

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



**2023**

## INTRODUCTION

PHA Europe serves as the umbrella association for pulmonary hypertension (PH) across Europe. Originating in Vienna, Austria, in 2003, it unites 37 PH patient associations from 32 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.

PHA Europe 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 PHA Europe’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 PHA Europe 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.

## **PHA EUROPE'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. PHA Europe is actively engaged in promoting awareness of this condition. In 2023, our efforts in this regard centered around two key initiatives: observing World PH Day and Awareness Month in November, along with running the O2Kids campaign.

### **World PH Day**

World PH Day (WPHD) is an annual campaign, the aim of which is to achieve greater visibility for the condition. The first World PH Day (WPHD) was held in Madrid in 2012, on the initiative of the Spanish PH association ANHP. The year 2023 marked the 11th anniversary of World Pulmonary Hypertension Day (WPHD), with PHA Europe continuing its significant role as the global coordinator for the events of this meaningful day. Taking on the coordination responsibility was not only a great honor but also entailed substantial responsibility, which we once again successfully navigated. The impact analysis reveals that the coordinated global campaign on Facebook and Instagram in the previous year resulted in over 5 million total impressions. This underscores the effectiveness of our efforts to strengthen awareness of pulmonary hypertension worldwide. Nearly all European PH associations hosted enlightening activities. The challenges associated with the global coordination of World PH Day are immense, yet in 2023, we once again triumphed over them. This success is reflected not only in quantitative reach but also in the quality of awareness campaigns launched by our member organizations on social media in November. PHA Europe was collaborating with PHA to raise awareness for Pulmonary Hypertension (PH) during the Awareness Month of November. Tailorable templates have been created for sharing on social media. There are two main annual awareness campaigns: World PH Day (May 5th) and Awareness Month in November. PHA Europe and PHA worked closely together on both events. PHA Europe leads World PH Day, while PHA spearheads the Awareness Month project. 2023 we were celebrating the resilient spirit of the PH community. People living with PH are invited to share their stories of 'Living Fearlessly,' defying the limitations of their diagnosis. By providing pre-defined posts for our associations, we ensured a cohesive and effective presence throughout the month. Maintaining this global coordination role requires not only dedication but also continuous adaptation to the evolving digital landscape and the needs of our member organizations. With pride, we reflect on the year 2023, confident that our collective efforts will continue to contribute to promoting understanding of pulmonary hypertension and effecting positive changes worldwide.

- WPHD in Europe and all over the world is coordinated by PHA Europe staff. As of 2021 PHA Europe has taken over the coordination globally: new webpage (WorldPHDay.org) has been launched and managed by us both in English and Spanish, ready-to-use materials were delivered in both of these languages. More specifically, in Europe our member associations apply to take part and submit projects for approval and funding. The campaign has a common theme and a professionally developed toolkit, including common artwork for T-shirts, banners, sea flags, merchandising and other materials, as well as templates for press conferences, flash mobs and other events being held for the occasion.
- WPHD started out as a campaign targeted at the general population, but has increasingly seen the involvement of national political and health authorities, academia, health care professionals and celebrities. To foster these activities an online petition has been launched for immediate actions to ensure access to treatments.

- WPHD has contributed to the empowerment of the member associations by providing them with the opportunity to hold national awareness raising, educational, advocacy and fundraising activities.
- We hosted a global WPHD webinar attended by participants worldwide. Professor Sean Gain delivered an engaging and inspirational presentation titled 'Emerging Hope in PH.' He briefly reviewed the history of PH care and medications before discussing the promising future with numerous innovative drugs on the horizon. He also highlighted the potential for more personalized PH care.
- The World PH Day events always have the same message: we are a big family!

## **Capacity Building**

Capacity building is another very important part of PHA Europe'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 PHA Europe.
- Albania is the only white spot country left in Europe with a population larger than one million citizens. (Albania has a population of 3.2 million.) We have established contact with a PH medical doctor, and we are working with her to find some patients and carers that can help start an association.
- The most popular activity in the MSP has been the implementation of a new web pages. This is due to the fact that PHA Europe themselves got new pages, and that a template was developed as a consequence. So now, several of PHA Europe'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 2023. The brochures are based on a template developed by PH Austria. More associations will follow in 2024.
- Many associations have established a hotline service due to the MSP

### **Fellowship**

PHA Europe'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, PHA Europe has been able to provide these associations with a part time English speaking assistant. The program started in 2013 with nine Fellows; in 2023 we were able to support 18 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 following countries were supported: Belarus, Bosnia & Herzegovina, 2x Bulgaria, Croatia, Czech Republic, Hungary, Israel, Latvia, North Macedonia, 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 2024, we would like to maintain at least the current level of support and possibly increase with 1 fellow in Lithuania, Luxembourg, Moldova, and Russia. The total number will then be 21 or 22 fellows.
- Goal is to make it possible to have a fellow for every member association of PHA Europe. At the moment we have 37 associations in 32 countries.

