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# 2003 Annual Report



Pulmonary Hypertension Association

*The **mission** of the Pulmonary Hypertension Association is to seek a **cure**, provide **hope**, support and education, promote **awareness**, and **advocate** for the pulmonary hypertension **community**.*

# Fulfilling Our Commitment



In the first issue of this year's *Pathlight*, I promised that PHA would increase our communication with you, our members and friends.

We have done what we promised.

Besides an expanded *Pathlight*, members have received *Persistent Voices*, a new version of the *Understanding Pulmonary Hypertension* CD-ROM, materials for our new *PH Aware* media campaign and a PH Awareness

Month mailing offering posters and awareness kits for those ready and willing to use them. Tens of thousands of doctors and many nurses are being educated through quarterly mailings of *Advances in Pulmonary Hypertension*, PHA's medical journal. The amount of information on our website, [www.phassociation.org](http://www.phassociation.org), is growing by leaps and bounds.

By informing you, the people who care most about the struggle against this illness, and by providing opportunities for those who want and are able to participate, we are building our community of hope into a movement that is making a true difference.

PH may be a rare illness but our voice has become louder in 2003. With your continued help and support, our message will be heard, and more people will join us in the fight against PH.

**Thank you** for all that you are doing and will do to help overcome this illness.

Sincerely,

A handwritten signature in blue ink that reads "Bruce Brundage". The signature is written in a cursive, flowing style.

Bruce Brundage, MD  
President

This report is a testament to this year's extraordinary advancement and growth in the struggle against pulmonary hypertension.

It is hard to believe how far we've come.

Fourteen years ago, the entire extent of the PH community's organization was four women in Florida. They had a dream that eventually became the Pulmonary Hypertension Association.

Less than five years ago - in 1999 - PHA was secure enough in its future to open a small office and add its first staff person, a part-time executive director.

Moving as quickly as our finances allowed, PHA built our programs and our research fund. By 2001, only two years ago, we began to convert a small part-time staff to full time employees to meet PHA's tremendous growth in opportunities and expectations.

PHA has always been an organization of patients, family members and medical professionals. Now, our growth is allowing us to sharpen our activities and services to each segment. As our individual parts strengthen in the fight against PH, so does the whole.

I hope you will see in this report that PHA has come a long way, very quickly. We also know we have much, much more to do before we can happily close our doors with the words "we did what we came to do."

With vision, focus, hard work and the support of members and friends like you, we cannot fail.

Sincerely,



Rino Aldrighetti  
Executive Director



# Putting PH on the "Medical Map"

**Outreach:** This year, the Pulmonary Hypertension Association (PHA) expanded its presence at medical conferences, hosting booths at the American Thoracic Society, American College of Chest Physicians, American Association of Critical Care Nurses and the Infusion Nurses Society, and the 3<sup>rd</sup> International Pulmonary Hypertension Symposium in Venice.

Thousands of doctors and nurses requested and received additional information from PHA...1,000 at the Critical Care Nurses meeting alone. Most importantly, many medical presentations were made by PHA's Scientific Leadership Council.

PHA was also pleased to co-sponsor the Tri-State Regional PH Educational Meeting in Cincinnati and the California PH Forum, an event organized by patients and family members. We will also be participating in the Florida Pulmonary Hypertension Symposium.

**Education:** In 2002, PHA launched *Advances in Pulmonary Hypertension*, the first and only medical journal devoted to pulmonary hypertension (PH). In 2003, the journal began quarterly publication. It is sent to all cardiologists, pulmonologists and rheumatologists in the United States and many foreign specialists and PH nurses - a circulation of 31,000. In addition, primary care physicians and patients are encouraged to read or print the journal from the website.

**Leadership:** PHA's Scientific Leadership Council (SLC) provides active leadership in the medical arena by setting the research agenda, educating other medical practitioners, and advocating for additional research funding. In 2003, the SLC wrote a new Consensus Statement for transplant, applied for funding to add Scientific Sessions to PHA's upcoming Conference 2004, supervised the publication of the medical journal, met to discuss multi-center research projects and much more.

**Professional resources:** Allied healthcare professionals - nurses, pharmacists and respiratory therapists - are key to good treatment for PH patients.

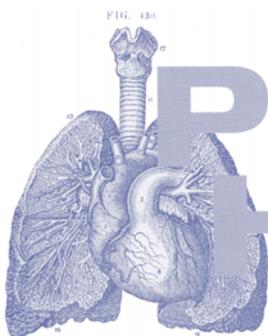
PHA has created the professional association PH Resource Network within PHA to provide support and education for nurses and others. In the Spring of 2003, over 60 medical professionals attended PH Resource Network's first Care Summit. In addition to two days of educational sessions and networking,

the Summit offered planning time for the peer-led group. Three committees (strategic planning, education and membership) are in place, and membership in the group is expected to reach 200 by 2004.

