



CONTACT

Renee Hockaday

PHA Communications

ReneeH@PHAssociation.org

240-485-0774

Unique International Tweet Chat Hosted by the Pulmonary Hypertension Association Opens New World of Information to Patients with a Life-Threatening Disease

Silver Spring, Md. (October 7, 2015) – Patients from around the world suffering from an under-diagnosed, misunderstood disease will participate in a first-of-its kind live Twitter event. A joint venture between the [Pulmonary Hypertension Association](#) (PHA) and [PHA Europe](#), the event will gather experts to answer questions as they introduce a new source of information for people with pulmonary hypertension (PH).

Our PH Library (www.OurPHLibrary.com) provides resources and information to patients around the world suffering from PH. PHA will host a live Twitter event (or tweet chat) on Monday, October 12, at 12:30 p.m. ET to discuss the website and answer questions about PH, its symptoms and ways to cope with the disease.

Participating in the tweet chat will be experts in the field of pulmonary hypertension, including a PH specialist, caregivers, a PH patient and representatives from PHA and PHA Europe. These individuals will offer assistance in navigating the Our PH Library website and help chat participants learn more about the disease.

To participate in the Our PH Library tweet chat, please go to the PHA twitter page, [@PHAssociation](#) and use the hashtag [#PHLibrary](#) in all tweets that are directed to the expert panel and other chat participants.

PH is high blood pressure in the arteries of the lungs that affects the functioning of the heart and can lead to death by right heart failure. With symptoms that include shortness of breath and chest pain, PH is often misdiagnosed as asthma or another less-threatening disease. Without proper treatment, the average survival rate for someone with PH can be as low as 2.8 years after diagnosis.

Our PH Library provides information on PH and a library of more than 200 high quality resources developed by patient groups around the world for individuals diagnosed with the condition and their family members and caregivers. The library includes an easy search function, which enables users to search for resources on specific topics related to the disease and find relevant materials. Our PH Library brings together resources on pulmonary hypertension from across the globe in a user-friendly format, so patients, families and caregivers can easily access the information they need. Resources are offered in several languages.

“PHA and PHA Europe are proud to collaborate with other organizations around the world on

this project. PHA is happy to host this tweet chat to raise awareness and connect with the global community of patients, caregivers and medical professionals,” said Rino Aldrighetti, PHA President and CEO. “As PHA approaches our 25th anniversary, we have come a long way in improving patient care and outcomes. The Our PH Library website is another tool to help navigate this devastating disease.”

The website is divided into three modules – About PAH, Research and Treatments, and Support – to make learning about, living with and coping with PAH more manageable. It offers resources in more than 20 languages and lists more than 70 patient groups in the patient organization directory. The list encourages patients with PH and their families and caregivers to contact patient groups in their local countries as well as increase awareness of the resources available to them in their language, driving traffic to global PH organization websites via the Index of Resources.

Our PH Library was developed with an educational grant provided by Actelion Pharmaceuticals, Ltd.

PHA, which marks its 25th anniversary in 2016, provides support for patients and caregivers, awareness and advocacy, medical education, and research to find ways to prevent and cure PH. November is [Pulmonary Hypertension Awareness Month](#), and PHA will highlight the awareness month theme — “Coloring the World Periwinkle for 25 Years” — with a new public service awareness campaign Heart2CurePH (#Heart2CurePH), which will run print, radio and TV advertising educating the public about PH.

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 offered 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 or to support PHA with a donation go to www.PHAssociation.org.

About PHA Europe

PHA Europe was founded in 2003 and is the umbrella organization for national associations of patients living with pulmonary hypertension (PH) in Europe. It is registered in Vienna, Austria, as an international non-profit organization. Membership currently includes 38 PH patient associations from 32 countries. PHA Europe works together with its members to enhance awareness of pulmonary hypertension across Europe, promote optimal standards of care for

people living with the disease, ensure the availability of all approved treatments, and encourage research for new medicines and therapies. Its activities include European awareness raising campaigns, advocacy initiatives at EU level, the dissemination of information about the disease and capacity building programs for its affiliates.

www.phaeurope.org

#