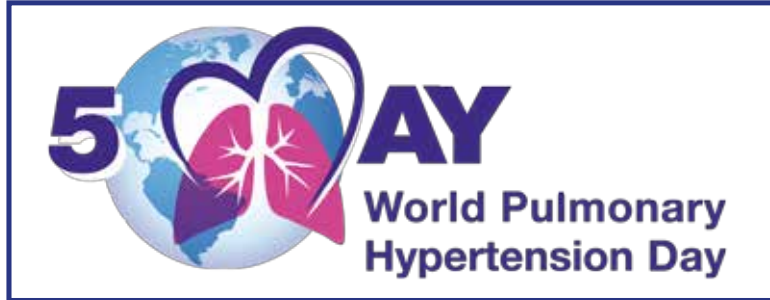




PULMONARY HYPERTENSION Mariposa Journal

SUMMER 2023 • PHA EUROPE'S OFFICIAL JOURNAL • N. 30.



Early diagnosis • Best treatment • Better quality of life • Working in 2023
PHA EUROPE
PULMONARY HYPERTENSION ASSOCIATION *for the patients*

Editor's memo

Summer edition 2023

Dear Friends, Colleagues, and Supporters,

Welcome to the summer edition of our magazine Mariposa. This edition is mainly dedicated to World PH Day and all the amazing events that were organised by our members and other associations around the globe. We are proud to have the world lead in this event, which was started by our Spanish association ANHP eleven years ago and then carried on by PHA Europe. It was started as a recognition of the urgency to improve awareness about pulmonary hypertension. This annual event, held on May 5th, brings together organizations, healthcare professionals, patients, and their families from across the globe to highlight the challenges faced by the PH community.

OUR WORLD PH DAY PROJECT HAS THREE MAIN OBJECTIVES AND BENEFITS:

- 1. Raising Awareness:** World PH Day serves as a platform to educate the public about pulmonary hypertension, its symptoms, and the impact it has on patients' lives. Through various awareness campaigns, including social media campaigns, educational events, and media coverage, PHA Europe aims to dispel misconceptions, reduce stigmas, and encourage early diagnosis.
- 2. Building a Global Support Network:** The World PH Day project acts as a catalyst for bringing together patients, caregivers, healthcare professionals, and advocacy groups. By fostering a sense of community, PHA Europe empowers individuals affected by PH to share their stories, exchange knowledge, and find solace in a supportive network.
- 3. Advocating for Improved Care:** PHA Europe leverages the visibility and momentum generated by World PH Day to advocate for better healthcare policies, increased research funding, and improved access to treatments and support services for PH patients. By partnering with medical professionals, policymakers, and other stakeholders, the organisation strives to address the unmet needs of the PH community on both national and international levels.

Once more, the inventiveness of our members has impressed us. They illuminated buildings with blue colour to create awareness for pulmonary hypertension, numerous sports events were held displaying the familiar T-shirts with our shared WPHD logo, healthy people got to experience how it is to live with PH as they breathed air through a straw and simultaneously had a clip on their nose, and the list goes on. Please find time to read about all the events that took place, even in countries currently experiencing trying times.

In addition, WPHD was also successfully posted on all our social media channels. By using professionally-looking visuals that were shared with associations across the globe, we have reached a vast audience. Please check the section dedicated to social media to learn more about our successful digital WPHD campaign.

PHA Europe's World PH Day project stands as a beacon of hope for millions of people living with pulmonary hypertension worldwide. Through its dedication to raising awareness, building support networks, and advocating for better care, PHA Europe has made significant strides in bringing this often-misunderstood disease into the spotlight. PHA Europe and the World PH Day project pave the way for a brighter future for those affected by pulmonary hypertension, fostering understanding, support, and enabling a better quality of life for all.