A similar professional association within PHA for physicians and researchers is targeted for a 2004 launch.

As more treatments become available, it is critical that medical education and awareness be expanded. The more doctors know about symptoms and treatments, the earlier diagnosis will be achieved and better patient care implemented. PHA has taken this challenge head on and is making a huge difference.

*Michael McGoan, M.D.  
Mayo Clinic - Rochester  
Chair, PHA Scientific Leadership Council*



## Advances in Pulmonary Hypertension

Official Journal of the Pulmonary Hypertension Association

Since PHA began fundraising for research in 1999, ten grants have been awarded and almost \$1,500,000 has been raised. In 2003 alone, almost \$400,000 has been raised for the research agenda. PHA's research funds support our two major research funding programs, with new awards granted annually:

### **Young Researcher Fellowships -**

These two-year, \$70,000 grants are designed to attract researchers at the front end of their careers to an interest in pulmonary hypertension research. Nine fellowships have been granted since 2000. The Young Researchers are working at some of the top universities in the country, including Columbia; Harvard; Johns Hopkins; Stanford; University of Colorado, Denver; and University of California, San Diego.

### **Mentored Clinical Research**

**(K08) Program** - These grants are the result of a cooperative agreement with the National Heart, Lung and Blood Institute (NHLBI) within the National Institutes of Health (NIH). PHA is working with this premier research support organization to jointly fund five of these five-year grants. One new fellowship is being awarded per year, beginning in February of 2003. The first award was made to Reda Girgis, MD, of Johns Hopkins University School of Medicine.

When the cycle is fully mature, PHA's annual commitment for this research program will be over \$300,000 per year. NHLBI has committed to funding approximately \$500,000 per year and is absorbing all administrative costs. This means our supporters, with \$300,000 in annual giving, will be leveraging a total of \$800,000 in new PH research each year.

At the suggestion of NHLBI, this program has been expanded beginning in 2004 to include applications for Mentored Patient-Oriented Research in Pulmonary Hypertension (K23 awards). As PHA increases research funding, this opens the future possibility of funding both a K08 and a K23 award annually.

Bringing new researchers into the field enriches the pulmonary hypertension research community with bright new thinking. Partnering with the National Heart, Lung, and Blood Institute brings great credibility to PHA's research program. The organization is doing the right things and deserves to be supported.

*Lewis J. Rubin, M.D.,  
Research Committee Chair  
PHA Scientific Leadership Council*

## Patient-to-Patient Telephone helpline: 1-800-748-7274

The helpline is one of PHA's most valuable resources. Currently, it is operating with 15

At 1:30 this morning, we got a call on the PHA Helpline. It was a nurse. She was very agitated. The Emergency Room doctor had a PH patient who had come in unconscious. The patient was on Flolan and the doctor didn't know anything about the drug. The nurse had found us on the PHA website. We told her that Flolan could not be discontinued and referred them to the Glaxo Flolan support line.

Pat Paton  
PHA Helpline volunteer

volunteers who answer an average of 12 calls a day. Fourteen of the fifteen are patients. All have lived with the illness at least three years. Six of the volunteers are also nurses. The fact that our helpline is answered by patients who are receiving the calls at their homes makes it possible for PHA to offer a unique and valued service to people struggling with pulmonary hypertension.

## PHA Support Groups: An Expanding Network

In 1990, PHA was founded out of a single support group. In 2001, PHA had 44 support groups. By the third quarter of 2003, the network had grown to over 110. Besides fellowship and help in dealing with the "aloneness" of PH, support groups are providing education on living with PH and many groups are becoming involved in advocacy.

PHA recognizes that servicing a network of 100 support groups is very different from supporting a network of ten or fifteen. Our goal for 2004 is to provide more targeted service to our support groups. To this end, PHA has staffed a new Volunteer Services position that includes responsibility for establishing regular communication with support groups and providing them with the necessary educational

tools as they strive to improve their levels of organization and service to patients.

In mid-2003, PHA sent all support group leaders a 90-minute training video with ideas to help them organize and strengthen their groups. The tape came out of a daylong peer-to-peer training session PHA had organized at Conference 2002.

## Publications

PHA's two newsletters continue to be well-received. The quarterly *Pathlight* grew to 24 pages by September of 2003. Editor Shirley Craig, a PH patient herself, involved more volunteers in the process than ever before. Jerry Wojciechowski, also a PH patient, continues to edit the reformatted *Persistent Voices*.

The third edition of the *Patient's Survival Guide* is being written by Gail Boyer Hayes, with support from a team of patient and medical volunteers, and is expected to be published by the end of 2004. Meanwhile, the 200+ page second edition is hugely popular both with patients and medical professionals.

