PVRi

Meet our IDDI Workstreams, Specialty & Regional Task Forces

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Innovative Drug Development Initiative (IDDI) Workstreams

The IDDI is a global, collaborative forum where clinicians, academics, pharma and industry partners, and drug regulators openly discuss questions surrounding the future of trials involving novel drugs. The IDDI aspires to explore novel approaches for combating and treating PVD and PH, focusing strongly on patient needs.

Access to Care Workstream

Leads: Vijay Balasubramanian, Yan Liu, Alex Kantorovich & Sandeep Sahay

The Workstream identifies gaps and regional variation in PH care to improve access to diagnosis, treatment, and education worldwide.

Recent initiatives

- Published Global Resource Disparities Between Pulmonary Hypertension Centres: Results From the International Survey by the PVRI IDDI Access to Care Workstream (Pulmonary Circulation, Jan 2026)
- Scoped the development of an Access to Care pilot consultative service informed by survey findings

Looking ahead

- Continue collaboration with regional Task Forces, including Latin America and India

> **“Implementing a global programme requires careful consideration of legal, logistical, and feasibility challenges across different healthcare systems”**

Want to get involved?
Experts with experience in webinars or consultative care models are encouraged to get in touch.

Lung Transplantation in PH Workstream

Leads: Howard Castillo & Reda Girgis

This Workstream addresses global inequities in access to lung transplantation for people with PH across diverse healthcare systems.

Recent initiatives

- Published *Approach to Lung Transplantation in PAH: A Delphi Consensus on Behalf of the Transplant Task Force of the Pulmonary Vascular Research Institute* (Pulmonary Circulation, April 2025)
- Delivered a paediatric-focused webinar, *Paediatric Bridge to Transplant*, July 2025, featuring expert presentations on mechanical support strategies for bridging to lung transplantation across the paediatric age spectrum

Looking ahead

- Plan a clinician-focused webinar to promote earlier referral to lung transplantation

- Continue collaboration with the PH Group III Workstream on a Delphi survey examining lung transplantation in PH-ILD
- Develop a PH provider survey to explore clinician perceptions, referral patterns, and barriers to referral, alongside a complementary patient survey
- Develop pre- and post-transplant white papers and a dedicated paediatric bridge-to-lung-transplantation paper

> **"There remains a need to better understand barriers to timely referral for lung transplantation in PH."**

Want to get involved?
Clinicians and patients interested in transplant access and referral pathways are invited to engage.

New Modalities & Technologies (NMT) Workstream

Leads: Luke Howard & Namita Sood

The NMT Workstream increases awareness of emerging technologies for PH and right heart failure diagnosis and treatment.

Recent initiatives

- Activated six new subgroups covering inhalation therapies, new therapies, device therapies, AI, metabolic & microbiome, and imaging technologies
- Advanced work on device-based interventions for the diagnosis and treatment of PH
- Established a dedicated Artificial Intelligence (AI) working group
- Established a metabolic and microbiome working group to evaluate targeting inflammation in PH and right ventricular dysfunction
- Initiated development of review manuscripts within the inhalation therapies and new therapies subgroups

Looking ahead

- Evaluate the role of device-based interventions in the treatment and management of PH
- Explore the use of imaging technologies to assess treatment efficacy and disease progression
- Assess how AI can be optimally incorporated into clinical practice and clinical trials

> **“The breadth of activity across multiple subgroups highlights the wide range of emerging technologies being explored in PH.”**

Want to get involved?
Colleagues with expertise in medical devices, digital health, imaging, AI, data science, or translational technology development in PH are encouraged to participate.

Paediatric Clinical Trial Design & Endpoints Workstream

Leads: Steve Abman & Sylvia Nikkho

This Workstream advances paediatric PH drug development through age-appropriate trial design, extrapolation strategies, and real-world evidence.

Recent initiatives

- Published ‘*Enhancing Drug Development in Paediatric PAH*’ (Pulmonary Circulation, July 2025)
- Shifted focus to early developmental PVD, with dedicated sessions on BPD-PVD and a manuscript outline in progress
- Hosted *Challenges of Developing Novel Therapies for Bronchopulmonary Dysplasia-Associated PH* (Nov 2025)
- Delivered paediatric trial design sessions at PVRI 2025 Rio
- Maintained monthly workstream meetings featuring scientific lectures and collaborative planning

Looking ahead

- Host a joint Paediatric IDDI and Task Force meeting ‘Breaking New Collaborative Ground in Paediatric PH’ at PVRI 2026 Dublin
- Submit manuscripts on BPD-PVD and paediatric extrapolation frameworks
- Expand collaboration with the PH Group III and technology-focused Workstreams to integrate digital tools and innovative modalities

> **“Early regulatory engagement and inclusion of patient perspectives are essential in paediatric trial design.”**

Want to get involved?
Experts in adaptive paediatric trial design for rare paediatric conditions are invited to contribute.