A big thank you goes out to all members, patients, family members, carers, and friends who contributed to making this WPHD, once again, a great success. And as always, special thanks go out to our industry partners, who continue to support our work. Our mission is clear: We want to raise as much awareness as possible in order to get people diagnosed at an early stage in their disease and, in this way, improve their quality of life (QoL) and extend their lifespan.

Hall Skaara
Project manager - PHA Europe

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CALL TO ACTION

Unmet needs of persons living with pulmonary hypertension



PHA Europe's original Call to Action paper was authored and presented at the European Parliament in 2012. A decade later, in 2022, it underwent revision, and a new event was organized at the EU Parliament in April 2022. This revision was necessary due to the fortunate rapid evolution and advancements within the pulmonary hypertension (PH) field. These positive changes can be attributed to advancements in medication, treatment, and the continuing efforts of our national PH associations. Nonetheless, the paper remains relevant, as there are still unmet needs for individuals living with pulmonary hypertension. In 2023, we undertook the translation of the executive summary of the Call to Action into 18 different languages. We printed

copies of the Call to Action document, originally produced in English, for distribution among all our members. Furthermore, we included a pocket on the end page to accommodate the inclusion of the executive summary in the local language. In this manner, the document becomes an invaluable tool for our members, when engaging with health authorities and decision-makers in their respective countries.

The Call to Action document, along with the executive summaries, was produced and dispatched to our members prior to this year's World PH Day. This ensured that our members could use the document during their local events.

We expect that the Call to Action will remain our primary strategic document for many years to come.



CALL TO ACTION

1. Improve access to expert care

- Establish, properly fund and maintain, and integrate expert centres in local healthcare systems:
 - High-volume expert centres, staffed by a multidisciplinary team of physicians who are trained and experienced in pulmonary hypertension (PH) care, should provide the diagnosis and care of PH patients
 - Expert centres are necessary to ensure that currently available drugs are prescribed and used appropriately
 - Patients where PAH or CTEPH is suspected should be referred to expert centres without delay
- Regularly review national and EU policies based on real life data to ensure and facilitate the implementation of the cross-border healthcare directive
- Increase access to transplantation by enacting and regularly reviewing organ donor policies and maintaining processes that enable organ transplantations. All EU countries should develop and maintain comprehensive and humane organ donation policies, which ensure high-prioritised status on the waiting list for eligible PH patients
- Develop and regularly update PH clinical practice guidelines
- Ensure that drugs or combinations of drugs for PH patients are prescribed by expert physicians, and that patient access is not limited by national policies
- Establish, regularly update and maintain national policies which ensure continuous access to care even in special situations

2. Improve awareness and screening

- Initiate PH awareness campaigns for both professionals and public
- Create training programmes on PH for health care professionals
- Create national screening and diagnosis programmes, tailored to PH patient subgroups
- Raise awareness of the potential for curative surgery and angioplasty for chronic thromboembolic pulmonary hypertension (CTEPH) and the need to appropriately evaluate CTEPH patients

3. Encourage clinical research and innovation

Ensure more policy, academic support, funding and incentives for:

- Fundamental, basic science, PH research
- Research that leads to effective treatments for all forms of PH and ultimately a cure for PH
- Capacity of existing centres to support clinical trials and investigational research
- Research to determine non-invasive methods for measuring pulmonary pressure and cardiac output

4. Empower patient associations

- Facilitate real-life information exchange between PH patient associations and policy makers through roundtables, working groups, and other activities to ensure that the patient voice is heard and considered during decision making
- Include patient associations in health care policy debates, early clinical trial design discussions, regulatory activities for medicines, and relevant decision-making processes
- Empower patients to make contributions through a proactive inclusive approach to ensure that people with PH are able to talk about their experiences and treatment, providing the input needed to make decisions fundamental to the lives of people living with PH
- Increase the capability of patient associations to serve patients more effectively, particularly through the provision of accurate, evidence-based, regularly updated information
- Encourage balanced financial support, including government funding, for patient associations so that they can continue to be independent

