



early diagnosis • best treatment • better quality of life • finding a cure

PHAEUROPE  *& Global*
PULMONARY HYPERTENSION ASSOCIATION



2025

INTRODUCTION

PHAEUROPE & GLOBAL serves as the umbrella association for pulmonary hypertension (PH) across Europe. Originating in Vienna, Austria, in 2003, it unites 42 PH patient associations from 37 different countries. The organization's activities are overseen by the Board of Directors, elected biennially by the General Assembly, and administered by dedicated staff members. The Board and staff comprise individuals with diverse nationalities and language proficiencies, bringing extensive expertise in areas such as patient advocacy, business, politics, law, accounting, IT, and project management. A significant number of board and staff members have personal connections to PH, either through direct experience or through family and friends.

PHAEUROPE & GLOBAL has over the years become a recognized stakeholder in Europe for PH. It has close working relationships with:

- EU institutions (EU Parliament, EU Commission, European Medicines Agency)
- European Reference Networks (ERN-Lung, ERN-Transplant-Child)
- Main EU level public health organizations (EPF, ESOT, EURORDIS, ELF)
- European federations for diseases of the lungs, heart, liver, kidney (EFA, ELPA, EKHA, EFKP, EHN, CCE, CCE...)
- Public health multi-stakeholder platforms dedicated to access issues (PACT)
- European professional societies for cardiology and pulmonology (ESC, ERS)
- Research organisations (PVRI)
- Individual members of the European PH scientific community
- Main companies in the pharmaceutical field involved in the development/distribution of PH drugs
- Other PH associations around the world

The 4 “pillars” on which PHAEUROPE & GLOBALS’s activity rests are: awareness, advocacy, capacity building and information.



- ✓ **AWARENESS** - to raise the profile of PH, still a little known condition which is diagnosed and treated very late, with dramatic consequences for patients
- ✓ **CAPACITY BUILDING** - to empower our member associations to reach the level of skills, knowledge, activity and services to effectively support PH patients and family members
- ✓ **ADVOCACY** - to strive for best standards of care and access to approved treatments and surgery as well as medical intervention at an affordable cost for all PH patients in Europe
- ✓ **INFORMATION** - to disseminate up-to-date and easy to understand news about PHAEUROPE & GLOBAL and PH generally with its member associations, other NGOs, HCPs, industry and all other relevant stakeholders through various communication channels, including own webpage and social media channels.

PHAEUROPE & GLOBAL'S MAIN ACTIVITIES

Awareness

PH remains a little known illness, with an average of 2-3 years passing from the onset of initial symptoms to a conclusive diagnosis. PHAEUROPE & GLOBAL is actively engaged in promoting awareness of this condition. In 2025, our efforts in this regard centered around two key initiatives: observing World PH Day and Awareness Month in November, along with running miscellaneous social media campaigns.

World PH Day

World PH Day (WPHD) is an annual global awareness campaign aimed at increasing visibility, understanding, and recognition of pulmonary hypertension (PH). Since its launch in Madrid in 2012 on the initiative of the Spanish association ANHP, WPHD has grown into a worldwide movement uniting patients, families, healthcare professionals, and advocacy organisations. In 2025, PHAEUROPE & GLOBAL continued its role as the global coordinator of World PH Day, a responsibility that remains both an honour and a significant undertaking.

The 2025 campaign proved to be the most successful World PH Day to date. Under the powerful slogan "Sometimes, It's PH," the campaign focused on early recognition of symptoms, timely diagnosis, and the importance of listening to patients' experiences. PH patients were placed at the centre of all activities, with more than 70 patient testimonials shared across platforms, supported by strong, awareness-focused visuals. The campaign achieved outstanding organic reach and engagement, resonating widely across Europe and globally.



Slovenia organised world record sailing!

Across all social media platforms, PHAEUROPE & GLOBAL recorded 9.4 million impressions, 83,669 content interactions, and a continuously growing community of more than 20,000 followers, demonstrating the growing visibility and impact of World PH Day. As in previous years, nearly all European member associations organised local and national awareness activities, reinforcing the campaign message and contributing to a strong and united global presence.

PHAEUROPE & GLOBAL once again collaborated closely with the Pulmonary Hypertension Association (PHA) in the USA to ensure alignment between World PH Day in May and the PH Awareness Month in November, strengthening transatlantic cooperation and consistency in messaging. Maintaining this global coordination requires continuous adaptation to evolving digital channels and the diverse needs of member organisations, but the results in 2025 clearly demonstrate the effectiveness of these efforts.

- WPHD in Europe and worldwide is coordinated by PHAEUROPE & GLOBAL staff. Since taking on the global coordination role, PHAEUROPE & GLOBAL manages the dedicated website (WorldPHDay.org) and provides ready-to-use campaign materials in multiple languages, enabling consistent and professional communication across countries.

- Member associations are invited to apply for participation and submit projects for approval and support. A common theme and professionally developed toolkit are provided, including artwork, social media templates, banners, merchandise designs, and communication materials to ensure a cohesive and recognisable campaign identity.
- While WPHD initially targeted the general public, the campaign increasingly engages policymakers, healthcare professionals, academia, and partner organisations, strengthening advocacy efforts and raising awareness at institutional and political levels.
- WPHD continues to empower member associations by supporting national awareness, educational, advocacy, and fundraising initiatives, enabling local activities that reflect both global messages and country-specific needs.
- PHAEUROPE & GLOBAL complemented the campaign with extensive digital storytelling, including patient testimonials, “WPHD Around the World” features showcasing member activities, and regular updates on research progress, treatments, and clinical developments, ensuring that patients and stakeholders remain informed throughout the year.
- The message of World PH Day remains unchanged: we are one global PHamily. Through unity, shared experiences, and coordinated action, we continue to strengthen awareness, improve access to care, and work towards better outcomes for all people living with pulmonary hypertension.



WPHD event in Slovakia

Capacity Building

Capacity building is another very important part of PHAEUROPE & GLOBAL’s activities. Our organisation’s ultimate goal is to put in place a strong European PH community consisting of empowered national associations, working together for the PH cause.

White Spots & Member Support Program

The White Spot Program is a program where we help to establish a PH association in a country where no association exists. Once established, the Member Support Program (MSP) takes over. In the MSP, we help associations to mature. The need for The White Spot program was greatly reduced in recent years, as there are almost no countries in Europe of significant size left without an association. The MSP is, hence, the most active program of these two at the moment.

Key info:

- The White Spot Program has been very successful, as we have helped establish more than 20 national PH associations in Europe.
- We have developed a guide, which describes step by step what actions need to be taken in order to start an association. Because of this structured approach, an association can be started by one dedicated person alone, as long as the person gets assistance from PHAEUROPE & GLOBAL.
- The most popular activity in the MSP has been the implementation of a new web pages. This is due to the fact that PHAEUROPE & GLOBAL themselves got new pages, and that a template was developed as a consequence. So now, several of PHAEUROPE & GLOBAL's members have new pages with the same look and feel as their umbrella association. We will continue to replace several of the members' webpages in the future.
- The MSP has been used to create new image brochures for several of our members in 2025. The brochures are based on a template developed by PH Austria. More associations will follow in 2026.
- Through the MSP, we paid for a hotline service, a patient meeting and a marathon awareness campaign in 2025.