Patient Engagement & Empowerment Workstream

Leads: Wendy Gin-Sing & Hall Skaara

This Workstream strengthens patient understanding, confidence, and involvement in PH care and research.

Recent initiatives

- Launched *How to empower yourself & others, an 11-part Patient Engagement & Empowerment video series* designed to support people living with PH, their families, and carers
- Developed co-brandable guides and leaflets for patient associations to share freely with their members

Looking ahead

- Develop practical proposals to increase acceptance of patient involvement in clinical trials, demonstrating how lived experience adds value across the trial lifecycle
- Improve patient understanding and participation in clinical trials by clearly explaining trial purpose, processes, assessments, and potential benefits for individuals, the patient community, and scientific progress
- Developing guidance to challenge traditional study design by embedding patients and service users as partners from inception

“Accessible, patient-focused education is most effective when developed collaboratively.”

Want to get involved?
Patient representatives, HCPs, and industry partners are encouraged to collaborate

PH Group III Workstream

Leads: Steven Nathan & Sylvia Nikkho

The Workstream advances understanding, diagnosis, and treatment of PH associated with chronic lung disease.

Recent initiatives

- Published *Significance of Pulmonary Vascular Dysfunction in COPD* (Pulmonary Circulation, Aug 2025)
- Progressed four COPD-focused manuscripts, marking a strategic shift from ILD-PH to COPD-PH
- Delivered sessions at PVRI 2025 Rio

Looking ahead

- Complete and publish the remaining COPD-PH manuscripts
- Develop guidance on clinical trial endpoints for COPD-PH
- Expand work diagnostic approaches and digital health solutions

> **“Gaps remain in digital diagnostic solutions, and expertise in imaging and AI-driven analytics is welcomed.”**

Want to get involved?
Researchers with access to shared datasets on phenotypes and clinical outcomes are encouraged to contribute.

Real World Evidence & Data Workstream

Leads: Greg Elliot & Kellie Morland

The goals of this workstream are to strengthen the research community's understanding of Real-World evidence in PH to facilitate clinical research advances and improve patient care.

Recent initiatives

- Initiated a Delphi survey to define a core data set for global PH registries
- Completed a scoping review of data elements collected within national PH registries

