

PHURDA Activity Report 2025

1. Patient Support and Community Care

The organization works 24/7 to provide informational, legal, and psychological consultations to PH patients and their family members. A dedicated hotline (tel. +380 97 151 09 01) continued to operate as a vital support channel as well as Viber PH support chat “Лішки” which has become a safe space for mutual assistance, sharing of experiences, and emotional support for patients from all over the country.

The PHURDA Psychological Support Project, supported by GAAPP, provided regular monthly closed online meetings for patients. These unrecorded sessions allowed for the discussion of sensitive personal issues.

During the year special thematic meetings were also organized for patients, including an online meeting dedicated to Rare Disease Day, a session on legislative changes in Ukraine related to disability registration in Ukraine. Several meetings on available digital resources for patients, including medical platforms and AI-based tools

Through collaboration with partner organizations, PHURDA has also responded promptly to individual patient needs, facilitating access to life-saving medicines and support.

2. Advocacy and Health Policy Engagement in Ukraine

PHURDA remained a strong advocate for patients' rights and access to treatment within the Ukrainian healthcare system. PHURDA representatives regularly participated in weekly meetings of the Ukrainian Respiratory Coalition, which PHURDA co-founded, ensuring coordination among patient organizations and medical community

Throughout the year, PHURDA was involved in key national policy discussions, including:

- A high-level discussion on underfinancing of medicines from the state budget, with representatives of the Ministry of Health, Ministry of Finance, and Medical Procurement of Ukraine
- The national forum “Reimbursement 2025. Partnership for Sustainable Development”, organized by the National Health Service of Ukraine
- The meeting “State–Patient–Producer: Search for Effective Solutions”, organized by the CF “Patients of Ukraine”
- A consultation meeting of the National Health Service of Ukraine with patient organizations on healthcare financing priorities for 2026

PHURDA continued its work as a member of the Working Group of the Ministry of Health of Ukraine on Rare Diseases and was also actively involved in the areas of transplantation and pulmonary hypertension, contributing to interdisciplinary dialogue and the formation of comprehensive solutions for patients with severe and orphan conditions.

In partnership with the Foundation "Patients of Ukraine", PHURDA also participates in joint advocacy for co-financing of orphan disease areas, emphasizing the need for sustainable and predictable mechanisms of state support.

3. Education, Awareness and Analytical Activities

Educational activities remained an important strategic direction of PHURDA's work. A series of webinars for patients and healthcare professionals were held within the PH Academy, aimed at raising awareness and professional dialogue.

An important event of the year was the first internship of a young specialist at the Pulmonary Hypertension Center in Lviv. This is an important step in forming a new generation of specialists and strengthening expert potential in the field of rare diseases.

In September, PHURDA implemented the Healthy Lungs for Life project in Lviv, which included educational lectures in schools, an online flash mob and placing information banners in the city. The campaign aimed to prevent smoking among adolescents, raise awareness about lung health and the impact of air pollution.

A separate direction of the year was active analytical work: PHURDA systematically collected information on the state of ecology in Ukraine, the impact of tobacco smoking on the population, and also analyzed the situation of patients with PH-ILD, those who are without therapy and in conditions of social isolation. These data form the basis for further advocacy and preparation of analytical materials.

4. International Cooperation and Representation

PHURDA actively represented the interests of Ukrainian patients at the international level, participating in regular meetings of PH PAG, PAG EPAP and EEA, as well as in events such as ELF Networking Day, ERS Congress, 6th International AAA Congress in Sarajevo and IRC Workshop 2025 in Amsterdam.

Significant events of the year were participation in APHEC and training within the European Respiratory Patient Academy in Prague, which became platforms for exchange of experience, professional discussions and presentation of the Ukrainian context at the European level.

An important step in organization development was PHURDA's membership in the European Federation of Allergy and Airways Diseases Patients' Associations (EFA). This membership significantly expanded the possibilities of international cooperation and advocacy for Ukrainian patients, especially in wartime conditions.

5. Fundraising and Sustainable Initiatives

With the support from Gossamer Bio employees, PHURDA also achieved a critical infrastructure milestone by purchasing a defibrillator for the Pulmonary Hypertension Center in Lviv, directly improving emergency preparedness and patient safety.

PHURDA continued its long-term social and environmental initiatives, including the fundraising campaign "*Cork for Life*." During the year, more than 8 tons of plastic caps were collected and recycled. The funds raised were directed to support patients and organizational activities.