Fellowship

PHAEUROPE & GLOBAL's official working language is English and, as the organisation expanded over the years to include more and more countries, communication started to become a critical issue with those associations where neither Board members nor volunteers had a good command of this language. Thanks to our "Fellowship" program, PHAEUROPE & GLOBAL has been able to provide these associations with a part time English speaking assistant. The program started in 2013 with nine Fellows; in 2025 we were able to support 19 patient associations with a Fellow. The program has been very successful in ensuring a smooth flow of communication and actively engaging our member associations in common activities. The fellows help with translations and support the associations on the basis of 8-10 hours per week.



The new fellow in Romania helped organise the first PH conference for doctors and patients.

- The following countries were supported: Belarus, Bosnia & Herzegovina, 2x Bulgaria, Croatia, Czech Republic, Hungary, Israel, Latvia, North Macedonia, Poland, Portugal, Serbia, Slovenia, 3x Spain, 2x Ukraine.

- The program has been very successful and has considerably improved communications, as well as the level of engagement of the national associations in common European projects.

- In 2026, we will re-evaluate the program. Associations with a solid financial position may be asked to cover the fellowship

cost themselves to help reduce costs for PHAEUROPE & GLOBAL.

- The ultimate goal is to make it possible to have a fellow for every member association of PHAEUROPE & GLOBAL. At the moment we have 42 associations in 37 countries.

APHEC (Annual PH European Conference)

The Annual PH European Conference, APHEC 2025, again took place in Castelldefels, Barcelona, from November 5th to 9th.

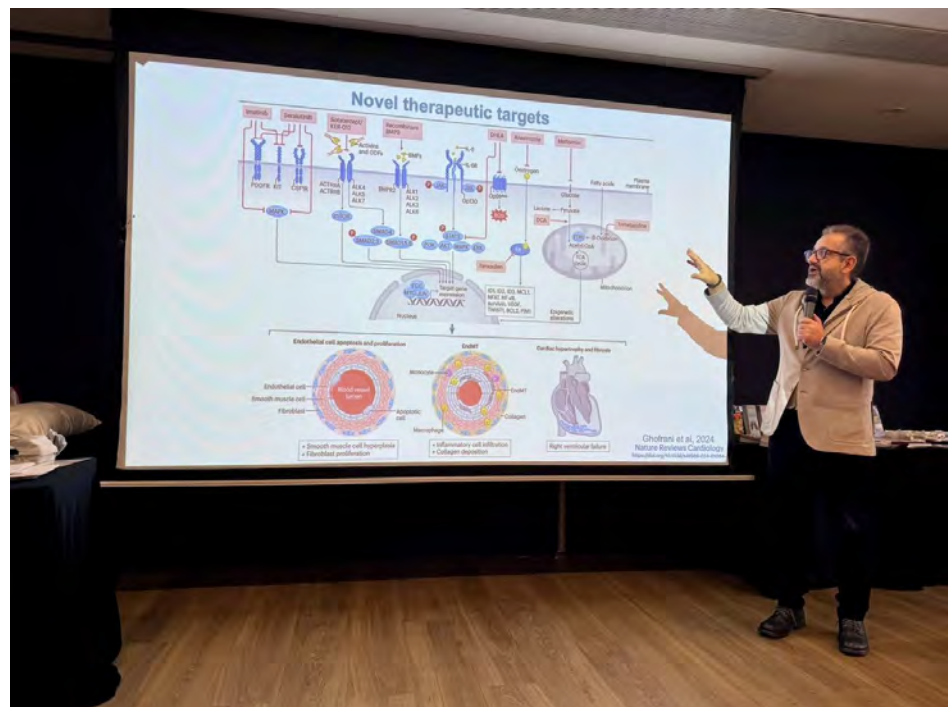


APHEC participants November 2025

The conference brought together participants from numerous countries, representing PH associations outside Europe. The conference served as a platform for the exchange of expertise, experiences, and best practices in the field of pulmonary hypertension (PH). Distinguished speakers from various parts of the world contributed to a diverse discussion, shedding light on the

latest developments in PH research, diagnosis, and treatment. A highlight of the event was the acceptance of a new member association, further strengthening the international reach and collaboration within the PH community. A Latin American PH umbrella association, representing 16 national PH associations, joined PHAEUROPE & GLOBAL as an associated member. The conference also provided space for interactions with representatives from the pharmaceutical industry, who presented their latest developments and research approaches. These partnerships are crucial for advancements in medical care and therapy for PH. We extend our gratitude to all participants, including our member associations, distinguished speakers, and pharmaceutical representatives.

By joining forces in our collective effort, we affirm that we stand together to address the challenges of pulmonary hypertension and raise awareness of this life-altering condition. APHEC 2025 was not only a platform for knowledge exchange but also a step forward in global collaboration for better care of patients with pulmonary hypertension.



APHEC attracts famous PH specialist. Here Prof. Ardi Ghofrani

Bel Air Club

Throughout the years of the pandemic, we have conducted virtual meetings, utilizing a virtual conference center created specifically for this purpose. In this virtual environment, we hosted presentations and explored booths of industry partners and associations. Additionally, participants had the option to engage in



Our newly acquired virtual PH conference centre

chats or take part in informal video conferences with one another. These virtual conferences proved highly successful, prompting us to leverage the benefits of our virtual conference center even after the pandemic subsided. As a result, we are actively evolving this virtual center into a PH hub accessible to patients, caregivers, healthcare professionals (HCPs), and other PH stakeholders worldwide, and we've named it our Bel Air Club. Recognizing that the club will be frequented by individuals of diverse nationalities, we have incorporated translation features. Furthermore, we are diligently working on

subtitling presentations, enhancing the social gathering space, establishing an area dedicated to artworks created by PH patients and HCPs, and more. The company that developed the platform decided to discontinue it in 2025. We therefore purchased our virtual solution and transferred it to our own server. This means greater flexibility for future adaptations.



Bel Air Center art gallery with photos and video snippets by PH doctors and patients

Information materials and resources

Sharing helpful information is a key part of building our capabilities. Learn more about it in the "Information & Education" section.

Advocacy activities

PHAEUROPE & GLOBAL's mission is to achieve best standards of care, equal and affordable access to treatment/surgery and better quality of life for all PH patients in Europe, including the very important and largely unmet psycho-social support needs. Despite enormous progress in past years, there are still very wide disparities and inequalities in Europe: not all approved drugs are available in all countries across Europe and there are countries where no drugs at all are accessible and where expert centers/surgical facilities do not exist.