Looking ahead

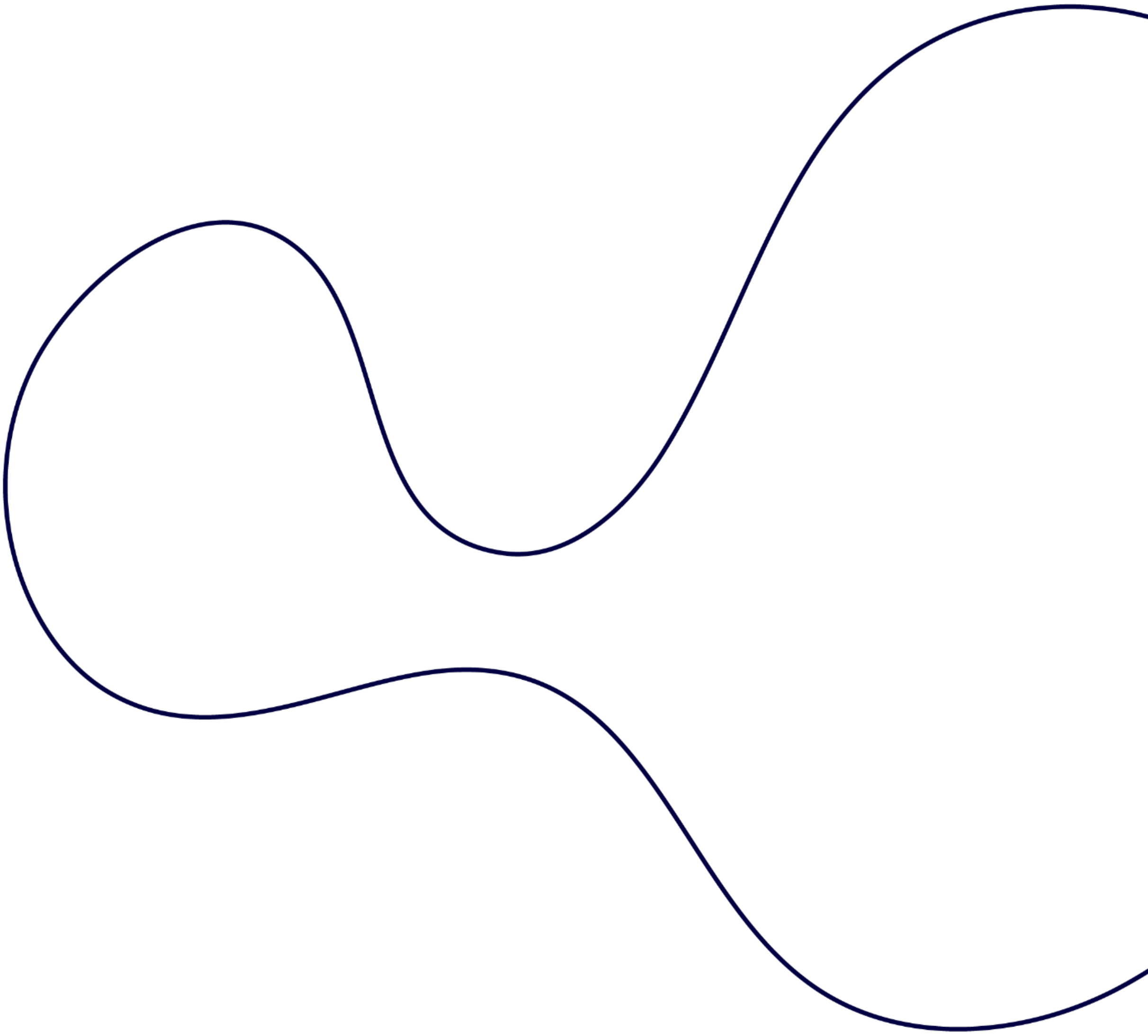
- Complete Rounds 2 and 3 of the Delphi and analyse the data
- Publish and implement Delphi and scoping review findings

> **“Standardising real-world data requires broad international participation.”**

Want to get involved?
Registry leads and data contributors, particularly from low- and middle-income countries, are invited to join the upcoming Delphi Rounds 2 and 3.

Regional Task Forces

Our Regional Task Forces focus on the key challenges facing patients, clinicians and researchers in their country or region.



Central Asia Task Force

Lead: Talant Sooronbaev

The Central Asia Task Force aims to strengthen PH diagnosis, care, and research across the region through education, collaboration, and capacity building. A core focus is supporting sustainable clinical networks, advancing regionally relevant research, and improving equitable access to PH care in low- and middle-income country (LMIC) settings.