5. Ensure availability of psychosocial support

- Ensure that PH treatment encompasses treatment for the "whole" patient. National systems of integrated care must be instituted, encompassing all aspects of medical, psychosocial, nutritional, and rehabilitative support for patients and their carers
- Ensure that patient associations have secure, sustainable sources of funding so that the people who best know what it is like to live with PH can support people living with PH, including through telephone help lines
- Afford disabled status to people living with severe forms of PH so that they can access key services, and are enabled to lead a more independent life

WPHD WEBINAR 2023

It has become a tradition to run online WPHD webinars, and this year was no exception. The renowned PH specialist Prof. Sean Gaine from Ireland ran an excellent presentation called «Work in Progress: Emerging Hope in PH». Several participants called the presentation «the best PH presentation I have ever seen!»

Prof. Gaine started his presentation by talking about the past in PH treatment when he, as a young doctor stationed in the US, was involved when the first PH medication entered the market back in the 1990s. It was a type of drug called prostacyclin, and it paved the way for PH expert centres, including PH specialists.

We have come a long way since then, with many new PH drugs on the market. According to Prof. Gaine it remains a work in progress, as there is still no cure for PH. However, there are many expected new drugs and advances in the PH field in the coming years, so Prof. Gaine claims there is «emerging hope in PH».

Prof. Gaine then put his attention to the clinical guidelines. He explained the importance of them and pointed out that patients, for the first time, were involved in developing the guidelines for treatment and diagnosis of pulmonary hypertension during the 2022 guidelines. The guidelines were presented at the 6th world symposium of PH. This is an important milestone. Furthermore, he explained the five groups of PH and pointed out that we now have PH drugs and treatments for three of the five groups (1, 3, and 4).

Prof. Gaine went on to mention that Artificial Intelligence (AI) also has its place in detecting PH in some clinical settings. AI can, for instance, be used to analyse echocardiograms and ECGs and detect patients that need further investigation due to suspected PH. This is one of many areas in which AI can play an essential role in the field of PH in the future.

Prof. Gaine continued his presentation by listing four emerging hopes in PH. The first being phenotyping. This term is being used medically to describe what kind of PH a person has. The better one can phenotype a patient, the more precise and well-suited the medication given to the patient can be. Prof. Gaine went on to give an example of group one PH, which is the group that goes by the term Pulmonary Arterial Hypertension (PAH). He described how the patients can be divided into three clusters, which all might require different types of treatment, despite the fact that they are all categorised as PAH patients. Prof. Gaine also talked about the relationship between genotyping and phenotyping. Genotyping refers to the analysis of a patient's genes as gene mutations and changes, often found in PH patients, relates to patients as different phenotypes. This fact will play an important role in future individualised and personalised treatment and appropriate medicating of PH patients.

According to Prof. Gaine, the second hope in PH was the introduction of risk stratification and the early use of current therapies. The term risk stratification refers to a list of parameters to identify the status of the patient in order to determine how the patient is doing. It classifies the patient into risk groups and decides if the current treatment is sufficient or if additional medication should be introduced. Risk stratification can also help the doctor understand when it is time to consider lung transplantation for a patient. The newest guidelines introduced more granular risk groups. The intermediate group is now divided into intermediate low and intermediate high. Prof. Gaine also pointed out that three non-invasive parameters can indicate which group a patient belongs to. The parameters are NYHA functional class, the six-minute walking test, and a biomarker called BNP or NT-proBNP.

Prof. Gaine then talked about new emerging drugs and modifications of older therapies as the third hope in PH. When it comes to older medication, new trials are being run in order to test the effectiveness of treatment with higher doses than originally called for. Secondly, there is a trial on combining two different drugs into one pill. Converting old drugs to be used as inhaled drugs instead of oral drugs is also another interesting concept. The drugs might better target the lungs and enable higher doses of the drugs without causing unwanted systemic side effects.

