



Photos from the event at the European Parliament

The Call to Action:

1. Improve access to expert care
2. Improve awareness and screening
3. Encourage clinical research and innovation
4. Empower patient associations
5. Ensure availability of psychosocial support

early diagnosis • best treatment • better quality of life • finding a cure

PHA EUROPE
PULMONARY HYPERTENSION ASSOCIATION

for the patients

PHA EUROPE'S CALL TO ACTION

A Call to Action on Unmet Needs of Patients with Pulmonary Hypertension.
Originally launched in the European Parliament in 2012,
it was renewed and relaunched at the European Parliament on April 26th, 2022



WHY ACTION IS NEEDED FOR PULMONARY HYPERTENSION

Most of us take breathing for granted. People living with pulmonary hypertension do not. They often struggle to breathe and doing any kind of activity can be difficult. Pulmonary hypertension (PH) is the broad, inclusive name for a group of chronic diseases that affect the lungs and the heart. Some forms of PH are rare, progress rapidly and are debilitating and deadly. In PH, the arteries that carry blood from the heart to the lungs narrow for reasons that are not yet entirely understood. The heart struggles to pump blood through the narrowed arteries, resulting in high blood pressure in the lungs and the enlargement of the heart. Eventually, the overworked heart wears out, and heart failure and death can result.

Global estimates suggest that PH affects 20-70 million people worldwide. It may be caused by several underlying conditions, but often there is no identifiable cause. Symptoms usually do not appear until the disease has progressed, meaning diagnosis and treatment may be delayed. PH does not discriminate, and while it is more common among females it occurs irrespective of age, race, and ethnicity. It can strike our colleagues, our neighbours, our family, and ourselves.

Unfortunately, generally approved treatments exist for only around one percent of people diagnosed with PH – those with two rare forms of the disease: Pulmonary arterial hypertension (PAH), Chronic thromboembolic pulmonary hypertension (CTEPH). Even with therapy, most patients with these forms of the disease have a reduced life expectancy, although timely diagnosis and better disease management can significantly improve that timeline.

The struggle to do something as essential as breathing is both frightening and debilitating and has a dramatic impact on people's lives. That is why this call to action is urgently needed.