Recent initiatives

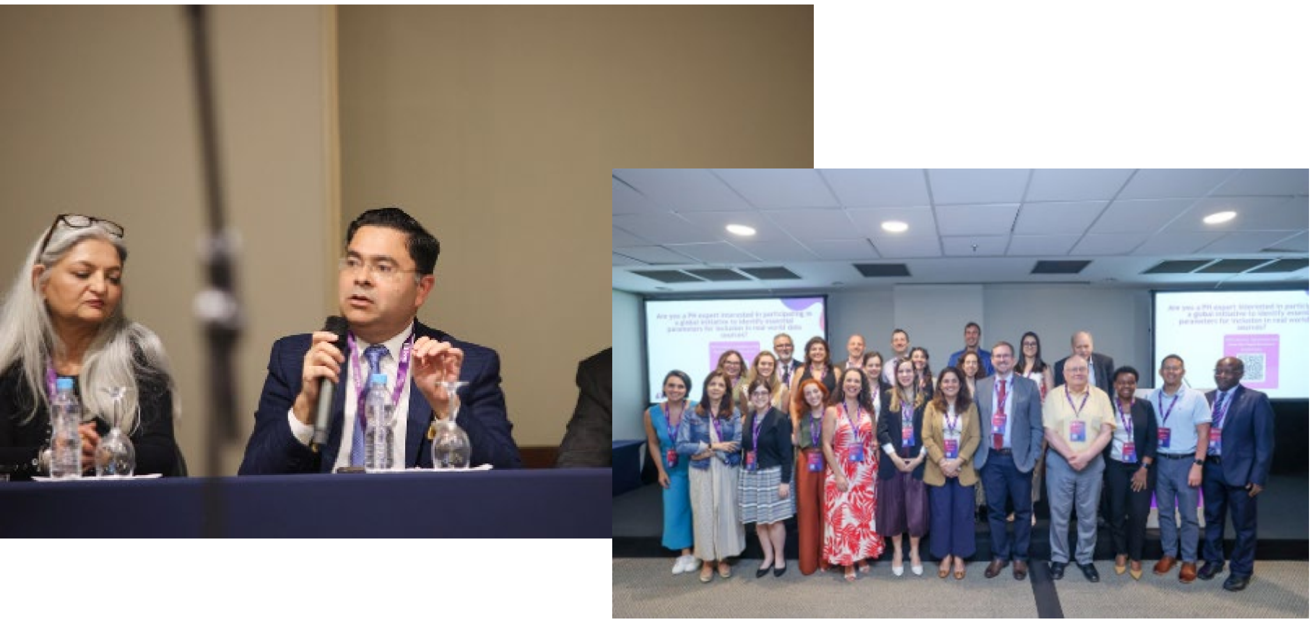
- Strengthened collaboration with the High Altitude Task Force, working closely with Silvia Ulrich's team to align research efforts on high-altitude–related PH
- Supported PH service development across Central Asia through the continued establishment of PH centres and expansion of regional PH registries

Looking ahead

- Convene a Central Asia Task Force meeting in 2026
- Collaborate with India and LATAM Task Forces on guideline development for low- and middle-income settings
- Work towards a consensus approach to non-invasive PH diagnosis

> **"Stronger integration with PVRI networks and other regional Task Forces accelerates progress in care, research, and education."**

Want to get involved?
We are seeking PVRI members to support webinars and training initiatives, particularly in right heart catheterisation, echocardiography, and PH clinical management.



China Task Force

Leads: Zhenguo Zhai & Lan Zhao

The China Task Force supports education, research collaboration, and knowledge exchange in PH across China. It aims to strengthen links between national PH centres and PVRI's global network.

Recent initiatives

- Expanded PVRI-linked national clinical networks for PH, CTEPH, and PE
- Initiated new collaborative research programmes and interventional training activities

Looking ahead

- Establish an in-country Young Education Group in China, operating within the PVRI framework
- Host global online meetings to connect young scientists to discuss imaging & research issues
- Host next annual PVRI China Task Force meetings
- Initiate PH-ILD research in early 2026

> **"Large national networks provide a strong foundation for education, training, and collaborative PH research."**

Want to get involved?
We are seeking PVRI members to support webinars and global online meetings for early-career researchers, particularly in imaging and PH research

India Task Force

Lead: Prashant Bobhate

The India Task Force aims to strengthen PAH care, research, and education in India through regionally relevant guidance and collaboration. The focus is on improving early diagnosis and standardising care.

Recent initiatives

- Finalised a national PAH guideline manuscript for submission to Pulmonary Circulation, representing the first-ever India-wide guidance developed through the PVRI India Task Force
- Initiated a multicentre yoga trial in PAH
- Implemented digital stethoscope screening initiatives to support earlier detection

Looking ahead

- Publish and disseminate the Indian PAH guidelines
- Expand participation in multicentre registries and pragmatic studies
- Host the PVRI India Biannual Conference (February–March 2026) and disseminate the national Indian PAH guideline

“Early multidisciplinary engagement is essential to develop guidance and research that is feasible, scalable, and relevant in the Indian healthcare context.”

Want to get involved?
PVRI members interested in PH guidelines implementation or research collaboration in India are encouraged to connect with Prashant Bobhate.

LATAM Task Force

Leads: Gabriel Diaz, Gustavo Heresi, Vinicio de Jesus Perez, Tomas Pulido, Mauricio Orozco-Levi & Rogerio Souza

The Task Force aims to strengthen regional collaboration in PH across Latin America; support education, research, and knowledge exchange tailored to regional clinical needs; and improve integration between adult and paediatric PH communities and promote engagement with patient organisations.