- PHAEUROPE & GLOBAL is active in its support to national advocacy activities by providing guidance and strategic advice, by writing letters and participating in meetings with national health authorities and other relevant stakeholders and by engaging in one to one talks with representatives of the pharma industry
- Since 2017 PHAEUROPE & GLOBAL has organised and supported the training of physicians from countries with serious drug access problems, the rationale being that these physicians can transfer the knowledge gained to colleagues in their own countries and can become future PH "champions" at national level. Unfortunately, this project has been put on hold due to the pandemic, but we hope in restarting it in 2026.
- At European level PHAEUROPE & GLOBAL has been active, within larger and very influential organisations (EURORDIS, EPF, PACT, ESOT) and within the main professional societies (ERS, ELF, ESC, PVRI) in contributing to the discussions on policies to reduce waste/improve investment in healthcare, in involving the patients in policy making, including the patients in the drug regulatory processes, including the patients in definition of clinical guidelines, including patients' goals in scientific agendas. PHAEUROPE & GLOBAL also plays an important role in ERN-Lung and was elected in the Medical Steering Committee.
- For the future, there is an absolute need to define what is really relevant in terms of outcomes from the patient's point of view. The different degrees of access to therapies leads to an adaptation of what is to be expected in real life at country level. This will also be conducive to evaluate the impact of the disease and of the available therapies, which is an extremely powerful tool in the advocacy field.
- Likewise, PHAEUROPE & GLOBAL intends to collect the expertise and experience of its members in order to contribute to the definition of clinical endpoints and composite endpoints that are as relevant for patients as for HTA agencies and physicians.
- PHAEUROPE & GLOBAL has also been very active in organ donation and transplant issues. Its 2015 Call to Action was endorsed by 90+ national and European organisations and a PHAEUROPE & GLOBAL initiated European Parliament (EP) event was held in 2016, whose media reach was over 70M. The EP event in 2016 was followed up with meetings in 2017 with the federations for heart, lung, liver and kidney diseases; a social awareness event was organized at the European Parliament in February, 2019 with the presence of members of the European Parliament and other stakeholders. Despite previous efforts organ donation and transplantation is still problematic in many countries. In order to identify the critical points to be improved we plan to launch a survey within our members.

Workshops and conferences

PHAEUROPE & GLOBAL representatives are increasingly invited to participate in significant congresses, symposia, workshops, and other essential events. They are also actively engaged in the work of advisory committees, task forces, and working groups within prominent scientific societies, EU regulatory agencies, and European NGOs.

- Attending these scientific events offers PHAEUROPE & GLOBAL valuable opportunities to both raise awareness of the disease and stay up-to-date with the latest developments in pulmonary hypertension (PH) and public health-related issues.
- Involvement in advisory committees, task forces, or working groups of prestigious organizations empowers us to advocate effectively and contribute to the formulation of health policies.
- Our training workshops play a pivotal role in education, equipping attendees to become more effective advocates at both the European and national levels.
- As members of larger organizations such as EURORDIS, the EUROPEAN PATIENT'S FORUM, and the EUROPEAN PUBLIC HEALTH ALLIANCE, we enjoy numerous benefits, including the ability to shed light on PH issues to broader audiences.
- Ultimately, all these meetings offer excellent networking opportunities, a vital element in our efforts to raise awareness and advocate for change.

Following, you will find a listing of events that PHAEUROPE & GLOBAL was present at in 2025:

Healthy Lungs for Life & EU Parliament advocacy events

Early in 2025, PHAEUROPE & GLOBAL participated in the Healthy Lungs for Life exhibition and related respiratory health events at the European Parliament, helping place lung health high on the EU policy agenda. Hundreds of policymakers, staff, visitors, and patient representatives underwent lung function testing, reinforcing the importance of prevention and early detection. PHAEUROPE & GLOBAL highlighted pulmonary hypertension specifically, explaining both the value and limitations of spirometry for PH and advocating for stronger prioritisation of respiratory diseases in EU health policy, given their substantial societal and economic burden.



PHAEUROPE & GLOBAL was represented numerous times at the EU Parliament in 2025

“Breathing Better – Scaling up EU Prevention Policies for Respiratory Health”

Later in the year, PHAEUROPE & GLOBAL returned to the European Parliament for the event “Breathing Better – Scaling up EU Prevention Policies for Respiratory Health,” where policymakers, researchers, and patient representatives discussed prevention strategies, cleaner air, and increased investment in respiratory research and care. PHAEUROPE & GLOBAL contributed the patient perspective, highlighting inequalities in access to PH treatment, the urgent need for innovation – particularly for PH-ILD, where no approved therapies exist – and the impact of environmental and climate factors on symptoms and quality of life.

9th ERN-LUNG Annual Board Meeting – Paris

At the 9th ERN-LUNG Annual Board Meeting in Paris, representatives from across Europe reviewed progress on registries, education, cross-border care, and future strategy. During the ePAG session, PHAEUROPE & GLOBAL presented the Bel Air Center, its virtual platform for education and collaboration between patients and professionals, which generated strong interest as a practical tool to support knowledge sharing and engagement. The meeting highlighted advances in patient-reported outcomes, quality management, and clinical research collaboration, while reinforcing the importance of strengthening participation across all European regions.

European Respiratory Patient Academy

PHAEUROPE & GLOBAL also engaged actively in the European Respiratory Patient Academy, organised by the European Lung Health Group. Several representatives from member associations participated in training activities aimed at strengthening knowledge, advocacy skills, and confidence in engaging with clinicians, researchers, and policymakers. The initiative supports capacity building within the PH community and helps ensure meaningful patient involvement in research and healthcare decision-making.

5th Baltic PH Conference – Kaunas

At the 5th Baltic PH Conference in Kaunas, PHAEUROPE & GLOBAL was represented as the sole patient voice among clinicians and researchers from Lithuania, Latvia, Estonia, and neighbouring countries. The programme covered right ventricular function, echocardiography, right heart catheterisation, PH subgroups, and emerging therapies, including sotatercept as a potential fourth treatment pathway. Strong cross-border collaboration and the active participation of young clinicians and students were particularly encouraging, and several sessions were recorded and later shared via the Bel Air Center to extend their educational reach.

PVRI Drug Discovery & Development Symposium – Amsterdam

PHAEUROPE & GLOBAL attended the PVRI Drug Discovery & Development Symposium in Amsterdam, an international meeting focused on emerging therapies and innovation in pulmonary vascular disease. Sessions addressed activin-pathway agents, inhaled kinase inhibitors, biomarkers, interventional devices, and catheter-based procedures, reflecting growing optimism that PH treatment may be entering a disease-modifying era. Discussions also emphasised equity in clinical trials, sex differences in PH, and the need for sustainable and inclusive research approaches.