Daily requests come in for PHA's two brochures, *Pulmonary Hypertension: Helpful Information for Patients and Families* and *PHA Lighting the Path: A Community of Hope*. PHA's educational materials are more heavily distributed than ever before, and PHA is looking to translate them into other languages to reach even more people.

## Online community - [www.phassociation.org](http://www.phassociation.org)

An enhanced version of PHA's website proved its value to the PH community in 2003. Added features such as daily news updates supplied visitors with the latest PH-related information, and a growing online community provided ample opportunities for people to connect with each other. These enhancements are attracting more people to the site each month. In August 2003, the website had between 2,000-4,000 visitors

per day, with a monthly total of over 70,500. With well over 300 messages being posted per week, the message boards are the most heavily trafficked part of the website. Visitors are also spending an increasing amount of time reading PHA's educational pages, including the Frequently Asked Questions, Medical Resources, and 'Learn about PH' sections.

Less than three years after its inception in May of 2000, PHA celebrated the 1,000<sup>th</sup> subscriber to its bi-weekly electronic newsletter *PHA News*, edited by PH patient Sally Maddox. Through increased visibility on the website, the subscription roster grew to over 1,800 between March and October of 2003.

In early 2003, internet support groups began to take shape. Participants in PHA's message boards began to take advantage of PHA's new online "chat" facilities and invited other patients to a weekly live-time electronic discussion. Now, regular chats are being held on PHA's website five days out of the week. PHA is working to establish more volunteer facilitators in order to have one chat each day of the week, and to generate more audience-specific chats. Chats for youth with PH, parents of children with PH, and moderated medical forums to be developed in conjunction with the PH Resource Network are on the agenda for 2004. This will allow us to provide access to, and direct conversation with, medical and patient leaders.

## Creating Awareness

This has been a year of increasing attention on PH. This is not an accident. It is the result of a plan and hard work by PHA and supporters across the country. We are reaching out as never before to media, decision makers, medical professionals, and the general public.

We know that media coverage of the illness leads to great things. Stories have led to awareness about both the disease and the organization, an increase in volunteerism by PHA members, and proper diagnosis and treatment from the medical community for individuals discovering they were previously misdiagnosed. Because news stories make such a difference, PHA focused on generating such coverage throughout the year. We enlisted the help of WNBA star Debbie Black, as well as patients and family members.

The *PH Aware* campaign was launched in July 2003. Combining the tools of a how-to brochure with a CD-ROM on PH, the campaign was designed to help patients tell their story to local

I wanted to do something to educate my community about PH and PHA. So, I decided to send a letter-to-the-editor of my local paper, using PHA's "Take Action" sample letter. It was published and a month later my neighbor saw the article. She also has PH and was amazed that someone else nearby shared this experience. She called Cara Ugolini, PHA's Advocacy & Awareness Manager to find ways she, too, could educate our community.

*Mel Newman*  
PH patient - Hilton Head, SC

media. Through local news stories, more people learn about the disease, and PHA can generate national news coverage. So far, more than 70 volunteers from around the nation have generated stories by visiting newspapers, radio and television stations.

While we work year-round to spread awareness, an all-out effort brings the entire PH community together each Fall. November is PH Awareness Month and the 2003 theme was *Pulmonary Hypertension: The Other High Blood Pressure*. This year's Awareness Month was bigger than ever - with events planned around the country and materials sent directly to each of PHA's 5,000 members to help them spread the word. PHA created Action Kits, posters, public service announcements, press kits, video news releases and much more to help get our message out during November. PHA continues to work with a professional PR firm to distribute public service announcements and video footage to thousands of radio and TV stations across the country.



### Kathleen O'Hara Softball Tournament

Kathleen O'Hara was a young woman who knew she had something more extreme than the asthma she was diagnosed with. By the time her PH was

diagnosed, she was in her late twenties and pregnant. After her death her friends and family created the Kathleen O'Hara Memorial Softball Tournament. The second tournament was held in the Bronx, NY in September 2003.

### Cure PH Houston Golf Tournament and Dinner

The Stibbs family created the first-ever PHA golf event in 1999, two years after their daughter, Emily, was diagnosed with PH. This year, they celebrated their fifth event. During this half decade, they have raised over \$700,000 for PH research.



### Betting on a Cure

Liz Rossi, the mother of a patient, and Donna Samuels, a patient herself, wanted to do something to make a difference. With their husbands' help, the original idea for a cocktail party evolved to "something more fun" - a September day at the races at the Arlington Park, Illinois race track. Their first event generated over \$60,000 for research.



*Through PHA's friends & all things be*

Despite the challenges of t continues to expand to expectations of our comm patient support program During the past five year increased from \$150,000 t has been made possible thr growing number of donors,

It is impossible to detail or people have done this year success in the fight agains just a few of the events tha also broadened awareness

In mid-2003, we release *Special Events FunRaising* mixes a motivational information on organ events, ranging from pizza nights. Fe excellent. The CD- from PHA and considering an e

### "Just Over the Next Horizon" Rochester PHA Gala

In October the second Rochester Gala was held. With Dr. Michael McGoon, his wife Bonnie and PH nurse Cathy Severson among the organizers, the event raised approximately \$40,000. The funds have been dedicated to patient support programs and activities.



