Declaration for Action on Pulmonary Arterial Hypertension (PAH)

Advancing Early Diagnosis, Equitable Access, and Societal Momentum

Date: 20 February 2026

Preamble

Pulmonary Arterial Hypertension (PAH) is a rare, progressive, and life-threatening disease characterized by elevated blood pressure in the arteries of the lungs.[1] The estimated prevalence of PAH is between 15 to 50 per million globally[2][3] with approximately 26,000 new PAH cases identified annually in the Asia Pacific region[4]. Emerging data suggest that PAH continues to contribute to a meaningful burden of disease across Asia, including morbidity and mortality[4]. Despite this burden, policy gaps remain for access to timely diagnosis and appropriate treatment[4].

Many PAH patients experience significant breathing difficulties that impact daily activities.[5,] Like other rare diseases, PAH contributes to hidden societal costs, including healthcare system expenses, productivity loss, and increased caregiver burden. [6,7] According to a survey conducted in 2012, its full impact on patients and their caregivers was still not well recognised, and guidelines may not fully reflect or address their needs.[5]

As PAH is a progressive disease without a cure, patients may require therapy escalation along the life-time course of their disease. [8] While therapeutic options are available, access to these therapies is not uniform[9]. Across the Asia Pacific region, patients experience delayed diagnosis, fragmented care, and non-uniform access to therapeutic

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[1] M. Clinic., "Pulmonary hypertension - Symptoms and causes. Mayo Clinic.," August 15, 2025. [Online]. Available: https://www.mayoclinic.org/diseases-conditions/pulmonary-hypertension/symptoms-causes/syc-20350697.

[2] Humbert M, Sitbon O, Chaouat A, et al. Pulmonary arterial hypertension in France. Am J Respir Crit Care Med. 2006;173(9):1023–1030

[3] Peacock AJ, Murphy MF, McMurray JJV, Caballero L, Stewart S. An epidemiological study of pulmonary arterial hypertension. Eur Respir J. 2007;30(1):104–109

[4] Huang, S., Qiu, J., Wang, A., Ma, Y., Wang, P., Ding, D., Qiu, L., Li, S., Liu, M., Zhang, J., Mao, Y., Yan, Y., Xu, X., & Jing, Z. (2025). Burden of pulmonary arterial hypertension in Asia from 1990 to 2021: Findings from Global Burden of Disease Study 2021. Chinese medical journal, 138(11), 1324–1333. https://doi.org/10.1097/CM9.0000000000003559

[4] Delcroix, M., & Howard, L. (2015). Pulmonary arterial hypertension: the burden of disease and impact on quality of life. European respiratory review : an official journal of the European Respiratory Society, 24(138), 621–629. https://doi.org/10.1183/16000617.0063-2015

[5] PHA Europe, "The impact of pulmonary arterial hypertension (PAH) on the lives of patients and carers: results from an international survey," PHA Europe, Sep. 2012. [Online]. Available: https://www.phaeurope.org/wp-content/uploads/PAH_Survey_FINAL.pdf

[6] Exposto, F., Hermans, R., Nordgren, Å., Taylor, L., Sikander Rehman, S., Ogley, R., Davies, E., Yesufu-Udechuku, A., & Beaudet, A. (2021). Burden of pulmonary arterial hypertension in England: retrospective HES database analysis. Therapeutic advances in respiratory disease, 15, 1753466621995040. https://doi.org/10.1177/1753466621995040

[8] Humbert M et al(2022). 2022 ESC/ERS Guidelines for the diagnosis and treatment of pulmonary hypertension. European heart journal, 43(38), 3618–3731. https://doi.org/10.1093/eurheartj/ehac237

[9] Huang et al., "Burden of pulmonary arterial hypertension in Asia," 1324–33.

treatment[9]. Therefore, it is important that individuals living with PAH have the right access to appropriate screening, diagnosis, and care, in accordance with current clinical guidelines and best practices.

We, the undersigned, recognize the need to address systemic barriers faced by the PAH community and to advocate for the inclusion of PAH within national health and rare disease agendas. We urge policymakers to consider PAH as a policy priority to help reduce the burden of this disease.

Vision Statement

We envision a future in which every person living with PAH can benefit from:

- **Early awareness and accurate diagnosis:** Promoting and increasing patient awareness of PAH's non-specific symptoms to enable earlier intervention and improved outcomes.
- **Sustainable and equitable access to appropriate therapeutic options:** Supporting appropriate access to therapies recommended by recognized international guidelines, including all available options, established and innovative.
- **Comprehensive, multidisciplinary, and patient-centered care:** Encouraging models of care that integrate specialist expertise, 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.

