Accredited Centers of Care, a development that we believed would change the future of PH care. Today, six centers have been accredited and dozens more have applied for accreditation as we work to ensure PH patients and caregivers know where to turn to get the best treatment.
- At the end of last year, we had just launched our Specialty Pharmacy Advisory Board with the goal of reducing the number of delivery issues patients faced getting their medications and aiding a swift resolution when those challenges arose. Today, that feedback form has been use hundreds of times and is viewed as a model for other disease states outside of our own community.
- Last November, we at PHA were deep in the throes of planning our 2014 International PH Conference and Scientific Sessions, the only gathering of PH patients, caregivers and medical professionals of its kind. Today, we are remembering the education, connection and support that took place at our largest and most successful Conference to date.

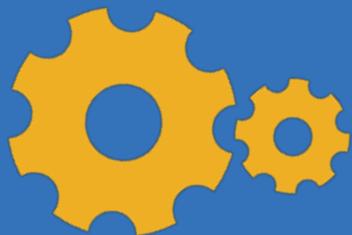
One year ago we were celebrating all this community had accomplished and dreaming of what was on the horizon. Today, we are planning for an even brighter future.

We invite you to read the rest of this annual report and see more of our PHAmily's achievements over the past year and join us as we build hope for the future.

Together for a cure,

Steve White  
Chair, Board of Trustees

Rino Aldrighetti  
President



## educat{ing}



Education is one of the most important tools at our disposal in the fight against PH, empowering patients in our community to learn more about this disease and supporting a new era of doctors as they learn the latest in PH treatments and care. In 2014, PHA's educational resources and initiatives united and advanced our common cause.

In June, more than **1,500** community members from **30** countries gathered together in Indianapolis, Ind., for the largest *International PH Conference and Scientific Sessions* PHA has ever hosted. Doctors and patients alike benefited from the **50+** breakout sessions and **96** research posters featured at Conference.

The learning continued in the fall with *PHA On the Road: PH Patient and Families Education Forums* in Houston, Texas, and San Diego, Calif. These full-day regional education forums allowed more than **500** patients and caregivers to hear from leading medical experts on a variety of topics right in their backyards. For medical professionals, our *PHA On-Demand* and *Preceptorship* programs hosted **60** in-person medical education events to provide doctors and nurses with the most up-to-date information on PH treatment and care.

For those who couldn't attend these in-person opportunities, or who prefer to learn about PH from the comfort of their own homes, *PHA Classroom* and *PHA Online University* kept the patient and medical education going all year. With dozens of new courses and webinars, thousands of people have benefited from these educational hubs.

"I have learned so much today as well as met so many people that are going to be a huge part of my support group."  
—An *On the Road* Houston attendee

## support{ing}

At our founding in 1991, our leaders' sought to end the isolation so often felt by patients and caregivers dealing with PH. At that first meeting those pioneers agreed they would do whatever they could to connect PHers across the country and world with each other as they joined forces for a better quality of life and to fight for a cure. That first meeting at a kitchen table in Florida was, in essence, the first support group meeting and, since that time, PHA has worked hard to keep that vision of connection alive.

More than **22** years later, PHA's **245+** support groups across the United States held more than **600** meetings in 2014. From education and lifestyle tips to camaraderie and support, these meetings are at the core of the PH community.



Support groups end isolation and bring patients and families together, but PHA recognizes that in-person meetings aren't accessible to everyone, which is why PHA ensures that these opportunities for connection are available in other ways as well. From our telephone support groups to our Patient-to-Patient Support Line, PHfriends mentors and our vibrant online communities of more than **10,000**, PHA helped bring connection and support to thousands of PH patients and their families across the country and around the globe in 2014.

"[PHA means] Being part of an amazing community devoted to educating, supporting and caring for each other. It means knowing others fight this battle hoping victory comes in the form of a cure."

## advocat{ing}



In 2014, PHA received an once-in-a-lifetime opportunity. Out of hundreds of applications, the pulmonary arterial hypertension community was one of only **16** chosen to meet with the Food and Drug Administration (FDA) and share patient perspectives on available treatments and future drug development. PHA spread word of this opportunity far and wide, including providing a bus for patients from New York and Philadelphia. More than **350** patients, caregivers and others with a stake in this disease participated in the conversations with FDA on May 13.



“As long as we keep our message clear, and continue to be honest about our experiences with each other and with those who can make a difference, it is us, the patients, and PHA, who will lead the charge to our better tomorrow.”

Each year, PHA expands the scope of our legislative agenda and the way we work with partner organizations to achieve it. This year’s priorities included increased funding for the National Institutes of Health, the *National Pediatric Networks Act*, which was passed into law and the *Patients’ Access to Treatment Act* which is currently one of the most-cosponsored bills in Congress. To advance our goals we worked closely with Women in Government, Rally for Medical Research, American Thoracic Society, American Association of Respiratory Care, and many others.