Recent initiatives

- Expanded membership across adult and paediatric PH
- Launched a regional webinar series focused on PH in Latin America:
    - *PH in Latin America*, October 2025
    - *Group 2 PH — associated with heart failure and fluid retention*, December 2025
- Published *Why Wait for Sick People to Get Sicker? The Paradox of the Treatment of Patients With PAH’* (Pulmonary Circulation, Nov 2025)

Looking ahead

- Delighted to present the 6th Paediatric and 3rd Adult LATAM PH Symposium in Lima (September 2026). All PVRI members are welcome to join
- Continue scientific output from LATAM contributors, including recent publications and manuscripts in development for 2025–2026
- Increased participation in global PH registries
- Strengthening partnerships with professional societies and patient advocacy organisations

“Regionally led, Spanish-language education is transforming engagement and building a powerful, connected PH community across Latin America.”

Want to get involved?
Clinicians, researchers, and patient advocates with an interest in PH in Latin America are welcome to participate.

Saudi Association for PH (SAPH) Task Force

Leads: Abdullah Al Dalaan & Hassan Alorainy

The SAPH Task Force provides a vital collaborative platform for PH clinicians and academics across Saudi Arabia and the wider Eastern Mediterranean and Gulf region.

Recent initiatives

- Successfully delivered the 18th SAPH Annual Conference, February 2025, Riyadh
- Delivered multiple scientific workshops and educational sessions

Looking ahead

- Welcome the PH community to the 19th SAPH Annual Conference (Jeddah, February 2026)

> **"Ongoing collaboration with PVRI and international PH societies remains central to strengthening clinical practice and research capacity in the region."**

Want to get involved?
Regional clinicians and researchers are encouraged to connect.

Sri Lanka Task Force

Leads: Laura Price, Mayooran Shanmuganathan & Shirmila Withana

The Sri Lanka Task Force aims to improve recognition, diagnosis, and care for PH through early detection, education, and development of structured referral pathways and national guidelines

Recent initiatives

- Initiated plans for an echocardiography-based early detection programme, online training, and mentoring
- Began development of a centralised national PH registry

Looking ahead

- Establish PH hubs across national and teaching hospitals
- Deliver targeted training to improve PH detection, referral, and prioritisation for right heart catheterisation
- Generate preliminary national PH data to support engagement with health authorities and policy recognition

> **“Building sustainable, locally relevant PH services requires early diagnosis, national coordination, and investment in clinical capacity”**

Want to get involved?
Clinicians, educators, and researchers with experience in PH diagnosis, echocardiography, service development, or registry work are encouraged to engage. Connect with Laura Price at PVRI 2026 Dublin using the congress app.

Disease and Speciality Task Forces

Our Disease and Specialty Task Forces focus on specific areas of PVD. They support our community in understanding and implementing our vision and mission.

Exercise Task Force

Leads: Franz Rischard, David Systrom & Aaron Waxman

This international, multi-speciality group, supported by PVRI, is made up of cardiologists and pulmonologists with expertise in exercise testing and interpretation.

Recent initiatives

- Submitted the manuscript "Knowledge gaps and controversies on cardiopulmonary exercise testing in the assessment of PVD. An official statement of the Pulmonary Vascular Research Institute Exercise and Right Ventricular Function Task Force" to Pulmonary Circulation

Looking ahead

- Holding a Task Force members meeting during PVRI 2026 Dublin to discuss future directions

> **"Exercise testing provides unique insights into pulmonary vascular and right ventricular function, but its value depends on careful interpretation and standardisation across clinical settings"**

Want to get involved?
Experts in exercise physiology are invited to engage.

High Altitude Task Force

Leads: Aastha Mishra & Silvia Ulrich

The Task Force brings together researchers worldwide who are interested in the effects of hypoxia and high altitude on the pulmonary vasculature and related physiology.

Recent initiatives

- Establishment of bi-monthly webinars in high-altitude medicine and research
- Organisation of in-person scientific meetings, both in conjunction with the PVRI Annual Congress and in other regions, to increase visibility of PVD at high altitudes

Looking ahead

- Continue delivery of the High Altitude webinar series
- Formation of a dedicated task group to define PH and right heart failure at high altitude
- Further in-person meetings, including:
    - PVRI 2026 Dublin
    - Dharamshala, India (October 2026)
    - World High Altitude Congress in Kyrgyzstan in 2027

> **“By combining webinars with in-person meetings, the Task Force is translating high-altitude research into shared understanding and clinical progress.”**

Want to get involved?
Researchers interested in hypoxia and altitude are encouraged to join.