### **APHEC (Annual PH European Conference)**

The Annual PH European Conference, APHEC 2023, again took place in Castelldefels, Barcelona, from November 8th to 12th. The conference brought together participants from 28 countries, representing 29 PH associations worldwide. The year 2023 marked a special occasion as four new member associations—Argentina, China, Germany and Japan—were accepted. So the total associated member associations are now five. 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 new member associations, further strengthening the international reach and collaboration within the PH community. 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 2023 was not only a platform for knowledge exchange but also a step forward in global collaboration for better care of patients with pulmonary hypertension.

### **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 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. Our grand opening for the club is scheduled for January 2024.

Significantly, in the year 2023, substantial progress has been made. The homepage of the Bel Air Club has been nearly completed. These advancements will enable club members to access a comprehensive and user-friendly platform providing both informative resources and a space for social interaction. We take pride in the fact that the Bel Air Club will be a significant resource for the PH community in the coming year.

### **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**

PHA Europe'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 psychosocial 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.

- PHA Europe 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 PHA Europe 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.
- At European level PHA Europe 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. PHA Europe 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, PHA Europe 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.
- PHA Europe 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 PHA Europe 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**

PHA Europe 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 PHA Europe 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 PHA Europe was present at in 2023:

### **The 4<sup>th</sup> Baltic PH Conference**

PHA Europe attended the 4th Baltic Pulmonary Hypertension (PH) conference in Riga, Latvia. The conference takes place biennially, alternating between Latvia, Lithuania, and Estonia. Given the small size of these countries, collaboration in the rare disease domain is crucial. Strong collaboration was evident as PH cases and information were seamlessly shared among the Baltic nations. Professor Andris Skride from Latvia welcomed a large audience, including a significant presence of medical students, boding well for the future of PH diagnosis in the Baltic region. International medical guests, Prof. Olivier Sitbon from France and Prof. Marcin Kurzyňa from Poland, were notably acknowledged. The conference also emphasized the participation of patients. The opening speech was delivered by Ieva Plume, emphasizing the importance of patient involvement. Prof. Skride highlighted the success of the first lung-transplanted PH patient from Latvia, who seemed to be doing well. The conference focused on two main themes: Chronic Thromboembolic Pulmonary Hypertension (CTEPH) and new guidelines. Discussion about the first Pulmonary Endarterectomy (PEA) in Latvia led to considerations of establishing a centralized center for PEA procedures in the Baltic countries. Balloon Pulmonary Angioplasty (BPA) was discussed as an alternative treatment, especially when clot removal in the lungs is challenging. The importance of PH medication, particularly noting challenges in reimbursing Riociguat in all three countries, was emphasized. Ricards Kaulins provided an overview of PH treatment and patient statistics in the Baltic countries. Despite still being a medical student, Kaulins displayed notable expertise, contributing to scientific publications, engaging in BPA research, and assuming a clinical coordinator role in a PH clinical study. Prof. Sitbon's lecture focused on current and upcoming PH

medications. Patient cases demonstrated the application of new guidelines and risk stratification models, indicating a high level of expertise among healthcare professionals in the Baltic region, ensuring qualified care for PH patients.

### **EPF's 20 years anniversary + AGM**

The European Patients Forum celebrated its 20th anniversary in 2023 with an event in Brussels titled "The Path of Patient Advocacy: Past, Present, and Future." EPF President Marco Greco delivered a welcome speech, reflecting on the organization's growth over the two decades and emphasizing the importance of learning from failures in patient advocacy. He drew parallels to the sports world, citing the example of Dick Fosbury, who transformed a failure into success with the development of the Fosbury flop. Greco also highlighted the accessibility of drugs, emphasizing that availability on the market is insufficient; drugs must be accessible to all patients when needed. Addressing the significance of Artificial Intelligence (AI) in healthcare, he stressed the need for an ethical framework. He concluded by asserting that proper functioning healthcare systems should be a natural right in civilized societies. Maleen Sorensen from the EPF Youth Group discussed their efforts to raise awareness for the needs of young patients in Europe. She mentioned completed projects on sexual well-being and upcoming initiatives supporting young members. Maya Mathews from the European Commission addressed key events impacting patients, including the 2011 Cross-Border Healthcare Directive, the 2020 COVID-19 pandemic, and the proposed 2023 pharmaceutical legislation changes. A panel debate on whether EPF fulfilled its founding promise followed, with the consensus that while EPF faced challenges, it successfully added value to both EU and patient associations. Workshops ensued, and one focused on developing effective policy and advocacy campaigns, generating valuable input from participants. The day included a presentation of a patient organization manifesto by a Czech Republic patient association, subsequently adopted by EPF. It emphasized principles such as political will, consultation, operational involvement, funding, and impactful participation.