New technologies related to inhalers and dry power production have also led to the development of new types of PH medication that are currently being tested out in trials. Prof. Gaine explained that some of these medications represent new pathways in addition to the three current pathways. The drug that is likely to hit the market first will be a drug that would be injected under the skin once a month. It is meant to rebalance the signaling between pro- and anti-proliferative pathways. It will most likely enter the US market during the first half of 2025, while it will probably only be available in Europe a little later. The drug's availability in different European countries will depend on the local laws in the respective countries. Other novel and upcoming pathways are related to serotonin and to a Serotonin drug and to inhaled drugs built on a drug tested years ago called Imatinib. According to Prof. Gaine, the original study on Imatinib had to be stopped due to serious unwanted side effects, but new inhalation techniques might result in effectiveness with much less systemic side effects. These, and other drugs, are currently being

tested and may yield effective new PH treatments in years to come. The last hope for PH that Prof. Gaine presented was lifestyle-related issues. These might be important, especially for the Quality of Life (QoL), as patients live longer with PH. Lifestyle might also prove important in the progression of the disease. Prof. Gaine talked about how individualised exercise has shown to be beneficial for PH patients. He also mentioned dietary factors that might influence the microbiome in the digestive system. These seem to have some effect on the PH, indicating that a healthier diet might positively affect a patient's PH. Prof. Gaine also pointed out how emerging technologies, like smart phones, implantable devices, Patient Reported Outcomes, etc. might lead to a difference in the way to follow up a patient. Automatically generated reports, for instance, might give early warnings about changes in the patient's condition. These tools might also prove very important when different drug therapies are tested out on a patient in the search of finding the optimal personalised medication.

Prof. Gaine's presentation gave an excellent view of the emerging hopes for the future treatments of PH patients. It generated a lot of interesting questions from the PH webinar audience, which Prof. Gaine gave very insightful answers to.

The webinar can be viewed on PHA Europe's World PH Day web pages. We highly recommend viewing it, and we thank Prof. Sean Gaine for an excellent presentation!

*Hall Skaara
Project manager
PHA Europe*



SOCIAL MEDIA CAMPAIGN

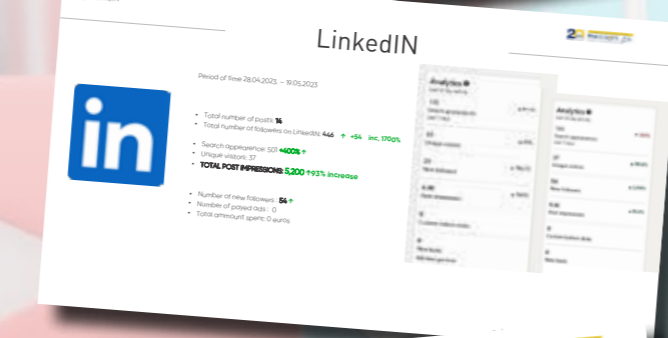
In the ever-evolving landscape of social media campaigns and branded content, our relentless pursuit of a unique tone and voice sets us apart. This year, our focus remains unwavering, but with a crucial twist: we are shifting our attention to the very essence of our content—the needs of patients.

Harnessing the power of social media campaigns offers numerous advantages, yet our proudest accomplishment lies in the global reach of our WPHD materials. Translated into over 15 languages, these resources and our toolkits (<https://worldphday.org/toolkit/>) have garnered widespread appreciation among associations worldwide. The utilization of Canva templates has made everything even simpler compared to the previous year(s).

Our social media campaigns become more than just a means to promote awareness—they become a vehicle for empathy, uniting individuals and organizations in a shared mission. By weaving together compelling narratives, captivating visuals, and thought-provoking messages, we ignite a global conversation that reverberates across borders and cultures. This year's empowering slogan „Inhale PH, Exhale Courage” and the hashtag #StillPHighting serve as a reminder that PH and its need for a cure is as present as ever.

