Declaration for Action on Pulmonary Arterial Hypertension: Advancing Early Diagnosis, Equitable Access, and Societal Momentum

Pulmonary Arterial Hypertension (PAH) is a rare, progressive, and life-threatening disease characterized by elevated blood pressure in the arteries of the lungs[1]. Emerging data suggest that PAH continues to contribute to a meaningful burden of disease across Asia, including preventable morbidity and mortality.[2] Despite this burden, policy responses have been limited, and access to timely diagnosis and appropriate treatment remains a challenge.[3]

Average PAH diagnosis journey may exceed **two years**[4-5] and an estimated median survival rate of only **3 to 5** years without treatment.[6]

Current treatments extend median survival to only **5 to 7 years**[7], and with a deteriorating quality of life as the disease progresses.

PAH has many hidden societal costs, including healthcare system expenses, productivity loss, and increased caregiver burden.[8-9]

The Declaration envisions a future in which every person living with PAH can benefit from[10]:

Early awareness and accurate diagnosis:
To enable earlier intervention and improved outcomes.

Sustainable and equitable access to appropriate therapeutic options:
Including all available and appropriate options, established and innovative.

Comprehensive, multidisciplinary, and patient-centered care:
Integrating specialist expertise and holistic services, and coordinated support across healthcare systems.

Quality of life and active participation in decision-making:
Upholding patients' rights to be informed and engaged in decisions affecting their care.

While therapeutic options are available, access to these therapies is not uniform. In Asia Pacific, reimbursement pathways are uneven, diagnostic tools may be limited, and specialist care is concentrated in urban centres.[2]

However, it is important that individuals living with PAH have access to appropriate screening, diagnosis, and care, in accordance with current clinical guidelines and best practices.

Within the scope of each organization's role and responsibility, this Declaration calls for urgent advocacy in the following areas[10].

Advancing Awareness and Diagnosis

- Launch education campaigns for healthcare professionals to improve disease recognition and referral, in collaboration with relevant medical societies.
- Encourage the strengthening of diagnostic pathways and specialist expertise, particularly in regional and rural settings.
- Support updates to diagnostic protocols across health systems and advocate for clinical guidelines for common conditions (e.g. heart failure, asthma, COPD) to reference PAH as a potential cause for unexplained symptoms.

Access to Evidence-Based Treatment

- Strengthen the voice of patients in treatment decision-making by supporting education and advocacy for patients and caregivers.
- Advocate for early access to PAH therapeutic options, aligning clinical practice with recognized international guideline recommendations.
- Support efforts to expand reimbursement for guideline-recommended treatments, and for expanded eligibility for early-stage treatment reimbursement where appropriate.
- Support the expansion of reimbursement schemes for rare diseases including PAH, recognizing the financial impact of PAH diagnosis.
- Explore and foster innovative, multi-stakeholder solutions to improve treatment access and availability in resource-limited settings.

Accelerate Societal Momentum and System Strengthening

- Advocate for inclusion of PAH in national rare disease policies and frameworks to enable broad access to appropriate therapeutic medicines.
- Support the introduction of patient-centric frameworks that inform policy, legislation, research, and HTA assessments.
- Advocate for the designation and funding of centers of excellence for specialized PAH care.
- Call for the establishment of local and regional patient registries to improve transparency and real-world evidence.
- Elevate public awareness for PAH by amplifying the patient voice and highlighting the disease burden and unmet needs for financial and social support.

Representing patient groups, healthcare providers, non-governmental organizations and the biopharmaceutical industry, this Declaration reflects a shared commitment to strengthening awareness, diagnosis, and care for PAH across the region, and to working collaboratively to support meaningful, sustainable improvements for people living with PAH.

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