Within the scope of each organization's role and responsibility of each organization, we call for urgent advocacy in the following areas:

Strategic Commitments

1) Advancing Awareness and Diagnosis

Delays in diagnosis remain common due to non-specific symptoms and limited awareness[10]. Supporting earlier recognition and referral can help ensure that people reach specialist care in a timelier manner.

The average PAH diagnosis journey may exceed two years, as early symptoms are often mistaken for other conditions such as asthma or COPD[11]. To address these delays, we propose the following advocacy initiatives:

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[10] Small, M., Perchenet, L., Bennett, A., & Linder, J. (2024). The diagnostic journey of pulmonary arterial hypertension patients: results from a multinational real-world survey. Therapeutic advances in respiratory disease, 18, 17534666231218886. https://doi.org/10.1177/17534666231218886

[11] Didden, E. M., Lee, E., Wyckmans, J., Quinn, D., & Perchenet, L. (2023). Time to diagnosis of pulmonary hypertension and diagnostic burden: A retrospective analysis of nationwide US healthcare data. Pulmonary circulation, 13(1), e12188. https://doi.org/10.1002/pul2.12188

- Launch education campaigns for healthcare professionals to improve disease recognition and referral, including content on pulmonary hypertension and PAH in professional development modules, in collaboration with the relevant medical societies.
- Encourage the strengthening of diagnostic pathways, including improved availability of key investigations (e.g., echocardiography, right heart catheterization) 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.

2) Access to Evidence-Based Treatment

We acknowledge that every PAH patient should have long-term and sustainable access to appropriate therapeutic options, independent of personal financial status. We commit to advocating for measures that promote equitable, timely, and uninterrupted access to PAH treatment, in line with recognized international guidelines:[12]

- Strengthen the voice of patients in treatment decision-making by supporting education and advocacy for patients and caregivers, including the translation of clinical guidelines into patient-friendly formats.
- 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 appropriate, broad 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.

3) Accelerate Societal Momentum & System Strengthening.

PAH can have wide-ranging personal, social, and economic impacts, including effects on daily life, employment, and caregiver responsibilities.[13] We recognize the need to address the socioeconomic impact of PAH by advocating for increased awareness and support:

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[12] Chin, K. M., Gaine, S. P., Gerges, C., Jing, Z. C., Mathai, S. C., Tamura, Y., McLaughlin, V. V., & Sitbon, O. (2024). Treatment algorithm for pulmonary arterial hypertension. The European respiratory journal, 64(4), 2401325. https://doi.org/10.1183/13993003.01325-2024

[13] Guillevin, L., Armstrong, I., Aldrighetti, R., Howard, L. S., Ryftenius, H., Fischer, A., Lombardi, S., Studer, S., & Ferrari, P. (2013). Understanding the impact of pulmonary arterial hypertension on patients' and carers' lives. European respiratory review : an official journal of the European Respiratory Society, 22(130), 535–542. https://doi.org/10.1183/09059180.00005713

- Advocate for the inclusion of PAH in national rare disease policies and frameworks to enable patient access to evidence-based treatment.
- Support the introduction of patient-centric frameworks that inform policy, legislation, research, and HTA assessments, including consideration of patient-reported outcomes and indirect costs.
- Advocate for the designation and funding of centres of excellence for specialized PAH care, with referral networks and updated treatment protocols.
- Call for the establishment of local and regional patient registries to improve transparency and leverage real-world evidence and lived experiences from patients to enhance awareness and education.
- Elevate public awareness for PAH by amplifying the patient voice and highlighting the disease burden and unmet needs for financial and social support.
- As treatment outcomes improve, policy approaches should also consider pathways that create a social framework for people living with PAH to remain socially and economically engaged, including access to vocational guidance and alternative work arrangements where appropriate.

Call to Action

This declaration reflects a unified 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. We, representing patient groups, healthcare providers, nongovernmental organizations and the biopharmaceutical industry, recognize the importance of equitable access to timely diagnosis, accurate information and sustainable care as fundamental pillars of PAH management. We affirm our dedication in supporting this cause through advocacy and collaboration.

Agreed virtually in English on February 20, 2026.

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