World PH Symposium Updates 2025

At the World PH Symposium Updates 2025 meeting, experts reviewed progress in clinical trials, endpoints, genetics, biomarkers, and novel therapies. PHAEUROPE & GLOBAL contributed directly to the programme with a keynote presentation on patient empowerment and patient-reported outcome measures (PROMs), underlining their importance in capturing lived experience and their continued underuse in routine clinical care. The meeting also highlighted persistent global inequalities in access to diagnosis, treatment, and patient support.



PHAEUROPE & GLOBAL representative with two legendary PH specialists

ERS Presidential Summit on Prevention – Dublin

PHAEUROPE & GLOBAL participated in the ERS Presidential Summit on Prevention in Dublin, where experts discussed primary, secondary, and tertiary prevention across chronic respiratory diseases. For pulmonary hypertension, where primary prevention is often not possible, the focus was on earlier diagnosis, access to advanced therapies, rehabilitation, and environmental measures to preserve quality of life. Patient testimonies reinforced the need for coordinated action across healthcare systems and policy sectors.

EPF Congress 2025

At the EPF Congress 2025, titled “Shaping the Future of Healthcare – Preparedness for Health Systems’ Resilience,” discussions focused on lessons from COVID-19 and ongoing vulnerabilities such as workforce shortages, fragmented research systems, supply chain weaknesses, and inequalities in access to care. Sessions also explored digital health, artificial intelligence, and future EU initiatives. Throughout the congress, PHAEUROPE & GLOBAL advocated for meaningful patient involvement as an essential component of resilient and responsive health systems.

ELF Networking Day

During the ELF Networking Day, patient organisations, advocates, and health professionals gathered to exchange experiences and strategies for driving policy and healthcare change. Presentations and interactive sessions covered topics such as clean air, disease awareness, digital health, and access to treatment. The event provided valuable networking opportunities and reinforced the growing influence of patient advocacy in shaping respiratory health policy across Europe.

ERS Congress

PHAEUROPE & GLOBAL was well represented at the ERS Congress, one of the largest global meetings in respiratory medicine. Representatives participated in scientific sessions, committee meetings, and stakeholder discussions across digital health, air quality, and patient inclusion, while also engaging with clinicians, researchers, and partner organisations. Beyond the formal programme, the congress offered important opportunities to strengthen collaborations and ensure that the patient perspective remains integrated into research, guidelines, and future respiratory health initiatives.

Information & Education

The dissemination of up-to-date information about pulmonary hypertension is another important part of PHAEUROPE & GLOBAL’s activities. It is instrumental both in raising greater awareness of the disease and in the empowerment of the national associations.



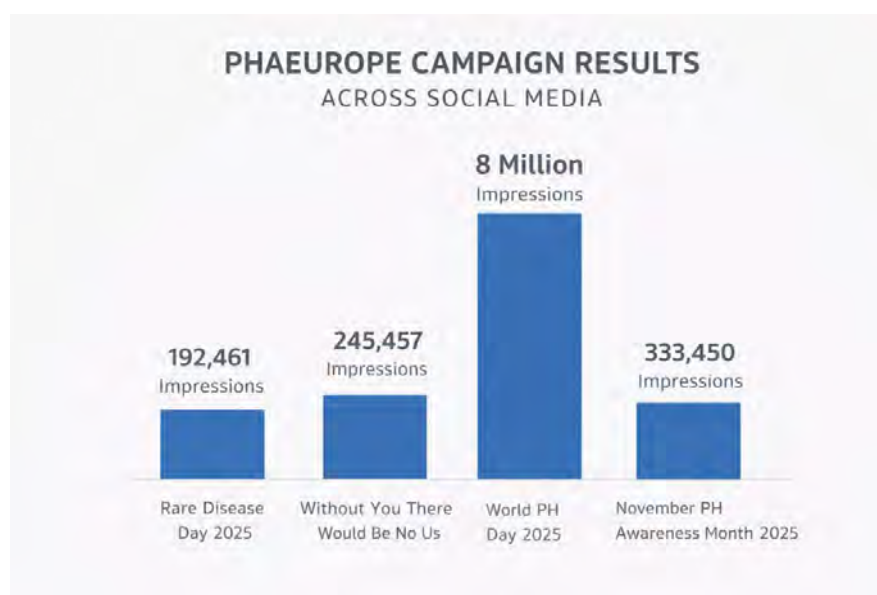
Journals

The Mariposa journal stands as our flagship "product." It is published biannually, with the entire summer edition dedicated to World PH Day. Within these summer releases, readers can delve into details about specific World PH Day projects at both the European and global levels, as well as on a country-specific basis. For more information, please explore the World PH Day section on our website. On the other hand, the winter edition comprehensively covers all activities undertaken by PHAEUROPE & GLOBAL or its member

associations. Distribution of the journal occurs through electronic channels such as our webpage and social media, as well as via email. Additionally, printed copies are distributed to physicians, decision-makers, representatives of pharmaceutical companies, and other stakeholders. The graphic design, printing, and distribution of these copies are centralized processes.

Website, social media and online platforms

One of the primary objectives of PHAEUROPE & GLOBAL is to provide accurate, timely, and reliable information to the pulmonary hypertension community. Our website remains the cornerstone of this effort, offering validated educational content, news updates, and information about conferences, learning opportunities, and new publications.



In 2025, PHAEUROPE & GLOBAL significantly strengthened its digital presence and influence across social media platforms, delivering strategic, patient-centred communication that combined advocacy, awareness, education, and community engagement. Through four major awareness campaigns, comprehensive coverage of the Annual PH European Conference (APHEC), and continuous collaboration with member associations, 2025 became PHAEUROPE & GLOBAL's most impactful year to date in terms of digital reach and engagement.

Key performance indicators show a 117% increase in overall reach compared to the previous year, alongside the addition of 2,570 new followers across social media channels. All results were driven by consistent, meaningful engagement with the global pulmonary hypertension (PH) community, with a strong emphasis on organic reach and shared resources.

Key Results at a Glance

- +117% increase in reach year-on-year
- 2,570 new followers added in 2025
- 4 major awareness campaigns delivered
- Millions of impressions, predominantly organic
- Extensive international reach, with content reused, translated, and adapted by PH organisations worldwide

Major Awareness Campaigns

RARE DISEASE DAY 2025 – 192,461 Organic Impressions

2025 started with a Rare Disease Day campaign specially customised for PHAEUROPE & GLOBAL, creating a campaign in its own right with editable CANVA templates disseminated for further use by our member associations. Focusing on three rare types of PH—PAH, CTEPH, and WHO Group 5 PH—PHAEUROPE & GLOBAL traditionally marks the entire month of February raising awareness of these PH groups. With 192,461 organic impressions and a joint effort of our member associations, this campaign once again proved to be a strong way to shine a light on rare forms of PH, while supporting the original Rare Disease Day campaign by EURORDIS and advocating for rare diseases at the same time. Fourteen different graphics, featuring PHAEUROPE & GLOBAL members and PH patient images, were used to advocate for better care, improved treatment, and greater awareness of rare forms of PH.