At the Annual General Meeting, EPF reported a budget of close to 2 million Euros, with goals for the future, including shaping a new European patient agenda and strengthening patient communities. A revision of pharmaceutical legislation was discussed, with an invitation for PHA Europe to participate in the upcoming EU Commission discussions on May 10th. In closing, Marco Greco encouraged unity among members, emphasizing that collaboration achieves more. EPF plans to develop common recommendations and comments for the pharmaceutical legislation revision, involving members in the process in the coming months.

### **EU Commission meeting**

The EU Commission has spent the past four years working on a significant revision of EU pharmaceutical legislation, marking the most substantial change in two decades. On May 10th, a stakeholders' dialogue on the pharmaceutical package took place at the Albert Borchette Congress Centre in Brussels. Hall Skaara represented PHA Europe at the meeting, joined by Wendy Vansteenkiste from the Belgium PH association online. The event hosted 44 representatives from both industry and patient associations, with over 100 participants online. Sandra Gallina, Director General of DG Sante, outlined the revision's goals: Improved patient access to treatments globally. A more competitive EU pharmaceutical industry Innovation in medicines to address unmet medical needs Strengthened supply chains to reduce shortages Development of environmentally friendly medicines The EU aims to achieve these goals through a mix of incentives and regulations. The "carrot" for the industry involves increased regulatory data and market protection for drugs meeting specific criteria. The current system provides 8 years of regulatory data protection and an additional two years of market protection. In the revised legislation, regulatory data protection is reduced to six years, but market protection remains the same. However, launching a drug in all 27 member states grants an additional two years of protection, with extra time for addressing unmet medical needs and conducting comparative clinical trials, resulting in a potential total of 12 years of protection. The EU estimates a 15%



increased access if a medicine is introduced in all member states, benefiting an additional 67 million people. For rare diseases, the incentive system is similar, potentially extending regulatory protection to a maximum of 13 years. To enforce regulations, the EU will impose stricter measures on the pharmaceutical industry regarding supply and environmental considerations. EMA will be strengthened, reducing red tape and allowing new medicines to enter the market sooner. Patient involvement in the EMA process will also increase. The focus on developing new antimicrobial medicines addresses the issue of Antimicrobials Resistance (AMR). The industry's efforts in this area will be rewarded with vouchers for other medications, extending protection periods. While pharmaceutical industry representatives welcomed the reduction of red tape, some expressed doubts about making medicines available to all 27 member states within the given deadline. Patient associations generally welcomed the legislative revision, foreseeing benefits for patients. However, concerns were raised about the potential shift to digital drug information, with fears that patients might not read it, leading to serious adverse effects. The adoption of the revision is not expected before 2025 due to the upcoming MEP election. The EU Commission will submit the revision to the EU Parliament and Council for approval. EPF, a full member of which PHA Europe is a part, will present a detailed overview of the revision on May 31st.

### **EURORDIS membership meeting in Stockholm**

EURORDIS invited to a membership meeting in Stockholm, promising engaging discussions on a holistic approach to addressing rare disease needs and promoting inclusion. Mental health was a key focus. Two workshops were offered on the first day, one on digital safety in healthcare digitalization and the other on enhancing mental well-being in the rare disease community. The digitalization workshop discussed EU legislation for the European Health Data Space (EHDS), aiming to address issues like limited data access and control. The legislation proposes digitizing EU citizens' health data for individual use (MyHealth@EU) and secondary access for research and policy (HealthData@EU). A computer expert highlighted data security risks and introduced the General Data Protection Regulation (GDPR), emphasizing minimal data collection. The following day focused on lifelong holistic care and full inclusion in society. Rare disease patients and caregivers shared their perspectives, emphasizing the need for a broader, more holistic approach. Mental health received considerable attention, with a teenager expressing wisdom on embracing life's ups and downs.

The second half featured workshops on living with a rare disease at different life stages. The diversity of the rare disease community, with over 6000 conditions, was evident. Many participants had heritable diseases, faced challenges from birth, and often required assistance. Medication advancements extended lives but brought additional complexities and mental health concerns. Representatives from PHA Europe, including Norway, Latvia, Ukraine, and Romania, actively participated, contributing to a lively and informative conference that expanded networks and knowledge about holistic care for rare diseases.

