



The PHA Story

from kitchen table to internationally-respected organization
or
The History of its foundation, development and growth

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At the time the Pulmonary Hypertension Association was being organized there were only 50 diagnosed cases of the illness.

There was no hope, little knowledge and little research.

In 1987, three pulmonary hypertension patients set out to change that bleak picture. They reasoned that if they could find each other, there were others throughout the country who were reachable...people who were isolated and alone, lacking contact with anyone else living with the disease. Given their own experiences with the illness, they knew there were many more living – and dying – amidst the confusion of misdiagnosis.

Ending Aloneness

The three patients, Dorothy Olson, Theresa Knazik, and Shirley Brown, found each other through the National Organization for Rare Disorders (NORD). A fourth patient, Pat Paton, soon joined the small planning group.

Their goals were lofty. By becoming advocates for patients, their mission was to:

- aid patients and their families in coping with this devastating disease,
- provide networking opportunities to end the “aloneness” of a rare illness,
- assist in locating doctors and medical facilities with expertise in treating pulmonary hypertension.
- form support groups to allow patients to network and open contact with others.
- begin to publish a newsletter that would build a sense of community

In early May of 1990, the first issue of PHA’s newsletter, *Pathlight*, was printed. This new newsletter was mailed to all patients who had been located by the founders and to doctors and University Hospitals. The total mailing was less than 100. As time passed, requests for the newsletter grew.

The name, *Pathlight*, was derived from the founders’ purpose. Dorothy Olson says, “We wanted to find ways to light the way to awareness.” The contacts developed through mailing to medical teaching hospitals and universities brought unexpected and important dividends. The women found that many of the doctors treating pulmonary hypertension were also working in isolation.

They were anxious to network their patients...and also to network themselves. The National Organization for Rare Disorders (NORD) had advised the founders to establish a Scientific Advisory Board early and to invite the leaders in the field. This was a central point on the agenda at PHA's first meeting. Combining reading of the literature with their own knowledge of the doctors treating the illness, PHA's board successfully formed a scientific advisory board of 15 highly regarded medical doctors and specialists within one year.

In October of 1991, Burroughs Wellcome (now Glaxo Wellcome) was working on a drug called prostacyclin, which was thought to be of possible benefit to pulmonary hypertension patients. Out of PHA's early activity, the organization was contacted and PHA's founding president Judy Simpson (a nursing educator) was invited to sit on the Treatment Investigation of New Drug (TIND) review panel. A PHA Board member was asked to run for the National Organization for Rare Disorders Board of Trustees. PHA was represented on the NORD Board from 1994-1999. A PHA Board member was also appointed to a four-year term to the National Institutes of Health Heart, Lung and Blood Advisory Council.

Beginning Structure and Program

In 1992, the organization began to formally structure itself. A not for profit corporation was formed in Florida under PHA's original name – United Patients Association for Pulmonary Hypertension (UPAPH). Volunteers wrote the by-laws, articles of incorporation and other needed documents. For most of the early and mid-1990's the organization was a kitchen table operation regularly seeking advice on organizational and management issues from NORD. Board meetings were held in a home centrally located in Florida. Patients and family members volunteered their talents and time, and paid for the initial costs involved in starting a group. The newsletter, phone calls and mailings were all contributed by volunteers.

For an association focused on a rare illness, PHA began to grow quite rapidly. As physicians and medical centers heard about PHA's work, they referred patients to the organization. PHA was able to provide support, education and networking to many patients and their families. An 800 number was established and began to accept hotline calls from around the country. To this day, all calls are answered by patient and family volunteers. The calls are of particular benefit to newly diagnosed patients and their families. It is not unusual for the hotline to receive a call from a new patient as he or she leaves the doctor's office with a diagnosis and a PHA brochure.

In 1992, the organization, as one of its immediate priorities, also began a list of doctors who treat pulmonary hypertension. At the same time, a team of PHA volunteers began compiling information about pulmonary hypertension and prepared a packet of basic information that could be sent to new patients.

The importance of educating patients and doctors has always been a major priority for PHA. As the organization grew, many members and hotline callers exchanged stories about the difficulty of getting the correct diagnosis. Some doctors were telling their patients they had no hope of survival. There were medical options and PHA was active in spreading the word. Prostacyclin, later renamed Flolan, was being tested in patients and was proving to be beneficial in a large number of cases. Coumadin was also shown to prolong survival.

Networking through Conferences

In 1994, PHA planned a major undertaking – its first International Conference. The event was held at Stone Mountain, Georgia, with almost as many doctors in attendance as patients. Patients, family members and medical professionals from the US, Canada and the UK were in attendance, sharing information and beginning to form a cohesive PH community.

PHA continued to grow and in 1996, sponsored its second International Conference...again at Stone Mountain. Our third conference was in Dallas, Texas in June, 1998. At that time PHA had a little over 1,000 members and five hundred people attended. In June of 2000, the conference was held in Chicago, Illinois. PHA membership had grown to over 2,500 and more than 800 attended.

Patients and their families, as well as medical professionals, now come from all over the world to attend PHA Conferences. In 2000, besides the U.S. and Canada, members and medical professionals came from Great Britain, Japan, Israel, Turkey, France and a number of other nations. At PHA Conferences, information is shared and friendships are made. Everyone is brought up to date on the latest treatments for pulmonary hypertension. The Conference is unusual in its collaborative mix of patients, family members and medical professionals. PHA subsidizes its conferences through outside fundraising so that patients in difficult financial circumstances will be able to attend. Many doctors and other medical professionals participate as presenters and observers. None has ever asked a fee.