Imaging Task Force

Leads: David Kiely, David Levin, Andrew Swift & Rebecca Vanderpool

The group aims to provide a forum for clinicians and researchers to discuss the role of imaging in suspected and known PAH. It also seeks to standardise imaging protocols to enhance international clinical and research collaboration.

Recent initiatives

- Held a satellite meeting at PVRI 2025 Rio featuring presentations discussing international imaging datasets, analysis methods, and clinical impact

Looking ahead

- Update the 2019 *Statement on imaging and PH from the Pulmonary Vascular Research Institute (PVRI)* article
- Launch a series of webinars and online Task Force meetings throughout the year to enhance engagement with our members and the PVRI community

> **“More input is needed on best imaging practices worldwide, especially from centres with limited imaging availability.”**

Want to get involved?
We are seeking global input on best imaging practices in PH, including protocol standardisation and priority research questions, particularly from centres with limited imaging access.

Infection in PVD (iPVD) Consortium

Leads: Sharilyn Almodovar, Ghazwan Butrous. Navneet Dhillon, Vinicio de Jesus Perez, Michael Lee, Peter Nyasulu & Rudolf Oliveira

The Infection in Pulmonary Vascular Disease (iPVD) Consortium's primary focus is to enhance awareness about the role of infection on PVD, and foster research collaborations in infectious diseases covering basic science, translational and clinical aspects, aiming to better understand its mechanisms and global impact.

Recent initiatives

- Continued delivery of the iPVD Virtual Symposium webinar series throughout 2025, highlighting the latest research on infection and inflammation in PVD

Looking ahead

- Continuation of the iPVD Virtual Symposium webinar series
- Submission of opinion article stemming from the 2025 PVRI Rio panel discussion regarding the diagnosis of schistosomiasis-associated PAH
- Coordinate potential satellite meetings or gatherings for iPVD members at major conferences/events in South Africa, India, Brazil and the US
- Increase participation of emerging investigators, with emphasis in LMIC regions

> **"Infection remains an under-recognised but critical driver of PVD, and global collaboration is essential"**

Want to get involved?
We welcome researchers from Asia to join the iPVD Consortium and contribute to collaborative research and global knowledge-sharing on infection and PVD

Paediatric & Congenital Heart Disease Task Force

Leads: Steve Abman, Maria Jesus del Cerro & Shahin Moledina

The Task Force brings together a global paediatric PH community to advance collaboration, research, and care, with a strong focus on using real-world registry data to improve disease understanding, phenotyping, and clinical trial design.

Recent initiatives

- Currently updating the Paediatric PVD Classification, which was first introduced at the PVRI 2011 Panama meeting

Looking ahead

- Publish the updated Paediatric PVD classification
- Hold the 6th Latin America symposium on PH in children and 3rd symposium in

adults in Lima (Peru) 25-26 September 2026

- Keep alive the collaboration with the IDDI Task Force through monthly webinars focused on paediatric PH

> **“Global collaboration and shared real-world data are essential to improving diagnosis, classification, and care for children with PH”**

Want to get involved?
Paediatric PH clinicians and researchers are encouraged to engage.

PAH-ICON Task Force

Leads: Michaela Aldred & Stefan Graf

PAH-ICON – the International Consortium for the Genetics of Pulmonary Arterial Hypertension (PAH-ICON) is a global consortium uniting basic and clinical science experts to advance PH research through genetics and genomics. By building larger, more diverse international multi-dimensional datasets, the group enables collaborative studies designed to address critical unmet needs in patient care.

Recent initiatives

- Regular monthly meetings throughout the year, alternating scientific presentations and business meetings, fostering research collaboration and sharing genetic data
- Active working groups focusing on topics including clinical genetics ([Clingen PH Gene & Variant Curation Expert Panel](#)); international patient advocacy and research initiatives like [TBX4life;](#) standardisation and harmonisation of phenotypes and endotypes; exploring and pioneering sample and data sharing strategies across boundaries; and twin studies.

Looking ahead

- 6th Annual P(A)H-ICON Symposium at PVRI 2026 in Dublin
- Support PVRI’s planned Genetics Symposium in June 2026
- Identify and undertake pilot projects to push boundaries around sample/data sharing and federated analyses.