WITHOUT YOU THERE WOULD BE NO US –

245,457 Organic Impressions

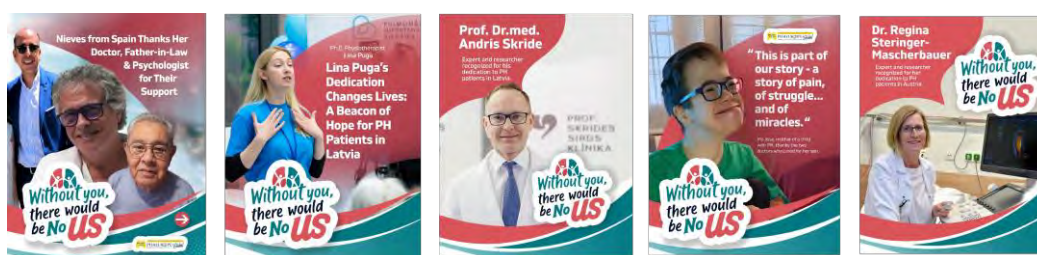
In 2025, we further expanded our social media presence with a heartfelt campaign focused on patients and their expressions of gratitude to those who have supported them throughout their PH journey. This campaign, titled “Without You, There Would Be No Us,” featured patients from across Europe thanking their doctors, carers, nurses, patient associations, and other stakeholders. It achieved impressive organic reach and received an exceptional response from our followers and the general audience. Patients thanked their family members, carers, doctors, nurses, PH researchers,



PHA Europe – Pulmonary Hypertension Association Europe, Wilhelmstr. 21, 1120 Vienna, Austria

www.phaeurope.org, email: info@phaeurope.org, registration number: ZVR-Zahl: 070826881

pharmaceutical companies, media, supporters, decision-makers, and all whose support made life possible for those diagnosed. With more than 35 stories of patients, carers, doctors, and supporters shared throughout the year—and reaching 245,000 completely organic impressions—this campaign proved to be a meaningful and engaging way to connect with our audience.

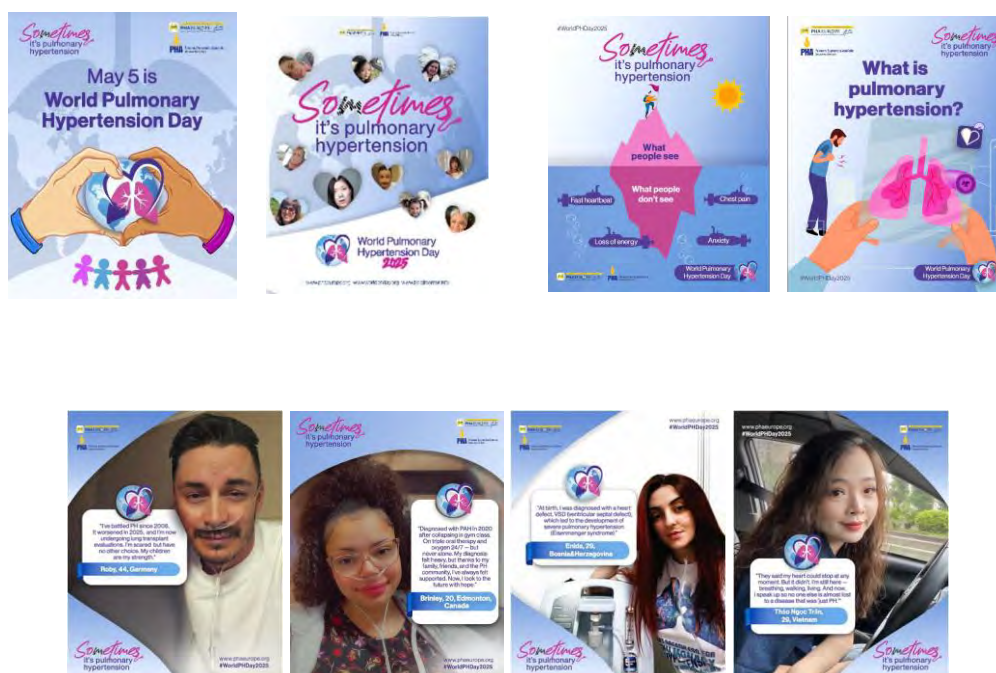
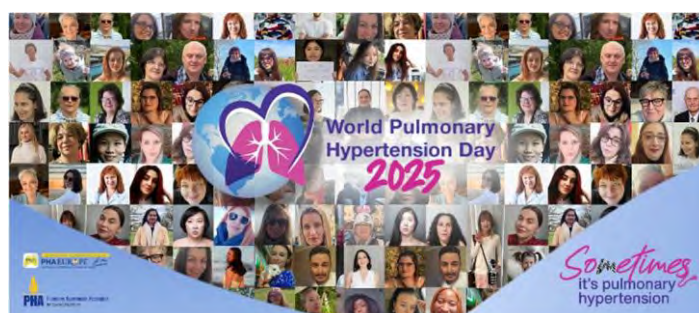


WORLD PULMONARY HYPERTENSION DAY 2025 – 8 Million Impressions / 2M organic

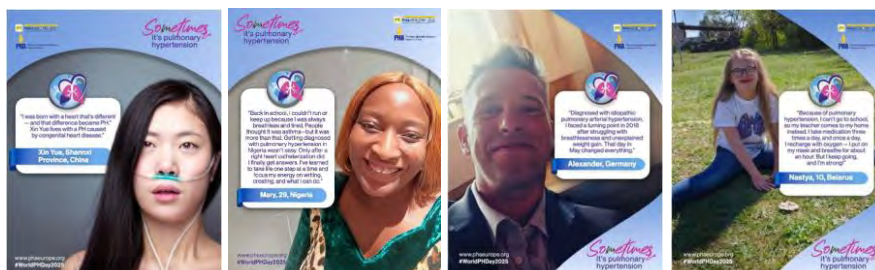
„Sometimes, it's PH“ Campaign

PHAEUROPE & GLOBAL's flagship campaign marking World PH Day on May 5th unites the global PH community. For the second year in a row, PHAEUROPE & GLOBAL extended this significant date into a month-long campaign throughout