### **IRC Summit in Lisbon**

The International Respiratory Coalition (IRC), established in 2021 during the pandemic, is a diverse organization representing the respiratory community, patients, and industry stakeholders. Founded by ERS and ELF, the IRC's mission is to advocate for lung health globally and enhance respiratory care. The organization envisions every country implementing a national respiratory strategy based on best practices, collaborating with policymakers to achieve this goal. Globally, approximately 550 million people live with chronic respiratory diseases, leading to about 4 million premature deaths annually. The recent IRC Summit in Lisbon, the second face-to-face meeting, focused on critical issues. Margarida Tavares, Portugal's Secretary of State for Health Promotion, highlighted tobacco use as the primary cause of lung diseases in Portugal, emphasizing the need to combat smoking and the rise of e-cigarette usage. Air quality was another significant topic, featuring a moving presentation by Ella Roberta's mother, who addressed the fundamental right to breathe clean air. The conference also discussed improving access to care, with a session chaired by PHA

Europe. Vaccine skepticism, a growing concern during the pandemic, was addressed, emphasizing the importance of clear scientific evidence to persuade undecided individuals. The second day centered on the manifesto for better respiratory health, outlining key focus areas: prevention, timely treatment, reducing health inequalities, and prioritizing research. These areas align closely with PHA Europe's goals in representing the pulmonary hypertension community. The IRC Summit in Lisbon was an enlightening experience, prompting PHA Europe to align with the IRC, given their shared commitment to improving lung health globally.

### **IMPAHCT conference in Barcelona**

Ferrer hosted the annual IMPAHCT conference for pulmonologists and cardiologists, with the fifth edition drawing 150+ healthcare professionals from 30+ countries. 2023, a unique addition was the inclusion of the "patient's voice," featuring presentations by PHA Europe and EU-PFF leaders. The "Patient Support in PH" session covered holistic treatment approaches and personal experiences, fostering audience engagement. During the presentation, PHA Europe's work was showcased, focusing on early diagnosis, optimal treatment, improved quality of life, and finding a cure. The organization's efforts center on awareness, capacity building, advocacy, and information. Key initiatives like World Pulmonary Hypertension Day events, the White Spot Program, and the Mariposa project were highlighted, along with a "Call to Action" for improvements in expert care, awareness, research, patient associations, and psychosocial support.

The remaining conference sessions delved into technical discussions on potential advancements in PH diagnosis, including blood tests and biomarkers. Phenotyping patients for optimal treatment selection, new guidelines, and the introduction of medication for Group 3 patients (PH ILD patients) were key topics. Networking opportunities during breaks and the dinner party enhanced collaboration among global healthcare professionals. Overall, the well-organized IMPACT conference proved to be an enriching experience, with a positive response to the patient-inclusive approach, prompting Ferrer's interest in continued patient involvement in future conferences.

### **PHA Europe represented at ELF's digital PAG**

PHA Europe maintains a close working relationship with both the European Respiratory Society (ERS) and the European Lung Foundation (ELF). The ERS comprises respiratory professionals, while the ELF's objective is to unite patients, the public, and respiratory professionals to promote lung health across Europe. ERS established Clinical Research Collaborations (CRC) to promote the exchange of research ideas among clinicians and affiliated scientists in Europe. There are currently 26 ongoing CRCs. One of the most recent is CRC CONNECT, which spans all eight major respiratory disease domains: airway diseases, interstitial lung diseases, pulmonary vascular diseases, sleep and breathing disorders, respiratory critical care, pediatric respiratory diseases, respiratory infections, and thoracic oncology. The vision of CRC CONNECT is "to enable knowledge exchange, create a repository of available respiratory technologies, promote standardized approaches to implementation research in digital healthcare, publish position papers on barriers and enablers to deployment at scale, and plan research that will inform, develop and evaluate the implementation of digital respiratory healthcare." ELF participates in CRC CONNECT through a newly established Digital Patient Advisory Group (PAG). The group is led by Keld Hansen, with Hall Skaara representing PHA Europe. The group plans to hold regular meetings at one to two-month intervals.

### **ESC 2023 Congress**

The European Society of Cardiology (ESC) held its annual congress in Amsterdam from August 25th to 28th, attracting 30,000 global participants, including 4,500 faculty members and presenters. The theme of the

event was "Joining Forces to Protect the Heart." ESC, or the European Society of Cardiology, closely collaborates with the European Respiratory Society (ERS) due to the overlap of lung and heart aspects in Pulmonary Hypertension (PH), making both societies essential for PHA Europe. The ESC Congress serves as a valuable platform for exploring PH research and treatment through medical sessions and networking opportunities with medical professionals and industry representatives. The sessions, held in auditoriums and on smaller stages, covered various aspects of PH research and treatment. During one session, a groundbreaking paper from China proposed using urine biomarkers for right ventricle failure, potentially revolutionizing the non-invasive diagnosis of pulmonary hypertension. Another presentation addressed the lasting impact of the toxic oil scandal in Spain from 1981 to 1987, revealing ongoing repercussions and mysteries surrounding the causes of PH. A session on risk assessment, moderated by Dr. Lina Gumbiene from Lithuania, discussed the updated 2022 guidelines for categorizing PH patients into four risk groups, enhancing treatment decision-making. The global stage featured discussions on the current status of PH management in Ukraine, highlighting challenges faced due to the ongoing conflict and the need for international support. The treatment perspectives of PH patients in France and Ukraine were presented by Professor Marc Humbert and Professor Olivier Sitbon. Challenges in Ukraine, including missile alerts and mass migration, were discussed, and efforts to integrate the PH department of the Kiev hospital into the ERN Lung were proposed to strengthen ties between Ukrainian and European PH communities. PHA Europe's presence at the ESC Congress was crucial, aiming to expand connections, raise awareness about initiatives, and enhance expertise to uplift the European PH community and patients. The organization will continue its engagement at the ERS Congress in the coming week.