## rais{ing} awareness

Raising awareness about PH is key to winning the fight against this disease for our patients and their families. The cornerstone to our success lies in waking up the world to what PH is; the more the world outside our community understands, the farther we can go.

PHA’s grassroots media campaign (formerly PHAware) is now called the Media Action Network. The name change is part of an exciting new opportunity to launch PHAware.org a new initiative that will serve as the megaphone to bring PH from rare to everywhere. From our public service announcements (PSAs), which went out to **11,000** TV and radio stations across the country, to celebrities tweeting about the cause and helping us reach **3.75** million people on its launch day alone, the PHAware campaign has created an unprecedented media reach for PH — and this is just the beginning.



This year also saw a huge expansion of the *Early Diagnosis Campaign: Sometimes It’s PH*. With five active committees and **36** endorsements, including the American Public Health Association and the American Association for Respiratory Care, the campaign is committed to reducing the delay between symptom onset and diagnosis for all PH patients.

The events PHA and grassroots event organizers host each year help local communities learn about this disease – we are educators and advocates, telling the world about PH. In 2014 more than **70** events took place across the country, raising money and awareness. Adding its voice to our shared cause, Team PHenomenal Hope competed in the Race Across America, a nonstop **3,000**-mile cycling competition, to raise PH awareness and funds to fight the disease. Countless people from around the world learned about PH from these amazing efforts and joined our PHamily to fight back.

“Getting the word ‘out there’ about PH is the most rewarding thing I have ever done, and I don’t intend to stop.”



The fight against PH takes place on many fronts, but one of the clearest ways to reach our ultimate goal is through investments in research. Twenty years ago there were no FDA-approved treatments for PH, but today we have **12**, with three released at the end of 2013 alone. The only way to continue this fast pace of treatment changes is to grow research programs even faster.

To date, PHA has committed more than **\$14,000,000** through five independently reviewed, cutting-edge research programs and supported more than **60** clinicians. Through this hard work, we know that we are getting closer to our ultimate goal, a cure.

“Compared to other diseases, such as cancer and stroke, pulmonary hypertension receives less attention and therefore the work of the PHA to support research is critical to improve outcomes for patients.”

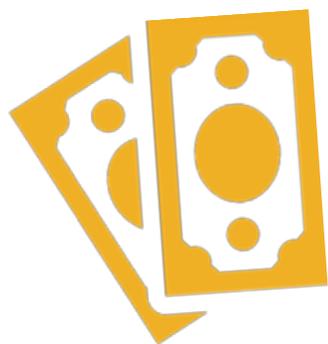
PH does not take a break, and neither does PHA. We made significant gains in 2014, but we're not done yet. PH patients deserve the best quality of care possible, and to that end, some of PHA's biggest accomplishments come from our vision for the future of patient care. PHA's Specialty Pharmacy Advisory Board and feedback form and Pulmonary Hypertension Care Centers seek to ensure that patients receive the best medical care and enjoy uninterrupted access to their medication.

Being a hub for concerns in the PH community, we at PHA began hearing stories of patients who were experiencing delays or inconsistencies receiving their life sustaining medications. Realizing that this was an issue that needed an answer, PHA worked to put in place the Specialty Pharmacy feedback form — a safe and secure way for patients and caregivers to address these issues, and also offer praise, directly to specialty pharmacies. This cutting-edge model has already seen more than **200** submissions and will continue to change the way patients and caregivers interact with their specialty pharmacies. With a disease like PH, medication delivery should never be in question.

In a field that has grown from **100** treating physicians to **10,000** treating physicians in just a decade, PHA and our medical leadership recognized that patients needed a way to identify where they could go for the best treatment possible. In 2014, PHA began accrediting PH Care Centers to make sure patients and families know where to turn when they are dealt this diagnosis. The last thing a PH patient needs is confusion and substandard care. So far, six centers have been accredited and dozens of applications have come in for the next wave of accreditation. These advancements will make a huge difference for patients, caregivers and medical professionals as we move forward.



# financials



PHA relies on supporters like you to fund these programs and further our mission. For this reason, we strive to be completely transparent about where your money goes when you give to PHA. In 2014, for the 11th consecutive year, PHA received a Four Star rating from Charity Navigator and continued its ranking as a Top-Rated Nonprofit by GreatNonprofits.

Additionally, PHA is recognized as a Silver Participant in GuideStar Exchange and as a member of the Better Business Bureau Wise Giving Alliance. Please see this snapshot of PHA's 2012 financials or visit [www.PHAassociation.org/AboutPHA/Financials](http://www.PHAassociation.org/AboutPHA/Financials) to see more, including PHA's 2013 financial information, so you can continue to have confidence in your gift to PHA. Every dollar you invest in PHA is used to make a difference in the lives of all people affected by this disease.

