



For Immediate Release

Contact: Jordan Jennings
JordanJ@PHAssociation.org
240-485-0768

Patient Voice Makes Pulmonary Hypertension Association a Leader in Rare Disease Fight

Pulmonary Hypertension Patients and Caregivers Push
Awareness into Action for 2016 Rare Disease Day®

Silver Spring, Md. (Feb.24, 2016) – People living with life-threatening, rare diseases — including pulmonary hypertension (PH) — struggle every day to raise their voices for better diagnosis, research, support and treatment. On Monday, Feb. 29, Rare Disease Day 2016, patients and caregivers will take to social media to celebrate the Pulmonary Hypertension Association (PHA) community’s recent awareness successes and demand meaningful action for PH patients and other people living with rare diseases.

PH, which affects children and adults, is high blood pressure of the lungs due to narrowing of the pulmonary arteries that can lead to death from right heart failure. Because PH is often misdiagnosed, for example, as asthma, the average length of survival without proper treatment can be only 2.8 years after diagnosis. For the past 25 years, PHA’s patient/family/caregiver community-focused strategy has served as a roadmap for rare disease awareness and action, pulling both patients and providers together and empowering them with knowledge and support. With PHA chapters and support groups across the U.S., the organization increasingly turns to social media and — in recent months — a national donated media campaign to connect the PH community, raise awareness and create paths to action for the 30,000 Americans diagnosed with PH, and many others who do not know they have the disease.

On Rare Disease Day, PHA is using social media memes to pose a question to the rare disease community — “How do we make the voice of rare disease stand out?” For the 30 million people living with rare disease, the answers range from public policy advocacy to community-building to sharing personal stories. The memes will foster engagement and discussion of these critical components of progress that PHA has led for 25 years.

PHA launched its Rare Disease Day campaign a week ago with a meme celebrating the success of its #Heart2Cure campaign, a public awareness advertising effort that in just three months has netted nearly \$14 million in donated TV, radio, billboard, transit, national magazine and Times Square advertising. The

unprecedented campaign has yielded pro-bono ads that have been viewed coast to coast and supported by both generous media donations and the PH social media community.

PHA is leveraging its community's social media interest by inviting influencers to join the fight. Earlier this month, PHA announced that actor and former BET and E! News host Terrence J will serve as celebrity ambassador for PHA. Terrence J, whose huge fan base includes nearly 2 million Twitter followers, will support the #Heart2CurePH campaign by serving as talent in the next phase of public service announcements and participate in a number of ways at PHA's upcoming International PH Conference and Scientific Sessions on June 18 in Dallas.

Social media advocacy comes second nature to PHA, whose Facebook community serves as an organic voice for the organization. Recent years have seen a jump in the PHA social network, which now includes almost 16,500 (a number greater than half of all U.S. PH-diagnosed patients) Facebook followers who support the rare disease non-profit. In addition to PHA's [Facebook](#) and [Twitter](#) profiles, where patients and caregivers share their stories with the public, PHA's secure [myPHA website](#) (<http://www.myphassociation.org>), launched last spring, has more than 1,200 patient and caregiver members communicating with people who share their form of the rare disease.

"PHA has seen great advancements in the areas of patient and caregiver support, medical education, PH Care Center accreditation, and research leading to 14 FDA-approved treatments — more than those for all but two of the nearly 7,000 identified rare diseases," said PHA President and CEO Rino Aldrighetti. "We are fortunate that at a time when social networking is key to raising the voice of rare diseases, the unique nature of PHA strengthens our awareness efforts which, in turn, empowers PH patients and their families."

Rare Disease Day is a global initiative to raise awareness among the general public and decision-makers about rare diseases and their impact on patients' lives. A disease or disorder is defined as rare in the U.S. when it affects fewer than 200,000 Americans. In keeping with the international spirit of Rare Disease Day, PHA will also highlight global resources through public and closed social media communications. PHA's global partnerships have created new opportunities for the worldwide PH community, and PHA serves as a model for more than 70 international PH organizations.

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 extend and improve the lives of those affected by PH; its vision is a world without PH, empowered by hope. PHA achieves 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 1 percent of all rated charities. For more information, please go to www.PHAssociation.org, [@PHAssociation](#) on Twitter or www.facebook.com/PulmonaryHypertensionAssociation.

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