### **ERS 2023 Congress**

PHA Europe actively engaged in the second major European congress hosted by the European Respiratory Society (ERS) in Milan, Italy. Similar to the ESC congress, this event featured numerous captivating sessions focused on Pulmonary Hypertension (PH) and showcased a wealth of research through a multitude of posters. The ERS Congress not only serves as a valuable platform for exchanging ideas within the PH community but also fosters collaboration with other organizations, including the European Lung Health Group (ELHG). ELHG comprises representatives from eight different respiratory patient associations, and this congress provides a unique opportunity for in-person interactions, a departure from our usual online meetings. Additionally, our participation in various groups under the European Lung Foundation (ELF), including the Patient Advisory Committee, is further enriched by this congress. Furthermore, PHA Europe had the privilege of engaging in the Clinical Research Collaboration PHAROS at the congress, which plays a pivotal role in coordinating future collaborative PH research efforts.

### **ESOT Congress 2023**

The ESOT Congress is Europe's largest gathering of the transplant community, uniting clinicians, surgeons, physicians, nurses, scientists, researchers, and patients.

**Purpose:** The congress aims to examine the latest advancements in transplantation across various fields, offering diverse session formats such as state-of-the-art presentations, solution rooms, debates, hands-on courses, and storytelling.

**Observations:** Attendees noted limited access for organ transplant recipients and association members to lectures. The focus was primarily on liver and kidney transplantation, with less emphasis on heart transplantation. Notably, advancements in anti-rejection drugs were highlighted.

**Recommendations for Patient Organizations:**

**Healthy Eating:** Emphasized the importance of a Mediterranean-style diet for post-transplant individuals, showcasing exceptional results in regulating metabolism and maintaining organ health despite medication side effects.

**Regular Exercise:** Highlighted the need for clear guidelines on post-transplant physical activity, underscoring the inadequacy of current advice from doctors. Advocated for incorporating exercise recommendations into annual programs to enhance patients' longevity.

**Mental Strength:** Stressed the necessity for improved support, understanding, and psychological treatment for transplant recipients. Urged associations to address mental health in their activities to raise awareness about the needs of post-transplant individuals.

**Raising Awareness about Organ Donation:** Efforts to increase awareness included presentations on projects like "The Value of Scars" and an art exhibition, "My Scar. May Life," showcasing photographs of transplant recipients' scars as symbols of strength and new life.

**Patient Engagement Room:** A dedicated space at the congress venue provided transplant recipients and their families with an opportunity to connect and find respite in the midst of the busy event.

**Opportunity for PHA Europe:** Recognizing the importance of discussing organ donation for potential transplant candidates, PHA Europe aims to integrate this awareness into its yearly plans. This aligns with ongoing awareness campaigns about pulmonary hypertension, ensuring a synergistic approach.

Participating in the congress with individuals shaping the future for countless patients was described as an extraordinary and emotional experience.

## **The European Health Data Space**

The Pulmonary Hypertension Association Europe, as part of a diverse multi-stakeholder group comprising 33 European organizations from various sectors within the healthcare ecosystem, has issued a joint statement expressing concerns about significant legislative shortcomings and uncertainties in the proposed Regulation for a European Health Data Space (EHDS). The group is raising these concerns in anticipation of the European Parliament's plenary vote scheduled for December 13, 2023. Additionally, they aim to address these issues before a COREPER meeting on December 6, 2023, with the hope that Member States will make essential changes to the legislative text before reaching a general approach.

The EHDS, currently fast-tracked through the European Parliament and Council, faces serious legislative problems that, if not addressed, could result in more risks than benefits. The lack of clear definitions, potential legal ambiguities, and uncertainties about its interaction with other legal frameworks are key concerns. The group specifically emphasizes the need for clear definitions, clarification of the EHDS's interaction with other legal frameworks, specification of the scope of electronic health data categories for secondary use, avoidance of excessive data localization, and the importance of involving stakeholders in EHDS governance for responsible and impactful implementation.

