

Pulmonary Hypertension Association History

The Early Days (Pre-1990)

Dorothy Olson would always remember the day in 1978 that her life was forever changed. While admiring a bunting bird outside her bedroom window, she collapsed on her bed and felt paralyzed. Dorothy was hospitalized for over five weeks without answers from her doctors.

In the sixth week, a young resident in the hospital meekly suggested he had read in a medical text about a rare disease called pulmonary hypertension. Although the doctors knew very little about the disease, they told her she would have only two years left. It was at this point that Dorothy developed her new motto: "If it's gonna be, it's up to me."

Unsatisfied with the prognosis from her doctors and determined to find hope, Dorothy and her husband Harry moved to Florida. She gathered information about pulmonary hypertension from libraries, university physicians, and the National Organization for Rare Diseases (NORD). Dorothy was discouraged by the insufficient information available about PH and decided to search for other patients like her. She spent nine years making phone calls and writing copious letters in an effort to end her isolation.

Finally, a few responses came in. The American Lung Association had put her in touch with another PH patient, Karen Cavanaugh. Unfortunately, Dorothy's connection to her was lost after Karen moved abroad.

In the fall of 1987, Dorothy was contacted by a PH patient, Teresa Knazik. Teresa had been given Dorothy's contact information through NORD and was eager to help. The two contacted another patient, Shirley Brown, and they began a PH pen pal group. Their goal was more than just friendship; they wanted to develop a patient association for PH. Their original name was the United Patient's Association for Pulmonary Hypertension (UPAPH).

Founding Our Community (1990-1999)

As professional awareness of PH was growing, Dorothy and Teresa saw a need to connect PH patients to helpful information and encouragement. They created a newsletter for PH patients called *Pathlight*, first published in May 1990. UPAPH sent out 50 copies of the first *Pathlight* to every patient they knew.

The first issue of *Pathlight* had a column designed to lift the spirits of PH patients, a personal piece about the frustrations of coping with PH, a short list of PH patients who

had recently died and an article about the Foundation for Pulmonary Hypertension. Readers were encouraged to join UPAPH, and they did.

UPAPH had 35 members by November 1990. The medical world began to take notice of this active and burgeoning group of PH patients.

In 1991, Dorothy and Teresa were connected yet again through NORD to another PH patient, Pat Paton, and her sister Judy Simpson. Fortunately, Pat, Dorothy, and Teresa were all living in Florida at the time. On January 12, 1991, Pat organized a meeting at her home in Florida, and she was joined by Judy Simpson, Dorothy Olson, Teresa Knazik, and their spouses. At this “Kitchen Table” gathering, considered the organization’s founding moment, the group began to draw up definitive plans for UPAPH.

The founders were dedicated to making UPAPH an organization that would:

- Create a network of support
- Keep patients and their families informed on current treatments, medications, and research
- Encourage the formation of patient support groups
- Maintain and build contacts with physicians caring for PH patients
- Encourage and support research on PH
- Educate patients and families about the disease

The organization officially achieved a 501(c)(3) not-for-profit status on February 11, 1992. It continued to be run entirely by volunteers, often working from their respective kitchen tables, for the following seven years.

As the association grew, they continued to seek out advice from NORD on organizational and management issues. They developed a PH support line that was manned entirely by volunteers. With the expansion of patient outreach came a need for increased medical guidance. The organization developed a list of doctors who treat pulmonary hypertension in 1992 and prepared a packet of critical information to send to newly diagnosed patients.

A clinical trial of the first real PAH drug, epoprostenol, took place in 1993. Medical centers in the United States and Canada were involved in this milestone for the PH community.

In 1994, UPAPH held its first International PH Conference in Stone Mountain, Georgia. The conference featured the first Research Room, led by Dr. Greg Elliott, where patients gave blood samples which later contributed to the discovery of the PH gene.

With the collaboration and research of the international community, UPAPH anticipated a rapid expansion.

