WHAT IS PULMONARY HYPERTENSION?

- Pulmonary hypertension (PH) is an umbrella term used to describe a group of complex, potentially fatal lung conditions characterized by high blood pressure in the vessels of the lungs that can lead to right heart failure.
- PH can occur in relation to left heart disease, lung disease, blood clots in the lungs and other conditions. Genetics can also play a role. In some cases, there is no known cause.
- Symptoms of PH include shortness of breath, fatigue and chest pain.
- Since PH often mimics symptoms of asthma and other less threatening illnesses, many people may go months or years without an accurate diagnosis, and are then unable to get the full benefit from available therapies once they are finally diagnosed.

WHAT IS PULMONARY ARTERIAL HYPERTENSION?

- One type of PH, pulmonary arterial hypertension (PAH), is a rare disease. Without treatment, individuals with PAH live 2.8 years past diagnosis on average.
- Fortunately, there are now 14 available FDA-approved targeted treatment options for adults and one FDA-approved drug for children. Although life expectancy has more than doubled*, these drugs are complex and expensive. Currently, there is no cure for PH.
- The disease commonly occurs in conjunction with connective tissue diseases, such as scleroderma and lupus; HIV infection; liver disease; congenital heart disease; and exposure to certain drugs, such as methamphetamine.

WHO IS IMPACTED BY PULMONARY HYPERTENSION?

- Adults and children of all ages can develop pulmonary hypertension.
- Women develop PAH more than three times as often as men and women of color have disproportionately poorer health outcomes.

WHAT IS THE PULMONARY HYPERTENSION ASSOCIATION?

• The Pulmonary Hypertension Association (PHA) is a community of patients, caregivers, families, medical professionals and researchers who work together to empower people battling the disease while supporting research toward improved treatments.

• PHA was the first organization in the world dedicated to providing comprehensive PH patient and caregiver support, medical education, specialty care services that improve patients’ quality of life and research.

• PHA’s mission is to extend and improve the lives of those affected by PH; its vision is a world without PH, empowered by hope.

HOW DOES PHA CONNECT THE PH COMMUNITY?

• PHA helps over 200 support groups plan, advertise, and run over 800 in 47 states, Puerto Rico, and Washington, D.C., serving more than 5,000 patients and caregivers annually.

• In addition to in-person support, PHA offers a telephone support line, taking an average of 20 calls each week, an email mentors program, monthly telephone support groups, and a variety of print and online publications.

• PHA’s International PH Conferences bring together more than 1,400 patients, caregivers, medical professionals and other friends of PHA every two years to share information on the latest research, treatments and lifestyle issues with PH.

HOW DOES PHA PROMOTE QUALITY PATIENT CARE?

• PHA has provided $7.7 million for PH research and provides continuing education for medical professionals through PHA Online University and an in-person CME program.

• Since 2014, PHA has accredited more than 60 hospitals and clinics as Pulmonary Hypertension Care Centers. Many of these centers will also provide data for the new Pulmonary Hypertension Association Registry (PHAR), a major advancement in PH care and research.

HOW CAN PEOPLE LEARN MORE ABOUT PHA AND PH?

• To learn about PH and PHA, visit www.PHAssociation.org; @PHAssociation on Twitter and Instagram; or www.facebook.com/PulmonaryHypertensionAssociation.