Call to action
April 2022
Gergely Meszaros
PHA Europe
Project manager
Call to action in 2012

Launched in the European Parliament

# Call to action 2022
Medical review committee

Prof. Marc Humbert
Prof. Marion Delcroix
Prof. Adam Torbicki

Prof. Marius Hoeper
Ass. Prof. Gabor Kovacs
Ass. Prof. Laurent Godinas

Roundtable members

Launch event speaker

34 members

# Call to action 2022

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PHA EUROPE for the patients

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# Call to action 2022
Freshly looking, modern paper
New visuals

Multiple purposes
- Standalone use
- Space saving
- More emphasis on these lists & content

SYMPTOMS OF PH
- Shortness of breath during physical activity, such as climbing stairs
- Shortness of breath when bending forward
- Fatigue
- Dizziness or light-headedness during exercise
- Fainting spells
- Chest pain during exercise
- Swelling of the ankles, stomach, and/or legs
- Bluish colour in the lips and skin, especially during and after exercise

A document describing standards of care for pulmonary hypertension centres should consider inclusion of standards about

- Patient-centred care
- Referral
- Diagnosis and assessment
- Care and treatment
- Patient monitoring, review, and follow-up
- Shared care
- Psychosocial support and palliative care
- Communication with healthcare professionals outside the expert centre
- Education and training of expert centre staff
- Research and development
- Transition of patients from paediatric to adult services
- Thoracic surgery and transplant

# Call to action 2022
What we kept...

• 5 main pillars
  • Access to treatment and expert centres
  • Clinical research and innovation
  • Psychosocial support
  • Empowered patient groups
  • Improved awareness and screening

# Call to action 2022
Call to action: Combined sections working doc

Why Action is Needed for Pulmonary Hypertension

Most of a task breathing for granted. People living with pulmonary hypertension do not. Having enough energy 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 new, progressive, rapidly fatal, and debilitating. It is PH, the serious that cause breath to the heart to the lungs and the heart to damage the lungs. Eventually, the overworked heart will fail, and heart failure and death can result.

Some estimates suggest that PH affects 0.13 million people worldwide. It may be caused by smoking, other underlying conditions, or other things that you are not sure of. 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 neighbors, our family, and ourselves.

Unfortunately, approved treatments exist for only about 5 percent of people diagnosed with PH. Those with rare forms of the disease, pulmonary arterial hypertension (PAH), chronic thromboembolic pulmonary hypertension (CTEPH), and PH due to chronic obstructive pulmonary disease (COPD), and those with the rarest 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 exhausting, and has a dramatic impact on people’s lives. That is why the call to action is needed.

Ph does not discriminate. Although some forms are more common in women and in women, and untreated people in living. The symptoms of PH, which may include shortness of breath, fatigue, dizziness, chest pain, and a heart attack, can be misdiagnosed. Heart failure can further reduce quality of life and can lead to death.

Types of Pulmonary Hypertension

Pulmonary hypertension is the broad term for a group of diseases that affect the heart. There are five subtypes of PAH, and some are more frequent. Each subtype has different underlying causes and may be treated differently. In each, underlying factors like some form of PAH may be misdiagnosed and even harmful, but are not as prevalent as others.

# Call to action 2022
Patient empowerment

“a process through which people gain greater control over decisions and actions affecting their health” and should be seen as both an individual and a community process.

Empower patients to make contributions through a proactive inclusive approach to ensure that people with PH are able to talk about their experiences and treatment, providing the input needed to make decisions fundamental to the lives of people living with PH


High or low literacy levels have different impacts, notably on the individual’s health and the efficiency of the health system. People with higher health literacy levels demonstrate healthier behaviours, are more adherent to treatment, report less chronic illness, feel healthier, and live longer.*

Importance:
- New technologies
- Demographic change and sustainability
- Self care and better adherence to therapies
- More efficient use of resources
- Mitigate the adverse effects of chronic diseases
- Increase the patients’ quality of life

... on a patient associations level

Facilitate real-life information exchange between PH patient associations and other stakeholders, and involve them in debates and discussions from the beginning

Participation in
• the creation and review of medical guidance
• steering committees for clinical trials
• scientific meetings at regulatory bodies
• advocacy activities in European and national level (eg. ERN, HTA)

Policy and decision makers at all levels should actively seek and involve patient associations to incorporate the perspectives of people living with PH

# Call to action 2022
EMPOWER PATIENT ASSOCIATIONS

Increase the capability of patient associations to serve patients more effectively, particularly through the provision of accurate, evidence-based, regularly updated information

- Up-to-date and reliable information
- Brochure, webpage, webinars
EMPOWER PATIENT ASSOCIATIONS

Encourage balanced financial support, including government funding, for patient associations so that they can continue to be independent.

- Long term commitment from various sponsors
- Diversified source of fundings
- Financial calls for NGOs

# Call to action 2022
PLEASE SUPPORT US, PH ASSOCIATIONS, SO WE CAN HELP PATIENTS LIVING WITH PULMONARY HYPERTENSION!