## **15 Year Anniversary of FCHP**

The Spanish association FCHP celebrated its 15th anniversary in Madrid on December 1st with approximately 200 diverse guests, including patients, caregivers, health authorities, researchers, specialists, social workers, psychologists, representatives from PHA Europe and PHA, TV celebrities, and pop musicians. The event highlighted FCHP's multifaceted work, with a focus on patient stories. A 15-year-old shared her challenges and fears related to an upcoming operation for an implantable pump, while a seven-year-old captivated the audience with a disease-related fairy tale she and her classmates wrote, accompanied by her illustrations. FCHP's commitment to PH research was evident through funds raised for various initiatives. Researchers presented their work on stage, emphasizing the importance of holistic care. Matt Granato from PHA underscored their collaboration, highlighting a forthcoming webinar featuring a Spanish researcher. In a speech, it was emphasized that FCHP, as one of 37 significant members, contributes to global PH research. The celebration concluded with FCHP presenting awards to key collaborators, showcasing their extensive reach. A renowned Spanish singer duo dedicated a song titled "We are all similar" to the association. The

successful event concluded with a cocktail reception, providing networking opportunities. Congratulations to Enrique and the FCHP team on a job well done!

## **Information & Education**

The dissemination of up-to-date information about pulmonary hypertension is another important part of PHA Europe'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 PHA Europe 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 PHA Europe is to furnish current and dependable information, and there is no better resource for this than a meticulously managed and regularly updated website. We place a strong emphasis on reliability, ensuring that our entries on pulmonary hypertension have been validated. Our news section serves as a valuable source of information, providing updates on conferences, congresses, learning opportunities, and new publications.

While we regard our website as a cornerstone of information, we have recognized the vital role of communication through social media. Consequently, we have directed more attention and invested additional effort in managing these platforms. The metrics associated with our activities are steadily increasing across all social media networks. Fortunately, this mirrors the broader trend seen in the activities of national associations, and the success is quantifiable and prominently visible. This is primarily evident in the escalating number of posts published on social networks. Recognizing the tremendous potential offered by social networks, associations, in collaboration with PHA Europe, are achieving substantial results.

Social media activities have also played a pivotal role in our two main projects: World PH Day and Awareness Month November.

In the following pages, you will find a listing of events that PHA Europe was also present at in 2023:

**Virtual (online) • January 12**

**PREPARATORY CALL WITH AOP ABOUT SURVEY**

Staff members attended this call with AOP to refine the survey questions AOP will use when talking to association leaders and patients.



**Virtual (online) • January 17**

**PREPARATORY CALL WITH EXPERT REGARDING EU APPLICATION**

Staff members attended this call with an expert helping us with an EU application for a grant covering some 2023 projects.

**Virtual (online) • January 18**

**WPHD PREPARATION MEETING**

Staff members ran a meeting with international PH community to discuss the upcoming WPHD activities. Plans for templates, WPHD landing page, WPHD webinar, etc were presented and discussed.



**Virtual (online) • January 30**

**KICKOFF MEETING FOR AOP SURVEY**

Hall and Monika attended this kickoff meeting with AOP for their patient and carer survey.

**Virtual (online) • February 8**

**EU PARLIAMENT RARE DISEASE EVENT**

Hall attended this EU webinar about rare diseases.





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



**Vienna, Austria • February 14-15**

**PHA EUROPE CORPORATE MEETING**

The board and staff ran a yearly meeting followed by a corporate meeting with industry partners highlighting plans for 2023.

**Virtual (online) • March 1**

**PREPARATORY CALL WITH AOP ABOUT SURVEY**

Hall attended this call with AOP to refine the survey questions AOP will use when talking to association leaders and patients.



**Virtual (online) • March 2**

**TALK WITH FERRER**

Staff members attended this call with Ferrer to plan collaboration activities for 2023.

**Virtual (online) • March 8**

**JANSSEN PHEN - GLOBAL STEERING COMMITTEE**

Hall, Eva and Tadeja had a Pulmonary Hypertension Empowerment Network (PHEN) global steering committee meeting with Janssen.



**Virtual (online) • March 10**

**WPHD PREPARATION MEETING**

Hall and Maleen ran a meeting with international PH community to discuss the upcoming WPHD activities.

**Virtual (online) • March 21****MIMI PROPOSAL MEETING**

Hall and Monika participated in a meeting with the MIMI team to prepare the application for grant from EU.

**Virtual (online) • March 27****MIMI PROPOSAL MEETING**

Hall and Monika participated in a meeting with the MIMI team to prepare the application for grant from EU.

**Virtual (online) • April 3****MIMI PROPOSAL MEETING**

Hall and Monika participated in a meeting with the MIMI team to prepare the application for grant from EU.

**Virtual (online) • April 6****MEETING WITH PH SPECIALISTS**

Hall had a meeting with Prof. Marion Delcroix and Prof. Marc Humber to discuss future collaboration between PHA Europe and PH scientific community.

**Virtual (online) • April 13****WPHD PREPARATION MEETING**

Hall and Maleen ran a meeting with international PH community to discuss the upcoming WPHD activities.





# MSD

## **Virtual (online) • April 14**

### **EUPDHA - CALL FOR APPLICATIONS**

Hall had a meeting with the group that will be judges for the MSD's EUPDHA.