1996 was a tumultuous year in the UPAPH community. A link was discovered between certain diet pills on the market and pulmonary hypertension. UPAPH was determined to keep fighting in this time of need. UPAPH hosted its second International PH Conference, seeking a new model of healthcare education for the 21st century.

In 1997, UPAPH reorganized and officially changed its name to the Pulmonary Hypertension Association (PHA). PHA launched its first website to disseminate valuable information across the globe. Just one year later in 1998, PHA published *Pulmonary Hypertension: A Patient's Survival Guide*. This was an easy-to-read guide to help patients deal with the daily issues associated with pulmonary hypertension, written by patient and author Gail Boyer Hayes with the help from other patients, caregivers and medical professionals.

A Period of Rapid Development (1999-2011)

PHA began to question whether its tireless volunteers could continue to provide the sole support for its expanding programs and services. The need to hire a staff member became increasingly apparent during this time of rapid growth. Rino Aldrighetti was hired as PHA's first staff member on January 1, 1999. Rino helped to facilitate the growth of PHA through strategic planning and fundraising at a critical time for the organization.

PHA expanded its strategic scope to include research efforts in addition to the support, education and networking services for its constituents. PHA created a Research Fund with the purpose of raising money for research and increasing public awareness of PH.

Beginning in 1999, PHA held golf tournaments in Houston and Dallas to continue to foster public awareness of PH, support research and sustain its growing programs. The value of these events was indisputable; PHA raised over \$130,000 that first year, and awareness of PH surged.

PHA's fervent awareness efforts drove individuals to the PH community. In order to keep up with the growing constituent pool, PHA installed a new database. At this time, new support groups were added at an average of one per month and the patient support line calls increased substantially.

Instrumental advocacy efforts in Congress heightened PH awareness as well. Representative Kevin Brady (R-TX), motivated by his personal connections with several

PH patients in his district, introduced the first PH-specific bill in Congress in 2000. Several years later, the late Representative Tom Lantos (D-CA) joined Representative Brady in introducing a new PH bill. These efforts pushed PHA toward closer relationships with Members of Congress, intensifying support for PH legislation.

The PH Professional Network (called PH Resource Network at the time) was formed as a part of PHA in 2000 in order to build a network among medical professionals who work with PH patients. This network was essential during a time when patient diagnosis was growing, clinical trials were expanding and the Food and Drug Administration was beginning to approve more treatments for PH. PHA organized its first educational forum for nurses and other allied health professionals in 2003, called the PH Professional Network Symposium. In 2004, PH Doctor, later renamed PH Clinicians and Researchers (PHCR), was established as the world's first professional association for PH-treating clinicians and PhD-level researchers. The additions of PHPN and PHCR accelerated collaboration and information-sharing among the medical community.

Rich dialogue within the PHPN and PHCR communities served as a catalyst in the development of PHA's medical education programs. PHA launched the first series of regional medical education programs in 2005, consisting of seminars held in various cities that educated medical professionals and patients alike. These seminars allowed PHA's constituents to access vital medical information from internationally recognized experts and connect to each other in what was becoming a rapidly growing field.

The external growth of the PH community steered PHA toward internal expansion. The success of the International PH Conferences led to the development of the International Services Program in 2004, which supported connections with PH associations across the globe. In 2009, PHA began to work with members of the PH community to expand programming among special populations of PH patients and caregivers. PHA developed the Patient Outreach and Services Department to help identify and prioritize the interests of these groups and create resources to meet identified needs.

What started as a small support group at a kitchen table became a dynamic organization composed of over 13,000 members only 20 years later. In 2011, the annual budget increased to over \$10 million. PHA's original one-page newsletter, *Pathlight*, grew to a 55-page quarterly publication. PHA worked closely with more than 50 PH associations around the world. PHA earned Charity Navigator's four-star rating eight years in a row, the highest recognition conferred by the leading charity evaluator in America. Though PHA expanded far beyond its original framework, it retained its grassroots, altruistic focus through the dedication of its hardworking volunteers.