> **“Only international collaborations capable of generating thousands of samples from patients with idiopathic and heritable PAH will have the power to help answer the major questions on the role of genetic variation in disease penetrance, phenotype and the clinical course of disease.”**

Want to get involved? If you're a basic or clinician scientist interested in P(A)H genetics, we would love to hear from you.

PH Global Patient Survey (PHGPS) Task Force

Lead: Matt Granato

The Task Force works to amplify the global PH patient voice by analysing and disseminating real-world patient and carer experience data across all PH groups.

Recent initiatives

- Analysed and disseminated PHGPS Phase 1 data, drawing on responses from almost 4,000 patients and carers across 90 countries
- Published *The PHGPS: Understanding the experiences and perspectives of patients* in ERJ Open Research, July 2025
- Published *PHGPS: A Call to Action in Pulmonary Circulation*, July 2025, outlining 10 global priorities to improve equity in PH care and research
- Presented PHGPS findings at international meetings, *including PVRI 2025, through posters* and scientific sessions
- Developed the PHGPS Data & Insights Guide to support responsible access to, and use of, the dataset

Looking ahead

- Planning for PHGPS Phase 2 to assess progress over time and expand representation, particularly in under-represented PH groups and regions
- Preparation of additional manuscripts using PHGPS data, including a paper focused on quality of life and patient-reported outcomes, a dedicated paediatric PH analysis, and analyses focused on PH Groups 2 and 3

Pulmonary Hypertension
Global Patient Survey

10 Calls to Action for Improving Pulmonary Hypertension Care Globally

1. Patients should be investigated rapidly to **reduce the time to PH diagnosis**
2. Patients should have access to a **specialist PH centre with diagnostics and therapeutics** including genetic testing, parenteral prostacyclins and mechanical interventions for management of CTEPH
3. Patient Reported Outcomes Measures (PROMs) should be used to **evaluate quality of life and guide holistic care**, including psychological and rehabilitative services
4. Patients should be empowered to engage in **shared-decision making** in partnership with their clinicians, including managing side effects
5. Patients with PH should be encouraged to access **PH associations** by their healthcare professionals for education and other resources
6. Patients with PH should be assisted in applying to make adjustments to employment or **applying for disability support**
7. Patients with PH should be empowered to engage with **digital and remote healthcare**, where appropriate
8. Patients with **Groups 2, 3 and 5 PH should be better represented** in research and specialist clinical care
9. Patients with PH should be offered the opportunity to **participate in clinical research trials and registries**, that have ideally been co-designed with patients
10. Patients and their carers should be invited to participate in **PHGPS-2** to evaluate progress over time and further widen representation geographically and in Groups 2 and 3

pvrinstitute.org/phgps

> **"PHGPS findings highlight persistent geographical variation in access to specialist care, diagnostics, and research participation."**

Want to get involved?
Researchers and patient organisations are encouraged to engage with PHGPS outputs.

Women's Health Task Force

Leads: Jessica Badlam & Meghan Cirulis

The Task Force addresses the intersection of sex and gender differences in PVD, with a renewed focus on research, clinical care, and advocacy. They promote global collaboration, advance understanding of sex differences, pregnancy, and reproductive health in women with PH.

Recent initiatives

- Relaunched the Task Force in August 2025 with new co-chairs
- Delivered a Women's Health & PVD webinar in September 2025 featuring expert presentations on the role of sex differences in PAH pathogenesis, and the impact of sex hormone treatments on PAH

Looking ahead

- A Women's Health Task Force 'Meet & Greet' session is scheduled during PVRI 2026 Dublin (12:05–13:30, Phoenix Boardroom, upper ground floor), providing an opportunity to connect with Task Force leads

> **"Focused attention on sex differences in PVD remains a priority."**

Want to get involved?
Interested members are invited to connect with the leads at PVRI 2026 Dublin to discuss their future direction

How to get involved

PVRI Task Forces and IDDI Workstreams are open to clinicians, researchers, patients, and partners who want to contribute to advancing pulmonary vascular research and care.

To express your interest, fill out the form in this webpage here: pvrinstitute.org/join-task-force-or-workstream

Thank you

PVRI would like to extend its sincere thanks to the leaders of all IDDI Workstreams and Speciality and Regional Task Forces for their commitment, leadership, and generosity in sharing their expertise.

We also thank every member who contributes their time, insight, and energy to these collaborative groups. Your collective efforts drive progress in research, education, and patient care across the global pulmonary hypertension community, and are central to PVRI's mission.