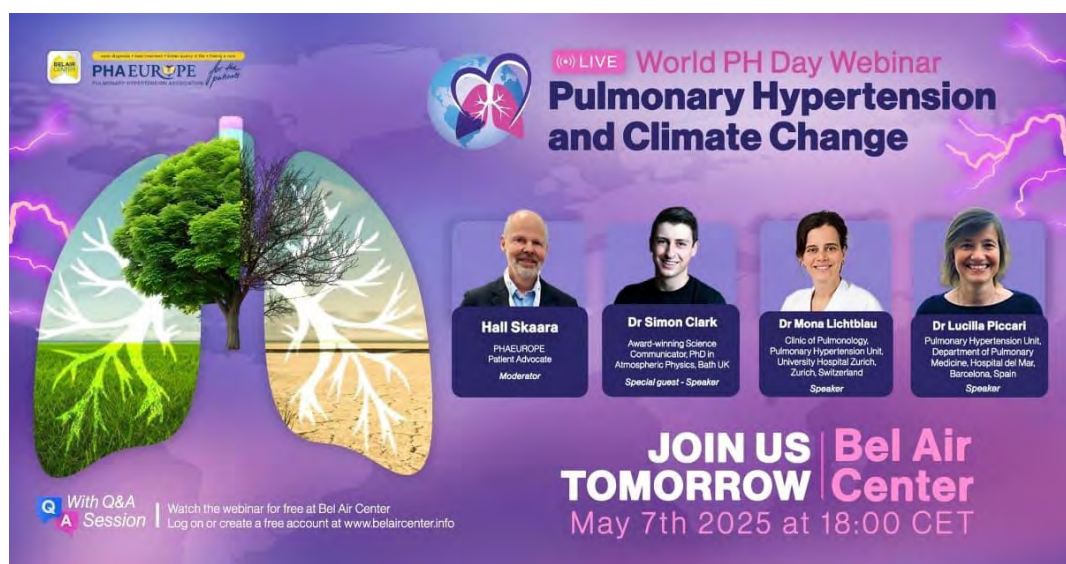
May. The 2025 theme—“Sometimes It's PH”—focused on early diagnosis, common misdiagnoses, and the importance of access to care. With over 70 patient testimonials from more than 30 countries across all inhabited continents, the campaign was extended through June. The famous Zebra video was once again featured, now translated into dozens of languages, fittingly complementing this year's WPHD campaign inspired by the video.



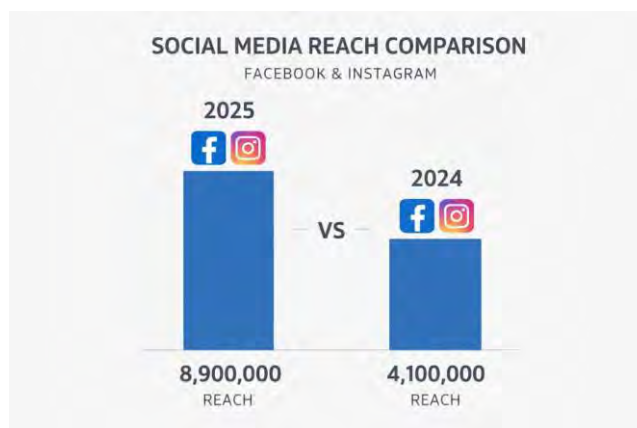
Staggering results demonstrate that year after year, WPHD continues to resonate deeply with the global PH community. With 70+ testimonials, 20+ infographics, six animated reels, and promotional banners—all provided by PHAEUROPE & GLOBAL as editable CANVA templates for further use and customization by PH associations worldwide—the true impact of the campaign extends far beyond the analytics reported on our platforms.



Traditionally, PHAEUROPE & GLOBAL hosted a WPHD webinar featuring eminent PH experts and speakers. The 2025 webinar focused on the intriguing topic of pulmonary hypertension and climate change, with contributions from PH experts as well as a science communicator and a scientist discussing the issue. The webinar was viewed 2,350 times on YouTube.



Constant presence across all four social media platforms led to steady growth year after year, with 2025 proving to be the most successful year in terms of social media results, showing a 117% increase in reach and other key metrics.



November PH Awareness Campaign 2025 – Organic 333,450 Impressions

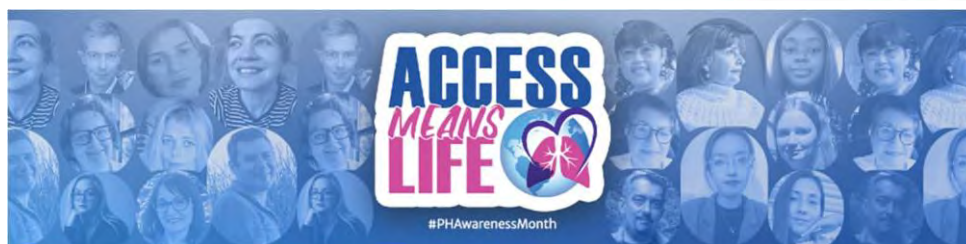
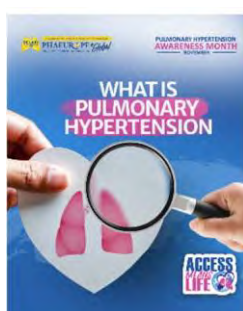
Compared to the previous year, when PHAEUROPE & GLOBAL marked November PH Awareness Month by sharing PHA US social media content, this year PHAEUROPE & GLOBAL not only partnered with the US association—an associate member of PHAEUROPE & GLOBAL—but also developed its own parallel social media campaign focusing on access to care and treatment. Access Means Life, created for November PH Awareness Month, continued this approach, raising



awareness of the urgent need for access to care, treatment, clinical trials, and medicines for all PH patients.

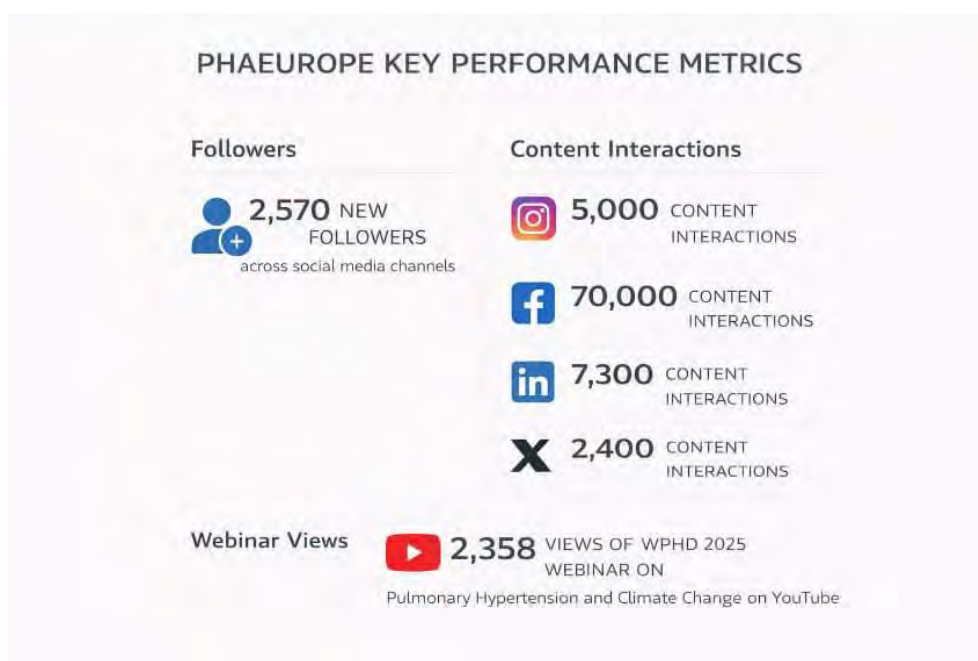
The campaign featured 30+ patient testimonials from more than 17 countries, highlighting challenges such as limited care, the absence of specialized PH centers, and disparities and barriers, while also celebrating the tremendous advances in research and novel targeted treatments that bring hope despite these difficulties. Coinciding with the APHEC – Annual PH European Conference in November, organized by PHAEUROPE & GLOBAL, the campaign concluded the year with a strong message and solidified PHAEUROPE & GLOBAL's goals for social media engagement.