### Darby's Drive 'Fore' a Cure



Five-year-old PH patient Darby Hetrick inspired her mom, Christi, and the Delaware-Valley, Pennsylvania support group to host its first annual golf event in April of this year. In addition to generating nearly \$10,000 for PH patient-related activities and research, the event earned incredible media coverage in the Philadelphia press, exceptional results for a first-time event.

### Matters of the Heart Cabaret

The Rocco and Meinert families came together when 14-year-old David Rocco was diagnosed with PH in August of 2002. Less than a year later - in June of 2003 - they hosted a PH benefit show that drew almost 1,000. David's uncle, Broadway performer Tom Rocco, joined with Kim Cea and other friends for a moving evening that (including a raffle for a golf date with Mario Lemieux) raised over \$70,000 for research.

**Matters of the Heart**

Monday, July 14, 2003  
Doors open at 6:30pm.  
North Allegheny High School Auditorium  
10375 Perry Highway • Wexford, PA  
\$25 per ticket

**A cabaret performance**  
starring Pittsburgh native  
and Broadway performer  
**Tom Rocco!**

More than \$5,000 in prizes will be raffled.  
All proceeds from this event benefit Pulmonary Hypertension research on behalf of David Rocco.

With special guest **Kim Cea**  
Featuring Maria Becoates-Bey  
Musical Director Deana Muro  
Director Matt DeLuca

Call 412-571-2656  
for tickets.

Special thanks to Pro King  
Cranberry Township, PA




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# Advocating for Patients

On March 18, 2003, PHA's strong Congressional advocate, Representative Kevin Brady (R-Texas) introduced the PH Research Act of 2003. Once passed, the bill will authorize:

- ⌘ An expansion of PH research at the National Heart, Lung, and Blood Institute
- ⌘ The institution of a PH data system and clearinghouse at NHLBI
- ⌘ The establishment of three "Centers of Excellence" to support:
  - ▶ Basic and clinical research into the cause, diagnosis, early detection, prevention, control and treatment of PH
  - ▶ PH training programs for scientists and health professionals
  - ▶ Continuing education for health professionals on PH
  - ▶ Dissemination of information to the public on PH

In order for the bill to become law, PHA members are making their voices heard in person on Capitol Hill and through a sophisticated web-based system in which PHA has invested. This system provides everything needed to become involved in the democratic process - information on bills, the impact on the PH community and easy access to members of Congress.

Over 1,000 members have contacted their members of Congress. To date, 18 Representatives have co-sponsored the bill, with more expected. PHA is currently arranging to have the bill introduced in the Senate and is working toward committee and floor votes before the end of the term.

In other Hill news, for the second year in a row, PHA was invited to testify before the House Labor-Health and Human Services Appropriations Subcommittee. PHA's testimony was presented

by Anne Caesar, M.D., a practicing physician at Georgetown Medical Center and also a PH patient.

After Dr. Caesar's testimony, the Subcommittee included the following language in their FY2004 Appropriations Report:

*The Committee continues to be interested in pulmonary hypertension, a rare, progressive and fatal disease that predominantly affects women, regardless of age or race. The Committee looks forward to reviewing a report (as requested in the FY03 omnibus appropriations bill) from the CDC outlining the progress that has been made in establishing a pulmonary hypertension awareness campaign focused on the general public and health care providers. Moreover, the Committee encourages CDC to give priority consideration to supporting a cooperative agreement with the pulmonary hypertension community designed to foster greater awareness of the disease.*

Special thanks are owed to Representatives Jesse Jackson, Jr. (D-IL) and Kay Granger (R-TX)

who successfully led support within the House Appropriations Subcommittee for the language quoted above. The support of Congressional leaders and others led to two very productive meetings with leaders at the Centers for Disease Control (CDC). As a result, an entire issue

I've been diagnosed with PH for less than a year. In the last election, I ran for Congress...and lost. Last month, I went to my opponent and asked him to co-sponsor our bill. He agreed and not only did we get a co-sponsor, we got a lot of press in the district describing the illness.

*Linda Pall  
PHA member - Moscow, ID*

of the CDC's widely distributed MMWR Surveillance Reports is being devoted to a new compilation of statistical data on PH.

Thanks also go to the many PHA members developing relationships with their elected officials - through you we are finding many friends and supporters in Congress.