## **Virtual (online) • April 19**

### **ELHG MEETING**

Hall and Monika participated in a meeting with the European Lung Health Group in which PHA Europe is one of the nine members.



## **Riga, Latvia • April 21-22**

### **4TH BALTIC CONFERENCE**

Hall attended the 4th Baltic conference in Riga, Latvia learning about PH health care in the Baltic region and meeting with the Latvian PH association.

## **Brussels, Belgium • April 28-29**

### **20TH ANNIVERSARY EVENT - EPF**

Hall attended European Patient Forum's 20th anniversary event in Brussels, Belgium.



## **Brussels, Belgium • May 10**

### **EU CONFERENCE**

Hall attended a meeting in Brussels together with other representative from disease associations and pharma companies to discuss the new suggested EU Pharma legislation.

**Virtual (online) • May 12**

## EHDS INTEREST GROUP

Hall attended a meeting with an interest group discussing EHDS opt-in/opt-out issues.

**Virtual (online) • May 16**

## FERRER PH-ILD VOP

Hall attended a meeting with Ferrer discussing the draft Voice of the Patient (VOP) patient related to PH-ILD patients and cares.

**Virtual (online) • May 16**

## FERRER IMPACT CONFERENCE PREPARATION MEETING

Hall attended a meeting with Ferrer preparing for the upcoming Ferrer Impact conference.

**Virtual (online) • June 14**

## ELF MEETING

Hall had a meeting with the European Lung Foundation discussing PHA Europe's participation in the World Village display at the upcoming ERS Congress.

**Virtual (online) • June 14**

## MEETING WITH WORDLY

Hall had a meeting with Wordly to discuss options for AI supported simultaneous translation at meetings and AI subtitling of presentations.





**Lisbon, Portugal • June 26-27**

**IRC SUMMIT**

Hall attended the International Respiratory Coalition summit in Lisbon, Portugal where world respiratory diseases were discussed.

**Barcelona, Spain • June 30, July 1**

**FERRER'S IMPACT CONFERENCE**

Hall attended Ferrer's Impact conference, gave a presentation and took part in a round table discussion focusing on the patient voice.



**ELF** EUROPEAN  
LUNG  
FOUNDATION

**Virtual (online) • July 4**

**ELF PAC MEETING**

Hall had a meeting with the European Lung Foundation Patient's Advisory Committee.

**Virtual (online) • July 5**

**MEETING WITH EPF**

Hall had a meeting with the European Patient Forum about the draft revision of the pharmaceutical legislation.



**BREATHE  
FOR  
2030  
VISION**



**Virtual (online) • July 6**

**ELHG MEETING**

Hall and Monika participated in a meeting with the European Lung Health Group in which PHA Europe is one of the nine members.

**Virtual (online) • July 10****MEETING WITH THE SAUDI ARABIA PH ORGANIZATION**

Gerry, Hall and Monika had a meeting with representatives for the Saudi Arabia PH organization to discuss participation in PHA Europe's APHEC and other collaborations.

**Virtual (online) • July 12****MEETING WITH EPF**

Hall had a meeting with the European Patient Forum to discuss issues related to paediatric medication.

**Virtual (online) • July 18****EHDS INTEREST GROUP**

Hall attended a meeting with an interest group discussing EHDS opt-in/opt-out issues.

**Virtual (online) • July 20****MEETING WITH ELF PH PAG**

Hall, Monika and Eva had a meeting with the the newly established PH Patient Advisory Group (PAG) of ELF.

**Virtual (online) • July 27****MEETING WITH PVRI**

Hall and Monika had a meeting with PVRI discussing the GPS survey. PHA Europe offered to help translate the elaborate survey to numerous languages and ask our members to participate.







**Virtual (online) • August 22**

**MEETING WITH PVRI**

Hall and Monika had a meeting with PVRI discussing the GPS survey. PHA Europe offered to help translate the elaborate survey to numerous languages and ask our members to participate.

**Virtual (online) • August 23**

**TASK FORCE 1 MEETING - WORLD PH SYMPOSIUM**

Hall attended a meeting in the task force 1 group preparing for the proceedings for the World PH Symposium in 2024.



**Amsterdam, Holland • August 25-28**

**ECS CONGRESS**

Hall attended the yearly congress of the European Cardiology Society in Amsterdam, Holland.

**Virtual (online) • August 30**

**ELF NETWORKING DAY PREPARATION MEETING**

Hall attended a meeting with ELF preparing for the patient networking day during the upcoming ERS conference.



**Virtual (online) • September 4**

**ELF NETWORKING DAY PREPARATION MEETING**

Hall attended the second meeting with ELF preparing for the patient networking day during the upcoming ERS conference.