THE PULMONARY HYPERTENSION ASSOCIATION, INC.  
STATEMENTS OF ACTIVITIES  
YEARS ENDED DECEMBER 31, 2012 AND 2011

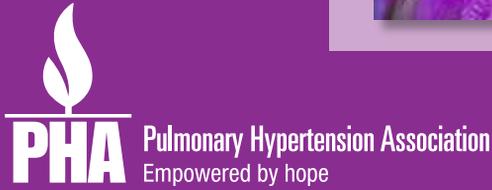
	2012				2011			
	Unrestricted	Temporarily Restricted	Permanently Restricted	Total	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
<b>REVENUE AND SUPPORT</b>								
Contributions	\$ 3,274,356	\$ 1,786,197	\$ -	\$ 5,060,553	\$ 4,780,529	\$ 1,461,276	\$ -	\$ 6,241,805
Contributions - research	-	849,567	-	849,567	-	1,183,303	-	1,183,303
In-kind donations	47,847	19,812	-	67,659	48,033	54,824	-	102,857
Conference	1,069,316	-	-	1,069,316	35,521	551,500	-	587,021
Grants	174,663	-	-	174,663	251,500	-	-	251,500
Membership dues	238,625	-	-	238,625	252,498	-	-	252,498
Merchandise sales	62,733	-	-	62,733	49,191	-	-	49,191
Investment income	389,299	569,594	-	958,893	166,437	66,334	-	232,771
Releases from restrictions	2,499,682	(2,499,682)	-	-	501,903	(501,903)	-	-
Total revenue and support	7,756,521	725,488	-	8,482,009	6,085,612	2,815,334	-	8,900,946
<b>EXPENSES</b>								
Program services	6,970,690	-	-	6,970,690	6,740,255	-	-	6,740,255
Management and general	795,010	-	-	795,010	659,666	-	-	659,666
Fund raising	442,757	-	-	442,757	394,858	-	-	394,858
Total expenses	8,208,457	-	-	8,208,457	7,794,779	-	-	7,794,779
CHANGE IN NET ASSETS	(451,936)	725,488	-	273,552	(1,709,167)	2,815,334	-	1,106,167
<b>NET ASSETS</b>								
Beginning of year	5,750,948	5,226,530	1,875,475	12,852,953	7,460,115	2,411,196	1,875,475	11,746,786
End of year	\$ 5,299,012	\$ 5,952,018	\$ 1,875,475	\$ 13,126,505	\$ 5,750,948	\$ 5,226,530	\$ 1,875,475	\$ 12,852,953

## THE PULMONARY HYPERTENSION ASSOCIATION, INC.

### STATEMENTS OF FINANCIAL POSITION

DECEMBER 31, 2012 AND 2011

	2012	2011
<b>ASSETS</b>		
<b>CURRENT ASSETS</b>		
Cash and cash equivalents	\$ 4,369,857	\$ 3,642,752
Contributions receivable	424,954	2,422,465
Prepaid expenses	148,280	11,091
Total current assets	4,943,091	6,076,308
RESTRICTED CASH	117,368	599,889
INVESTMENTS - at fair value	5,498,162	4,796,300
ENDOWED INVESTMENTS AND ACCUMULATED EARNINGS - at fair value	3,823,711	2,786,102
EQUIPMENT AND LEASEHOLD IMPROVEMENTS, NET OF ACCUMULATED DEPRECIATION	14,206	23,587
OTHER ASSETS	63,217	84,215
Total assets	\$ 14,459,755	\$ 14,366,401
<b>LIABILITIES AND NET ASSETS</b>		
<b>CURRENT LIABILITIES</b>		
Accounts payable	\$ 325,465	\$ 489,756
Accrued expenses	57,666	39,179
Grants payable - current portion	306,250	349,124
Total current liabilities	689,381	878,059
GRANTS PAYABLE - NON CURRENT PORTION	500,000	521,374
DEFERRED RENT	143,869	114,015
Total liabilities	1,333,250	1,513,448
<b>NET ASSETS</b>		
Unrestricted		
Available for operations	5,039,758	5,482,771
Designated for contingencies	245,048	244,590
Designated for equipment and leasehold improvements	14,206	23,587
Total unrestricted	5,299,012	5,750,948
Temporarily restricted	5,952,018	5,226,530
Permanently restricted	1,875,475	1,875,475
Total net assets	13,126,505	12,852,953
Total liabilities and net assets	\$ 14,459,755	\$ 14,366,401



801 Roeder Road, Suite 1000

Silver Spring, MD 20910

301-565-3004 (t) | 301-565-3994 (f)

Patient-to-Patient Support Line: 800-748-7274

[www.PHAssociation.org](http://www.PHAssociation.org)