A New Name...An Eye on Treatments

In 1997, the association was re-organized and formally changed its name from UPAPH to the Pulmonary Hypertension Association, PHA. A web site was designed and launched – **www.phassociation.org** – and the organization's reach instantly widened. People who don't have access to PHA's printed brochures can still find the organization within days, often within hours of being diagnosed. The web site allows PHA to provide a whole new level of information development and dissemination. Through a variety of interactive message boards and e-mail lists patients, family members and medical professionals are able to provide mutual support, exchange information and stay in regular contact.

PHA plays an active role in supporting the advance of treatment for pulmonary hypertension. As mentioned earlier, the organization had a patient advocate representative on the Burroughs-Wellcome TIND review panel during the clinical trials for prostacyclin (later known as Flolan). Two patients from PHA testified before the Federal Drug Administration when Flolan was approved for use. A Flolan Patient Advisory Committee from PHA was formed to help the Glaxo-Wellcome Company select the home health company provider for Flolan when it went on the market in 1996. A series of meetings between PHA and Theracom began in early 2000 when Theracom was announced as a second Flolan provider. Information is provided through the Scientific Advisory Board as it becomes available on other drugs of potential value, such as UT-15.

Flolan carries a per patient cost of approximately \$120,000 per year. This drug and earlier diagnosis are helping patients live longer than ever. Ironically, because of this, they and their families are often faced with mounting financial difficulties. Increasingly, PHA's hotline volunteers are called upon to provide information and referrals regarding insurance and social service issues. PHA maintains close contact with ACCESS, a Gentiva-funded insurance advisory program for patients. For its own part, PHA made the decision that it will never refuse full membership to any patients who cannot afford to make even a minimal membership contribution.

In 1998, PHA published *Pulmonary Hypertension: a Patient's Survival Guide*. The book is exceptionally popular and is ordered by patients, doctors and hospitals alike. It is now in its third printing. The Survival Guide, at over 120 pages, is a collaboration between a member who is a professional writer and PHA's Scientific Advisory Board. It breaks this complicated illness and

the options it presents into plain and understandable language. A revised and updated version is currently being written and is projected for publication in the fourth quarter of 2000.

A Focus on Research

Originally, PHA's goals were support, education and networking. In January, 1999, the PHA board felt that the organization had grown sufficiently to be able to incorporate the goal of supporting research to find a cure for PH. A Research Fund was established and the organization chose a strategy that would not only raise money for research but also increase public awareness of the illness.

In 1999, golf tournaments were held in Houston and Dallas. A collection of note and holiday cards were created using art submitted by children living with pulmonary hypertension. Over \$130,000 was raised and, just as importantly, an awareness of this new thrust was developed among PHA's members and friends. In 2000, golf tournaments will be held in Houston (April 13) and Miami (April 15). The Houston event will include a gala dinner (April 15). Dallas will have their second tournament on September 26. Los Angeles is currently being scheduled for a tournament and Maryland is under discussion.

With the recommendation of the Scientific Advisory Board, the PHA Board focused its initial fund distribution on attracting young doctors at the beginning of their careers into the field through research fellowships. It was felt that with the amount of money available, this was the most effective path to follow. PHA arranged for the American Heart Association to rank the grant applications. The first three (possibly four) research fellowships will be awarded at the PHA Conference in Chicago in June of 2000. As the Research Fund grows, it is expected that PHA will review its funding priorities.

While PHA had not involved itself in direct funding for research prior to January, 1999, through its advocacy work with the National Heart Lung and Blood Institute (NHLBI) and with Congress, the organization played an active role in Congress' 1998 and 1999 listing of pulmonary hypertension as a NHLBI priority. Great credit for this success goes to PHA's Scientific Advisory Board and the grass roots advocacy of members all across the United States. The Congressional mandate has resulted in \$12,000,000 of pulmonary hypertension research through NHLBI. PHA's efforts are being felt as far away as Australia, where changes are currently underway in health care policy.

PHA has done much since its founding a decade ago. As member growth continues to accelerate, it can and must do more in the twin struggles for a cure and for providing support for those struggling to live before the cure arrives.

In 1999, PHA hired its first professional staff person and moved the organization from the president's home to an office in Silver Spring, Maryland. A second professional was hired at the beginning of 2000. Activity levels are high and expanding:

- A new database was installed to improve contact with a membership that grew from 1,400 to 2,500 between 1999 and 2000.
- Hotline calls have increased to well over 2,000 per year. A similar Internet service is now over 1,000 contacts per year.
- Support groups around the country now stand at 47 with an average of one new support group being added each month.
- Advocacy work is expanding. Congressman Kevin Brady of Texas is working with PHA leaders on wording of a bill to increase federal support for pulmonary hypertension research.

- Printed and electronic publications are being reworked to make information provided by the organization more readable and inviting for patients, caregivers and medical professionals.
- Nurses are being organized as a section within PHA. Their group, Pulmonary Hypertension Resource Network (PHRN), is focused on exchanging information and providing resources for new nurses entering the field.
- A funding strategy has been designed to help centralize many services, while focusing the volunteer spirit of the organization on areas such as support groups, advocacy and public awareness where coordinated volunteer efforts can make a great difference.

PHA has been identified by an eminent PH physician/researcher as a hallmark patient support association that works collaboratively with physicians, researchers, pharmaceuticals, home health agencies and government. As such PHA has established a new paradigm, which is becoming a model for other groups.

In many ways, PHA is still a young organization. Much of its growth has been in the past three years. Yet, the foundation that was set from the beginning was solid and allowed for that growth to occur. PHA has held to its goals and expects continued successes in the future...as we march toward the one great success that will allow us to say, "This organization is needed no more".