As with previous campaigns, PHAEUROPE & GLOBAL prepared all social media materials and toolkits for use by our member associations and global PH organizations through editable CANVA templates, enabling the campaign to reach a broader audience with content translated into 10+ languages.



Beyond its own content, PHAEUROPE & GLOBAL's member associations made significant contributions to social media posts in 2025, demonstrating the power of collaboration—a momentum that will continue into 2026 and 2027 with a major focus on expanding our reach. Our regular #goodPHnews posts, alongside updates on PH research, novel therapy developments, and advocacy activities at conferences, summits, and congresses, continued to reflect PHAEUROPE & GLOBAL's mission and garnered substantial engagement across social media in 2025.

Looking ahead, PHAEUROPE & GLOBAL aims to keep highlighting positive PH news from across Europe and the globe, while broadening its social media content to diversify topics, formats, and engagement strategies. By making content more interactive and accessible, PHAEUROPE & GLOBAL seeks to strengthen its visibility, reach new audiences, and ensure that the global PH community remains informed, connected, and inspired.



Surveys and Research: Identifying Patient and Caregiver Needs

In 2025, PHAEUROPE & GLOBAL played an instrumental role in supporting and promoting two major surveys that provide valuable insights into the needs, priorities, and experiences of people living with pulmonary hypertension (PH) and their caregivers. These surveys, conducted at both European and global levels, strengthen the evidence base needed to improve care, guide advocacy, and inform the development of patient-centred support programs and policies.

Multinational Survey on Unmet Needs in Europe

In 2023, a multinational survey was conducted across nine European countries (Germany, Italy, Austria, Spain, Sweden, Poland, Hungary, Czech Republic, and Slovakia) to better understand the unmet needs of patients with PH and their caregivers. A total of 619 participants (527 patients and 92 caregivers) completed the survey, with the highest participation from Germany, Italy, and Austria.

The findings, presented in 2025, showed that many patients across all participating countries require additional support to improve their quality of life. Particularly high levels of unmet needs were reported in

Germany and Poland. Significant differences between countries were observed, especially regarding access to guidance on exercise, nutrition, and rehabilitation.

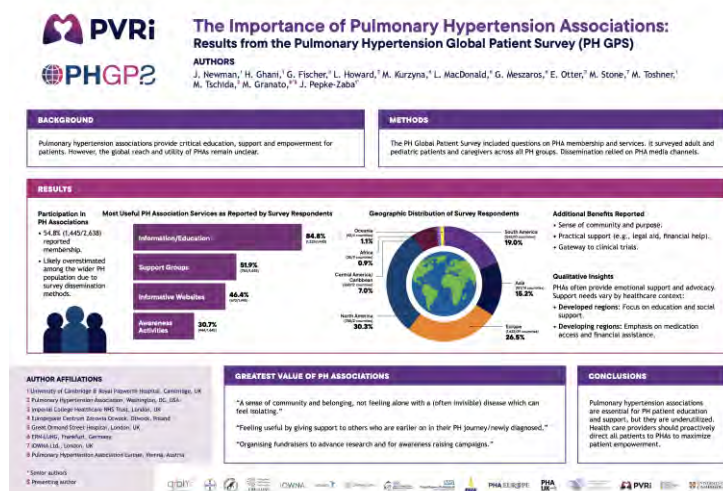
Caregivers reported distinct unmet needs compared to patients, with a particularly strong demand for psychological support. This need varied considerably between countries, ranging from relatively low levels in Sweden to very high levels in Poland and Hungary.

These findings highlight the importance of adapting support programs to national and local contexts and underscore the critical role of national patient organizations in developing tailored support systems that address the specific needs of their communities.

The Pulmonary Hypertension Global Patient Survey (PHGPS)

PHAEUROPE & GLOBAL has also been actively involved in supporting and disseminating the findings of the Pulmonary Hypertension Global Patient Survey (PHGPS), conducted by the Pulmonary Vascular Research Institute (PVRI). This is the largest survey to date exploring the experiences of people living with PH, with 3,329 adult patients from 90 countries participating. The survey examined key areas including diagnosis, treatment, quality of life, support, digital health, and participation in research.

The results highlighted important progress in some areas, such as diagnosis timelines and increasing patient engagement in self-monitoring. However, significant disparities remain in access to specialist care, research opportunities, and support services. While 19.1% of patients reported participating in clinical research, over 70% of those who had not participated expressed willingness to do so if given the opportunity.



PHAEUROPE & GLOBSL helped create posters and moderated a webinar related to the PHGPS survey



PHA Europe presented a PH survey at ERS 2025

Impact and Future Direction

Together, these surveys provide strong evidence to guide advocacy, policy development, and patient support initiatives. The European survey highlights the importance of locally tailored support programs, while the global PHGPS underscores the need for systemic improvements in access to care, patient empowerment, and research participation.

PHAEUROPE & GLOBAL will continue to use these findings to strengthen advocacy efforts, support its member associations, and contribute to improving the quality of life and care for people living with pulmonary hypertension across Europe and globally.

PHAEUROPE & GLOBAL Board Activities 2025

In 2025, the PHAEUROPE & GLOBAL Board continued its active engagement at both European and global levels, strengthening collaboration and amplifying the voice of pulmonary hypertension (PH) patients.

Traditionally, Board members contributed to the annual European Respiratory Society Congress (ERS) with presentations and active participation. This year, Eva Otter, Nina Kobler, and Natalia Maeve represented PHAEUROPE & GLOBAL, delivering impactful contributions and ensuring strong patient representation throughout the congress.

A major highlight of the year was the PHAEUROPE & GLOBAL Annual PH European Conference (APHEC 2025), held in Castelldefels, Barcelona. The conference brought together representatives from 40 member associations across 35 countries, alongside medical experts, researchers, and key stakeholders, reinforcing unity and collaboration within the PH community.