PHA recognizes the importance of working with other groups to pass legislation of importance to our community. This Spring, PHA joined a

coalition to support expanded access to prescription drugs through the Medicare bill. In July, PHA signed onto a letter with 500 health groups urging Congress to increase the NIH budget. The following month, PHA signed onto a letter with the National Coalition for Heart and Stroke Research and the NHLBI Constituency Group supporting the Specter-Harkin-Feinstein amendment to increase funding for NIH. PHA's members used the 'Take Action' section of the website to campaign for these important issues, along with others.

PHA's advocacy work doesn't end with Congress. In 2003, PHA launched a campaign to protect the important option of transplantation for many PH patients.

As a rare disease organization, PHA has always sought to multiply our strength by building partnerships. This year we expanded our cooperation with other health organizations. We are an active member of the National Organization of Rare Diseases (NORD), working with them for a strong federal Office of Rare Diseases. PHA also continues to maintain an excellent working relationship with the Scleroderma Foundation, foreseeing this as a model for developing similar relationships with other associations involved with illnesses that affect our members' lives.

As a founding member of the American Thoracic Society's Public Advisory Roundtable, PHA maintains an ongoing and active role not only with this important medical association but also with eight other patients' associations concerned with lung-related ailments. Judy Simpson, a retired teaching nurse and PH family member is PHA's representative to this group.

In March, the United Network for Organ Sharing (UNOS), the governing body for organ distribution for transplant, began to circulate guidelines that would have shifted the waiting list priorities against PH patients. PHA's Scientific Leadership Council reacted immediately and strongly. A letter was sent to each of UNOS' board members.

The American College of Chest Physicians supported our position, as well, and sent a powerfully worded statement to the UNOS Board. During the September public comment period, PHA organized a

letter-writing campaign and our members sent over 300 separate communications to UNOS. Individual meetings and discussions continue as we move toward the UNOS decision which is expected by the end of the year.

On October 6th, 2003 it will be eight years. I have watched my children grow up. My eldest is now in his second year of college, another is a Senior in High School, and my daughter is now Student Council President in the 8th Grade... I recently celebrated my 43rd birthday and thank God for each and every day.

*Angie Eldam  
Diagnosed with PH: 1990  
Double lung transplant: 1995*

## Building Partnerships

PHA also remains an active participant in the NHLBI's Public Interest Organizations meetings, and has long maintained strong relations with NHLBI. During the past two years, we saw NHLBI's research portfolio for pulmonary hypertension expand by over 50 percent, from \$12 million to over \$19.3 million.

Two years ago, PHA started our Corporate Committee as a way to partner with the companies that serve the PH community on common goals. The 11 corporate members met three times in the last year to map out new ways to increase PH awareness among the general public and medical community. Working in cooperation, PHA's message is reaching a larger audience.

### Corporate Committee Membership

Accredo  
Actelion  
Caremark  
Encysive Pharmaceuticals  
GlaxoSmithKline  
Myogen  
Pfizer  
PhRMA  
The Lash Group  
TheraCom  
United Therapeutics

## 6<sup>th</sup> International PH Conference

This is my third conference and I'm really impressed with the information and networking opportunities. ...each time I attend a conference, I feel more confident about the power I have over my disease and my life. It gives me strength to see the amount of people that are working on this problem and doing everything they can to improve my quality of life. I enjoy getting to know my doctors and nurses on a more personal level, as well as being able to put a face with the researchers and specialists.... Although it is difficult to find that some acquaintances from past conferences have succumbed to PPH, I continue to attend and network in their honor, as well as for myself.

*Christie Breault  
PH patient - Benton, KS*

PHA's 6<sup>th</sup> International Pulmonary Hypertension Conference will be held June 24-27, 2004, at the Hotel Intercontinental in Miami, Florida. Two planning committees are working on the medically led and patient-led sessions, which will be held June 25-27. A new Scientific Session designed specifically for medical professionals and to be held on June 24 (and the morning of June 25) is being added to the Conference. This is a major development and is designed to advance the research agenda and improve patient care.

The planning of the biennial PHA Conference is a huge undertaking, handled almost entirely by volunteers who are recruiting speakers, creating a scholarship fund and promoting the event.

Up-to-date Conference information can be found at [www.phassociation.org/Conference/](http://www.phassociation.org/Conference/)

## Building a Global PH Community

While most of PHA's members are in the U.S., PHA serves people in 45 other nations. At PHA Conferences, we have met with these members and encouraged them to organize local associations to deal with the unique problems in their own countries. We have been told that information sharing and organizational advice are the most valuable things PHA in the U.S. can provide. In response to this need, PHA recently received a three-year grant of \$191,000 from the Medtronic Foundation to further develop our international program. As PHA is better able to act as a hub for information sharing around the world, we expect that patients and their medical professionals will benefit from shared experience and deeper ties.

Our contact with international patients and caregivers has grown rapidly in the last several years. We are in contact with PHAs in the United Kingdom, Japan, Israel and Canadian Provincial Societies, as well as patients groups and individuals in Italy, Ireland, France, Belgium, Portugal, Australia, Chile, Mexico, Brazil, Venezuela, India, Singapore, and the Philippines (among others). Physicians from Canada, France, Italy, Ireland and Germany also serve on our Scientific Leadership Council.

