

New Campaign to Raise Awareness About a Life-threatening Disease Too Often Mistaken for Asthma

Public Service Campaign to Debut during Pulmonary Hypertension Awareness Month

Silver Spring, Md. (September 9, 2015) On the eve of its 25th anniversary year, the [Pulmonary Hypertension Association](#) (PHA) is mobilizing resources to let the public know about a progressive, life-threatening disease too often misdiagnosed as asthma.

This November, promoting [Pulmonary Hypertension Awareness Month](#), PHA will unveil **Heart2CurePH** (#Heart2CurePH), a new national pulmonary hypertension (PH) public service awareness campaign developed in partnership with national cause marketing firm, The CauseWay Agency. **Heart2CurePH** print, radio and TV advertising educating the public about the disease will begin running in donated media starting in November. At the same time, through www.PHANews.org, a mobile-responsive website, the ads will also be available to the public for downloading, printing and sharing. The site will offer free subscriptions to PHANews, a weekly e-newsletter featuring PH patient stories, breakthroughs and resources.

PH, which some people call “the other high blood pressure,” is increased blood pressure in the blood vessels of the lungs that can lead to death from right-sided heart failure. Periwinkle, symbolic of the color of the lips of some PH patients when they are oxygen deficient, has come to represent hope and courage for PH patients, as well as for their caregivers and the healthcare professionals who treat them.

“The need to raise awareness about PH is pressing because symptoms of the disease, which include chest pain and difficulty breathing, are similar to those of asthma and other less threatening illnesses,” said PHA President and CEO Rino Aldrighetti, who will retire during the association’s 2016 anniversary year after serving as the association’s only executive leader. “When undiagnosed and untreated, the average survival time for someone with PH is 2.8 years. Yet, with earlier diagnosis, new treatments are extending life expectancy and improving PH patients’ quality of life.”

Founded by patients in 1991, PHA 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.

Supporting PHA’s 2015 “Coloring the World Periwinkle for 25 Years” Awareness Month theme, the association’s member patients, caregivers and supporters are urging one another to make PHA’s Pulmonary Hypertension Awareness Month badge their profile picture on their social media sites in November. Members will also continue the November 1 tradition of posting photos of themselves wearing periwinkle pins, ribbons, clothing and lipstick. PHA’s 16,600 member patients and caregivers comprise one of the nation’s strongest and most social media-active rare disease association communities.

PHA's Awareness Month public awareness efforts will include organization of the 2nd annual CTEPH Awareness Day activities on November 17, 2015 to educate patients, healthcare professionals and the public about chronic thromboembolic pulmonary hypertension or CTEPH, a form of PH caused by old, organized blood clots in the lungs. Frequently, patients are unaware that 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. The 2015 CTEPH Awareness Day celebration will include a November 17 Twitter chat (#CTEPHchat), a Thunderclap event, and two educational webinars with live Q&A for patients – in Spanish and in English – on *PHA Classroom*, PHA's patient education platform. In addition, PHA will encourage CTEPH survivors to share short video recordings on social media. PTE centers and PHA's regional offices around the country will also host CTEPH Awareness Day celebrations.

PHA's Awareness Month recognition will include a celebration of 25 PHA Periwinkle Pioneers, individuals selected by the PH community for playing a significant role in the organization's success in providing patient and caregiver support, public awareness and medical education, as well as funding research to find a cure for the disease.

"In a little more than two decades, working with an amazing patient, caregiver and scientific community, PHA has successfully worked to influence advances in PH patient care, support services, medical education and research," Aldrighetti said. "The number of PH treatments has grown from one to 12; donors have provided more than \$16 million in research commitments; and more than two dozen Pulmonary Hypertension Care Centers have completed our new accreditation review program."

"At the same time, the need for awareness about the disease is great, as too many people are dying simply because they don't know about PH," Aldrighetti continued. "Our pre-anniversary year Awareness Month campaign is focusing on early and accurate diagnosis and letting the world know that at PHA, we're putting our hearts into finding a cure."

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. Among its programs, PHA facilitates more than 245 support groups around the country and delivers continuing education for medical professionals through *PHA Online University*. For 12 consecutive years, PHA has received the highest rating—four stars—for fiscal accountability and transparency from Charity Navigator, placing it in the top half of one percent of all rated charities. For more information, please go to www.PHAssociation.org.

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