**Milan, Italy • September 8-17****ERS CONGRESS**

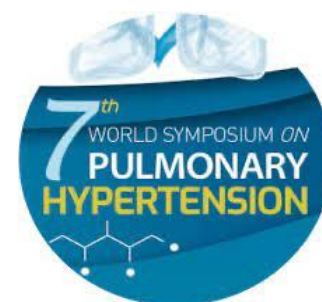
Several PHA Europe board and staff members participated in the annual congress to the European Respiratory Society. PHA Europe had a stand in the World Village.

**Athens, Greece • September 17-19****ESOT CONGRESS**

Tadeja and Natalia participated in the annual ESOT Congress in Athens, Greece.

**Virtual (online) • October 3****TASK FORCE 1 MEETING - WORLD PH SYMPOSIUM**

Hall attended a meeting in the task force 1 group preparing for the proceedings for the World PH Symposium in 2024.

**Virtual (online) • October 5****ELHG MEETING**

Hall and Monika participated in a meeting with the European Lung Health Group in which PHA Europe is one of the nine members.

**Vienna, Austria • October 5****MEETING WITH PHA**

Gerry, Hall, Eva and Monika had a face-to-face meeting with Matt Granato discussing possible areas for collaboration between PHA Europe and PHA





**Vienna, Austria • October 18**

**ELF ANNUAL STAKEHOLDER MEETING**

Hall and Monika participated in ELF's online annual stakeholder meeting.

**Virtual (online) • October 23**

**ELF ANNUAL STAKEHOLDER MEETING**

Hall and Monika participated in ELF's online annual stakeholder meeting.



**Virtual (online) • October 25**

**MEETING WITH PVRI**

Hall and Monika had a meeting with PVRI discussing the GPS survey. PHA Europe provided, among others, translated surveys.

**Virtual (online) • October 26**

**MEETING WITH SUBLY**

Hall had a meeting with Subly discussing possibility to use AI technology to subtitle presentations that will be available in the Bel Air Club.



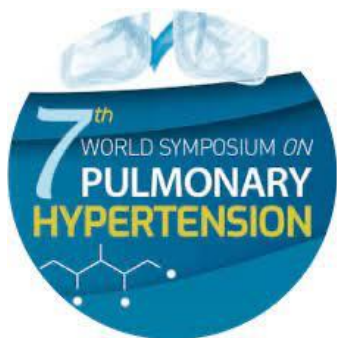
**Virtual (online) • October 27**

**MEETING WITH PHAWARE**

Hall had a meeting with Steve in PHAWARE to discuss the possibility to include their podcasts into Bel Air Club.

**Virtual (online) • October 31****MEETING WITH WORDLY**

Hall had a meeting with Wordly to discuss options for AI supported simultaneous translation at meetings and AI subtitling of presentations.

**Virtual (online) • November 6****TASK FORCE 1 MEETING - WORLD PH SYMPOSIUM**

Hall attended a meeting in the task force 1 group preparing for the proceedings for the World PH Symposium in 2024.

**Barcelona, Spain • November 8-12****PHA EUROPE - ANNUAL PH EUROPEAN CONFERENCE (APHEC)**

Staff and members ran the annual PH conference in Barcelona together with their members. See a separate report.

**Virtual (online) • November 13****EHDS INTEREST GROUP**

Hall attended a meeting with an interest group discussing EHDS opt-in/opt-out issues.

**Virtual (online) • November 22****ERN-LUNG ePAG**

Hall attended a meeting with the ERN-LUNG ePAG group and was accepted as a member. ePAG members will ensure that the patient voice is heard throughout the ERN development process.



European  
Reference  
Network

Respiratory Diseases  
(ERN-LUNG)

**BREATHE  
FOR 2030  
VISION**



**Virtual (online) • November 30**

**ELHG MEETING**

Hall and Monika participated in a meeting with the European Lung Health Group in which PHA Europe is one of the nine members.

**Madrid, Spain • December 1**

**FCHP ANNIVERSARY EVENT**

Hall attended FCHP's anniversary event and gave a speech thanking congratulating them on their day and thanking them for the work they do as a member of PHA Europe.



**Madrid, Spain • December 5**

**ELF PH PAG MEETING**

Hall, Monika and Eva had a meeting with the the ELF PH Patient Advisory Group (PAG). Plans for 2024 were discussed.



**ELF** EUROPEAN  
LUNG  
FOUNDATION

**Virtual (online) • December 7, 11 and 14**

**TASK FORCE 1 MEETING - WORLD PH SYMPOSIUM**

Hall attended a meeting in the task force 1 group preparing for the proceedings for the World PH Symposium in 2024.



**Virtual (online) • December 18**

**FERRER IMPACT CONFERENCE PREPARATION MEETING**

Hall had a first preliminary meeting with Ferrer preparing for the 2024 Ferrer Impact conference.

***Virtual (online) • December 29*****PREPARATORY CALL WITH EXPERT REGARDING EU APPLICATION**

Hall and Monika attended this call with an expert helping us with an EU application for a grant covering some 2024 projects.