PHA's materials, including the *Patient's Survival Guide*, are increasingly being translated into other languages. The authorized translation of PHA's *Patients Survival Guide* into Japanese was completed in September, and we are working with Portugal, Brazil and Spain toward authorization of Portuguese and Spanish translations. In October, PHA of Japan also became the second PH Association to sign a cooperative agreement with PHA. Other cooperative agreements are under discussion.

I have a meeting with about 20 patients at St. Vincents Hospital on Monday to see if we can get the ball rolling for the group. I will be taking all the information you sent in with me, so they can see what is possible, even though we'd be considerably smaller. It's really great to know you are all there, just an email or website away.

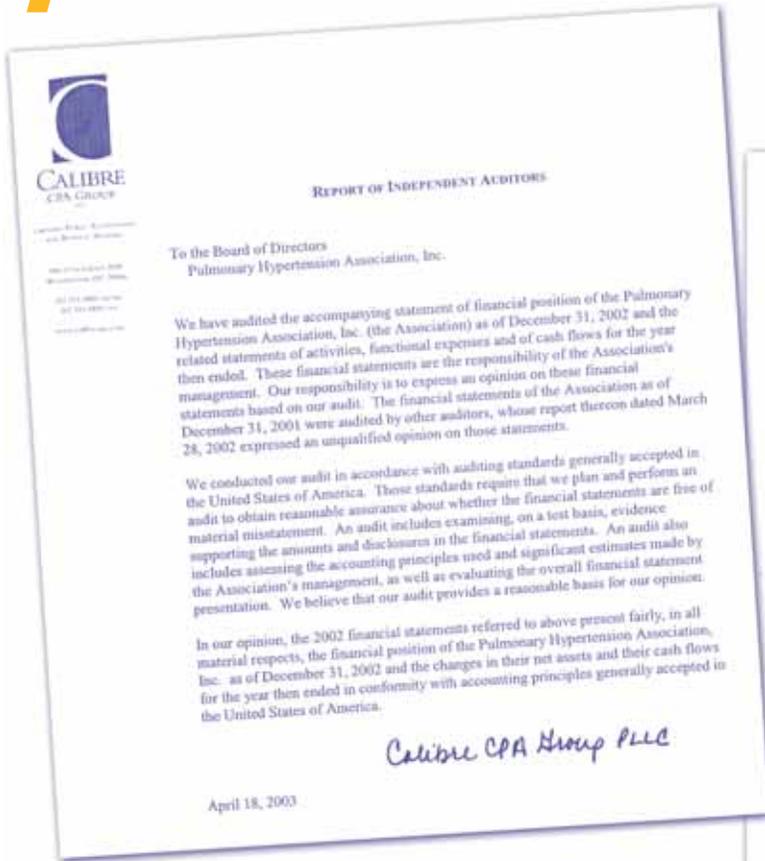
*Jan Bonham  
Australian PH patient*

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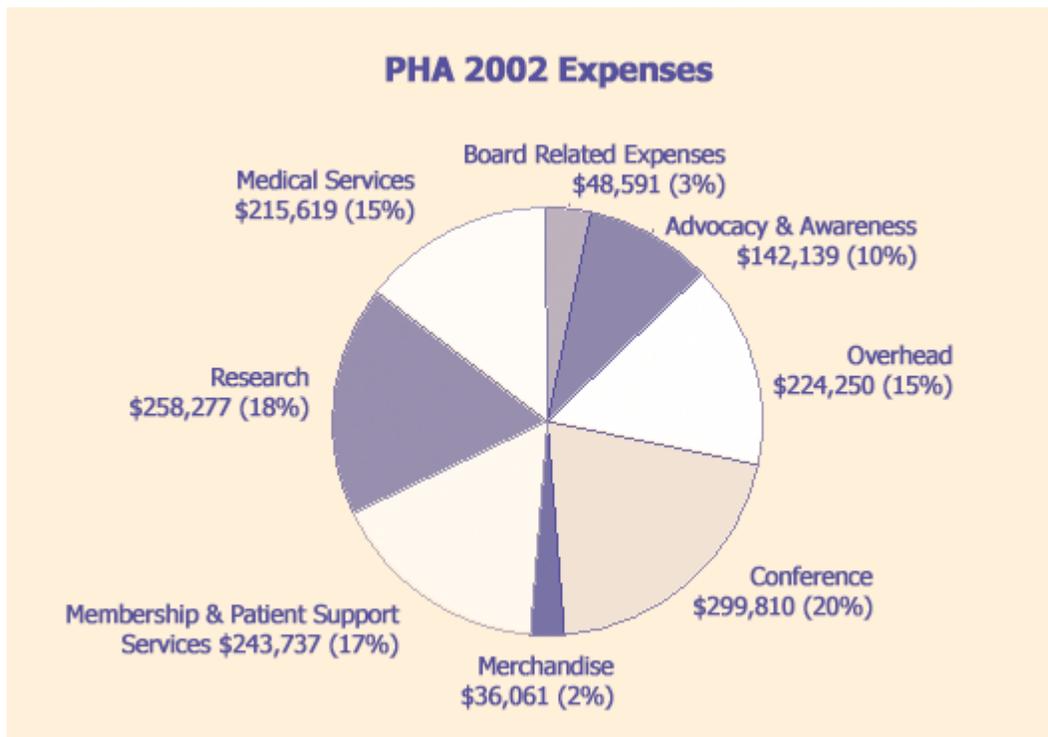
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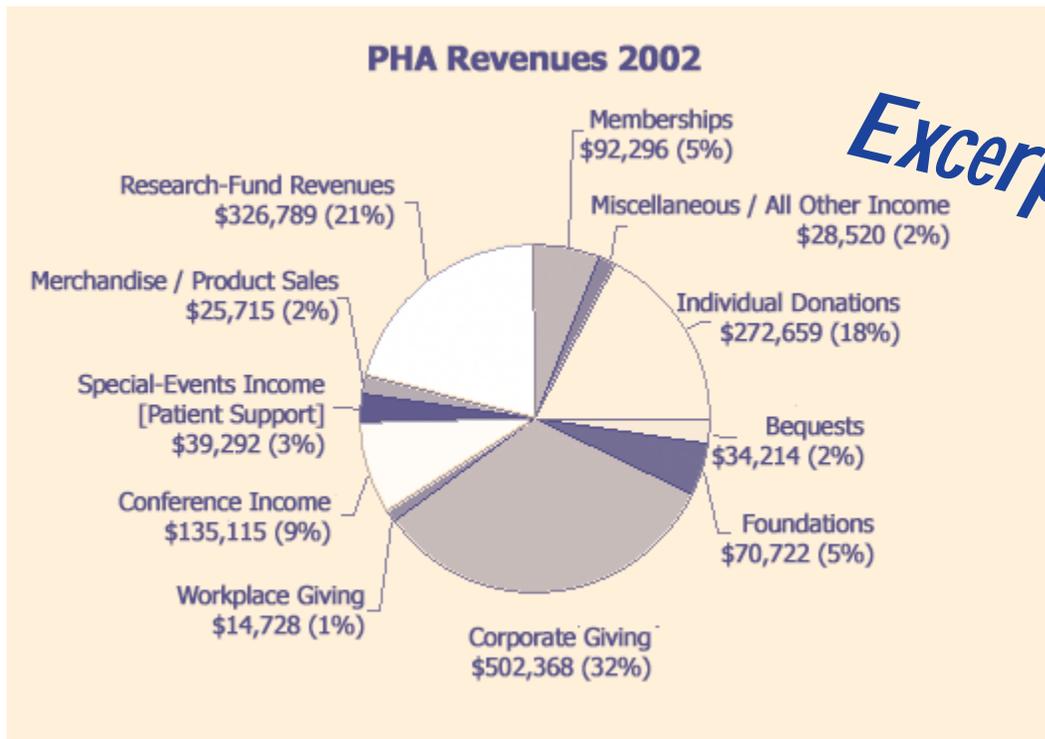
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David Langleben, M.D. Jewish General Hospital • Montreal, Canada	Carol E. Vreim, Ph.D., <i>NHLBI Liaison (non-voting)</i> Division of Lung Diseases, NHLBI • Bethesda, MD
James E. Loyd, M.D. Vanderbilt University Medical Center • Nashville, TN	JoAnne Sperando-Schmidt, <i>Patient Liaison (non-voting)</i> Huntington, NY
Vallerie McLaughlin, M.D. University of Michigan • Ann Arbor, MI	<b><i>Emeritus Members:</i></b> Bruce H. Brundage, M.D. • Bend Memorial Clinic Alfred P. Fishman, M.D. • University of Pennsylvania Health System