During the General Annual Meeting (GAM) in November, a new PHAEUROPE & GLOBAL Board of Directors was elected with a mandate until 2027. The newly elected Board (2025–2027) consists of:

- Zdenka Bradač – President
- Eva Otter – Vice President
- Tuulia Nikulainen – Treasurer
- Tadeja Ravnik – Vice Treasurer
- Natalia Maeve – Secretary
- Vittorio Vivencio – Vice Secretary
- Peter Baarnhielm – 1st Auditor
- Bogdan Burduja – 2nd Auditor



PHA Europe Board of Directors

The new leadership team is committed to building on past achievements and further strengthening PHAEUROPE & GLOBAL's role as a global umbrella organisation, expanding its activities and reinforcing its mission to connect, support, and empower PH patients and associations across Europe and beyond.

Board members are often asked or invited to be part of Advisory Boards of pharmaceutical companies, as well as Steering Committees of various scientific societies

In addition, the president of PHAEUROPE & GLOBAL Zdenka Bradac proudly took part in the 17th anniversary celebration of the Spanish member association, Fundación contra la Hipertensión Pulmonar, reaffirming strong international collaboration and solidarity within the PH community.

Through advocacy, education, international cooperation, and patient empowerment, PHAEUROPE & GLOBAL continues to advance its mission of improving the lives of people living with pulmonary hypertension worldwide.

PHAEUROPE & GLOBAL back office

Our office in Vienna, located at Wilhelmstraße 21, 1120 Vienna, is open from Monday to Thursday, 09:00–16:30. The office phone number is (+43) 1 402 3725.

We handle all administrative tasks, bookkeeping and project coordination. We work closely with our tax office to ensure proper financial management and compliance. In addition, we are responsible for customer communication, document management, appointment scheduling and coordination with partners. We store and distribute various brochures and informational materials and ensure the smooth organization of internal processes. Furthermore, we are responsible for the complete organization of our annual APHEC conference.



Tamara - head of back office

In the following pages, you will find a listing of major events that PHAEUROPE & GLOBAL was also present at in 2025:

Vienna, Austria • January 21st**PHAEUROPE & GLOBAL CORPORATE MEETING**

PHAEUROPE & GLOBAL held its corporate meeting, during which it presented its business plan and discussed future directions and activities.



early diagnosis • best treatment • better quality of life • finding a cure

PHAEUROPE & Global
PULMONARY HYPERTENSION ASSOCIATION

**Brussels - Belgium, February 4th - 5th****HEALTHY LUNGS FOR LIFE**

Hall represented PHAEUROPE & GLOBAL in the European Parliament together with our partners in the European Lung Health Group. This included presentations and lung function testing of Parliament employees.

Virtual - February 6th**EU**

Hall represented PHAEUROPE & GLOBAL in the first of three webinars in which the EU presented the European Health Data Space (EHDS). PHAEUROPE & GLOBAL has been part of a working group providing input to this initiative..

**Berlin – Germany, February 20th – 21st****INTERNATIONAL EXPERT MEETING****Reshaping Prostacyclin Therapy in Pulmonary Hypertension**

A scientific committee, such as I. Lang, M. Kurzyna, K. Tello, and R. Steringer-Mascherbauer, met in Berlin. The focus of this conference was the progress in the development of the new implantable pump. The patient perspective was discussed by Eva.

Paris - France, March 24th - 25th**ERN-LUNG**

Hall participated in ERN-LUNG's annual board meeting in Paris and presented PHAEUROPE & GLOBAL's Bel Air Center to the audience.



Kaunas - Lithuania, May 9th**5TH BALTIC PH CONFERENCE**

Hall participated in the fifth Baltic PH Conference in Lithuania, where specialists from the Baltic countries met to discuss the latest advances and opportunities for collaboration.

***Brussels - Belgium, May 23rd - 25th*****EPF**

Hall participated in EPF's Annual General Meeting in Brussels. PHAEUROPE & GLOBAL is a full member and voted on, and provided input to, the items on the agenda. The strategic plan for 2027–2031 was discussed on the second day.

Dublin - Ireland, June 11th - 13th**ERS**

Hall participated in an ERS Summit focused on prevention. This is particularly important in relation to lung diseases, and Hall provided input related to pulmonary hypertension and tertiary prevention.

***Amsterdam - The Netherlands, June 15th - 17th*****PVRI**

Hall represented PHAEUROPE & GLOBAL at PVRI's Drug Discovery & Development Symposium in Amsterdam.

Bologna - Italy, July 3rd - 5th

WORLD PH SYMPOSIUM UPDATE

Hall participated in the symposium update in Bologna and delivered a presentation entitled "From Patient Empowerment in Pulmonary Hypertension to PROMs: the Patient Perspective."



Brussels - Belgium, September 1st

EU PARLIAMENT

Hall represented PHAEUROPE & GLOBAL in the European Parliament and delivered a speech to Members of the European Parliament on living with a chronic respiratory disease and the importance of not overlooking the respiratory dimension in the new EU cardiovascular health plan.

Amsterdam - The Netherlands, September 25th - 26th

GAAPP

Hall participated in GAAPP's annual conference. This was the first time PHAEUROPE & GLOBAL was represented at the conference and it marks a closer collaboration between the two associations.



Amsterdam - The Netherlands, September 27th

ELF

PHAEUROPE & GLOBAL had several representatives at the ELF Networking Day. PHAEUROPE & GLOBAL is actively involved in ELF through participation in several advisory groups and committees.

Amsterdam - The Netherlands, September 28th - October 1st
ERS

PHAEUROPE & GLOBAL was well represented at the large ERS Congress. Representatives contributed as speakers in both studio sessions and regular sessions and participated in committees such as CRCs, ELF PAG, ELF PAC, and ELHG. Eva presented a poster together with AOP Health based on their patient survey. The Congress also provided an excellent opportunity for networking.



Barcelona - Spain, November 4th - 9th

APHEC

PHAEUROPE & GLOBAL's annual conference was held as usual in Castelldefels, outside Barcelona. Most of PHAEUROPE & GLOBAL's members participated in a successful conference that included advisory board meetings, the AGM, pharmaceutical presentations, and presentations by leading PH specialists.

Prague - Czech Republic, November 13th - 16th

ELHG

Hall was part of the steering committee for the Respiratory Patient Academy organised by the European Lung Health Group (ELHG), of which PHAEUROPE & GLOBAL is a member. Five representatives from PHAEUROPE & GLOBAL's member associations participated in the academy.



Fundación Contra la
Hipertensión Pulmonar

Rome - Spain, November 20th

FCHP

PHAEUROPE & GLOBAL's President, Zdenka, represented the Spanish PH association FCHP at its anniversary event in Rome, delivering a speech to commemorate their important work.

Virtual - November 21st**Romanian patient association**

The Romanian patient association organised a patient meeting attended by both patients and doctors. Hall joined via Zoom and delivered a presentation on pulmonary hypertension and rehabilitation.

**Brussels - Belgium, November 25th - 27th****EPF**

Hall participated in EPF's congress entitled "Shaping the Future of Healthcare – Preparedness for Health Systems' Resilience."