Pulmonary Hypertension Association Meeting Highlights Role of Nurses and Other Health Professionals in Caring for Patients with Rare Disease

Silver Spring, Md. (September 16, 2015) – Pam Kehoe suffered for years, being diagnosed with bronchitis, asthma, chronic obstructive pulmonary disease (COPD) and a number of other conditions before she finally learned she had chronic thromboembolic pulmonary hypertension (CTEPH), a form of pulmonary hypertension (PH), caused by old, organized blood clots in the lungs. The person who first suspected it was her sister-in-law, a home health nurse who had cared for PH patients and knew the symptoms all too well.

PH is high blood pressure in the blood vessels of the lungs, a debilitating, progressive disease that puts increased pressure on the heart and can lead to death from right heart failure. Without treatment, the average survival rate is 2.8 years after diagnosis. Treating PH is complex, and patients and their caregivers rely on a multidisciplinary community of healthcare professionals to guide them through their treatment plan.

Kehoe saw a specialist who confirmed she had CTEPH. Frequently, patients are unaware they have CTEPH, and that they may be candidates for pulmonary thromboendarterectomy or PTE, a surgical procedure that can significantly reduce or even normalize lung pressures.

“My sister-in-law reviewed copies of my medical records; told me I couldn’t give up and immediately helped me get into the right doctor,” said Kehoe.

Kehoe will share her story this week at the Pulmonary Hypertension Association (PHA)’s 2015 PH Professional Network (PHPN) Symposium. Since PHA formed the PHPN in 1999, it has grown as the leading network for non-physician clinician members, dedicated to enhancing communication, professional development, research and education among PH healthcare professionals. Meeting every other year since 2003, the 2015 Symposium will convene Thursday, September 17 – Saturday, September 19, 2015 at the Crystal Gateway Marriott in Arlington, Va.

The 1,100-plus-member PHPN community—working with physicians, patients and caregivers—has contributed significantly to improved care and outcomes for PH patients and families. Since its founding, PHPN has helped build links among allied health professionals around the U.S. and abroad. The colleague-to-colleague connection that PHPN provides has significantly contributed to improved care and outcomes for PH patients and families.

“PHPN is a diverse group of individuals involved in PH practice, including nurses, pharmacists, physician assistants, nurse practitioners, respiratory therapists, physical therapists, social workers, dietitians and more,” said PHPN Chair Melisa Wilson, ARNP-ACNP-BC. “We recognize
the importance of collaboration across many disciplines and work to provide support and targeted resources for all of those involved in PH patient care.”

PHA, which marks its 25th anniversary in 2016, is the world’s first and nation’s largest comprehensive nonprofit PH association. PHA recently received for the 12th consecutive year Charity Navigator’s highest rating—four stars—for fiscal accountability and transparency, placing it in the top half of one percent of all rated charities.

“Allied Health Professionals are the advocates, the planners and the glue that holds it all together when it comes to patient care,” Kehoe said.

Participants can earn up to 11 hours of continuing education credits through multidisciplinary education sessions led by experts in the PH field. This week, members attending Symposium can also take part in an Advocacy Day visit to Capitol Hill, where they will join patients to educate Members of Congress about the needs of PH patients and the medical professionals who treat them. Symposium will include an opening dinner presentation from Team PHenomenal Hope – an ultra-endurance sports team racing to raise awareness about PH. New this year is a Networking Fun Walk to help raise funding for patient scholarships to attend the 2016 PHA International PH Conference and Scientific Sessions, June 17 – June 19, 2016 in Dallas, Texas.

About the Pulmonary Hypertension Association
Headquartered in Silver Spring, Md., with a growing list of chapters across the country, the Pulmonary Hypertension Association (PHA) is the country’s leading pulmonary hypertension organization. Its mission is to find ways to prevent and cure pulmonary hypertension and provide hope for the community through support, education, research, advocacy and awareness. PHA does this by connecting and working together with the entire PH community of patients, families and medical professionals. PHA relies on donations to fund its many programs, including early diagnosis efforts, more than 245 support groups around the country and continuing education for medical professionals through PHA Online University. For more information or to support PHA with a donation, go to www.PHAssociation.org.

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