PULMONARY HYPERTENSION ASSOCIATION, INC.		
STATEMENTS OF FINANCIAL POSITION		
DECEMBER 31, 2002 AND 2001		
	2002	2001
<b>ASSETS</b>		
<b>CURRENT ASSETS</b>		
Cash and cash equivalents	\$ 231,377	\$ 286,317
Contributions receivable	39,746	5,000
Interest receivable	4,175	-
Prepaid expenses and other assets	5,379	8,239
Total current assets	280,677	299,556
INVESTMENT - at fair value	1,201,189	884,358
EQUIPMENT AND LEASEHOLD IMPROVEMENTS	95,771	81,319
OTHER ASSETS	10,381	-
<b>Total assets</b>	<b>\$ 1,588,018</b>	<b>\$ 1,265,233</b>
<b>LIABILITIES AND NET ASSETS</b>		
<b>CURRENT LIABILITIES</b>		
Accounts payable	\$ 64,277	\$ 10,010
Accrued payroll and payroll taxes	8,027	495
Grants payable	241,551	52,500
Total current liabilities	313,855	63,005
<b>NET ASSETS</b>		
Unrestricted		
Available for operations	376,439	154,587
Expended on equipment and leasehold improvements	95,771	81,319
Total unrestricted	472,210	235,906
Temporarily restricted	801,953	966,322
Total net assets	1,274,163	1,202,228
<b>Total liabilities and net assets</b>	<b>\$ 1,588,018</b>	<b>\$ 1,265,233</b>

*Excerpts Only*





*Excerpts Only*

## Financial Transparency

PHA posts our annual report on the website. This year we added our audit, as well as expense and income charts. PHA recognizes our responsibility to donors, and is pleased to make this information easily accessible. Updated reports and new financials will be posted as they become available.

### Pulmonary Hypertension Association, Inc.

#### Statements of Activities

December 31, 2002 and 2001

	2002			2001		
	Unrestricted	Temporarily Restricted	Total	Unrestricted	Temporarily Restricted	Total
<b>Support and revenue</b>						
Contributions	\$ 654,757	\$ -	\$ 654,757	\$ 277,150	\$ -	\$ 277,150
Contributions - research	-	298,253	298,253	-	556,125	556,125
In-kind donations	-	10,515	10,515	3,342	-	3,342
Conference revenue	356,193	-	356,193	10,176	-	10,176
Grants	20,822	50,000	70,822	100,500	-	100,500
Membership dues	152,296	-	152,296	56,832	-	56,832
Merchandise sales	19,751	-	19,751	19,839	-	19,839
Investment income	18,081	28,913	46,994	14,625	5,360	19,985
Other income	1,066	-	1,066	7,781	-	7,781
Releases from restrictions	552,050	(552,050)	-	385,003	(385,003)	-
<b>Total support and revenue</b>	<b>1,775,016</b>	<b>(164,369)</b>	<b>1,610,647</b>	<b>875,257</b>	<b>176,482</b>	<b>1,051,739</b>
<b>Expenses</b>						
Program services	1,223,048	-	1,223,048	512,617	-	512,617
Management and general	136,006	-	136,006	73,397	-	73,397
Fundraising	109,431	-	109,431	54,826	-	54,826
	1,468,485	-	1,468,485	640,840	-	640,840
Direct cost of special events	70,227	-	70,227	132,464	-	132,464
<b>Total expenses</b>	<b>1,538,712</b>	<b>-</b>	<b>1,538,712</b>	<b>773,304</b>	<b>-</b>	<b>773,304</b>
<b>Change in net assets</b>	<b>236,304</b>	<b>(164,369)</b>	<b>71,935</b>	<b>101,953</b>	<b>176,482</b>	<b>278,435</b>
<b>Net assets</b>						
Beginning of year	235,906	906,322	1,202,228	133,953	789,840	923,793
<b>End of year</b>	<b>\$ 472,210</b>	<b>\$ 801,953</b>	<b>\$ 1,274,163</b>	<b>\$ 235,906</b>	<b>\$ 966,322</b>	<b>\$ 1,202,228</b>

See accompanying notes to financial statements.

***What to Look for in 2004:***

- ⌘ Continuing growth in support and membership programs
- ⌘ Launch of PH Doctors, a professional association for physicians and researchers within PHA
- ⌘ Continuing growth of PH Resource Network, a professional association within PHA to provide support and education for nurses, pharmacists, respiratory therapists and other allied healthcare professional
- ⌘ Increasing cooperation with PH groups in other nations
- ⌘ PHA's 6<sup>th</sup> International PH Conference in Miami, Florida (June 24 - 27, 2004)
- ⌘ First ever Scientific Sessions at Conference, designed specifically for physicians and researchers, but open to all attendees (June 24 - 25, 2004)
- ⌘ More volunteer opportunities for our members and friends
- ⌘ Increased visibility for PH in the media
- ⌘ More special events to raise awareness and funds for research and patient-serving programs
- ⌘ Acceleration in research opportunities and advances
- ⌘ Moderated chats and other new services on the website
- ⌘ A Capitol Hill Day to educate decision makers on PH
- ⌘ More educational materials, including a new brochure on available treatments
- ⌘ *...and much more*

To our Committee of Ten members; bequest, memorial and tribute donors; the founding members of our new Leaders & Community Circles; foundations; corporations; and, most of all, the thousands of members, friends and donors who contribute of your time, your talent and your treasure, PHA thanks you.

You make all we do possible!



**Pulmonary Hypertension Association**

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