We strived to carefully measure the overall success of our social media campaigns and, with the invaluable support of numerous global PH associations, we can all take pride in the outstanding results achieved during this year's WPHD 2023. Remarkably, all key performance indicators (KPIs) experienced a significant surge, highlighting the tremendous reach of our impactful voice united to transmit a singular message of HOPE for all PH patients.

The combined efforts of PHA Europe's Facebook and Instagram pages, alongside the World PH Day Facebook and Instagram pages, achieved an impressive milestone, surpassing 4 million total impressions. This remarkable figure represents a 10 percent increase compared to the previous year, emphasizing the staggering reach of our impactful materials.



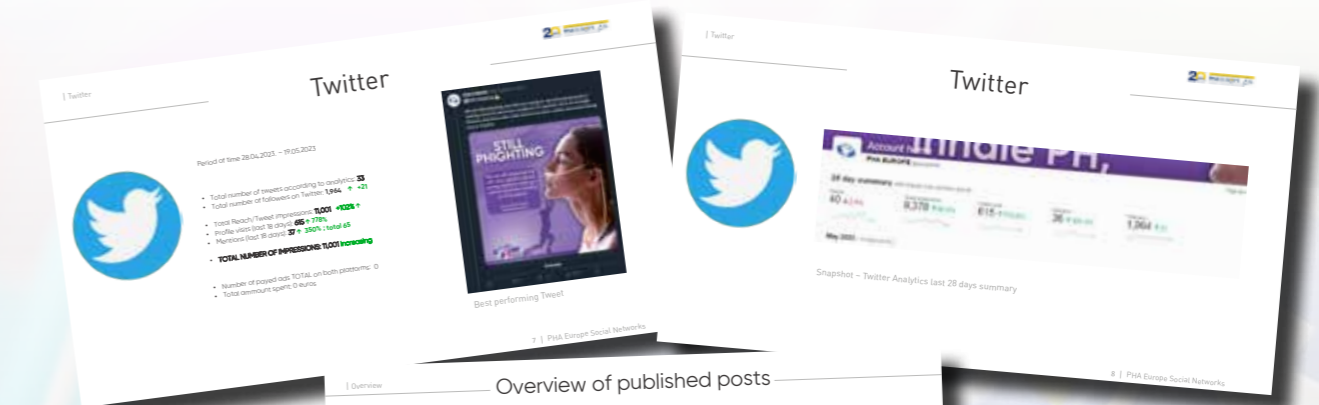
Across four prominent platforms—Facebook, Instagram, Twitter and LinkedIn, the expansion of our fanbase and followers was nothing short of remarkable. Over the span of only 15 days, we witnessed a dramatic surge, gaining nearly 250 new followers. Furthermore, the translation and dissemination of our ready-to-use materials and visuals by numerous international associations further contributed to our global impact and numbers.

While the precise calculation of total numbers (of total reach) remains challenging,

we estimate that the PHA Europe-led WPHD 2023 campaign reached an estimated 6 million individuals worldwide. This expansive reach signifies the powerful resonance and widespread influence of our global initiative.

We take immense pride in the collective PHight and extend heartfelt gratitude to all the associations who joined us in our mission. This shared dedication brings an added responsibility to make every future project even more meaningful for patients, leaving an impact that cannot be ignored.

The PHA Europe Digital Media Team



THANK YOU



AUSTRIA



WORLD PH DAY AT MILESTONE SQUARE IN VIENNA'S PRATER

This year, we hosted a remarkable event for World PH Day at Milestone Square in Vienna's Prater. Prior to the event, we precisely cleaned up the venue to ensure it radiated in all its glory. As the main highlight, we enlisted the talents of graffiti artists to creatively interpret our World PH Day logo and spray it live on a large screen at Milestone Square, situated in front of the planetarium and the iconic Vienna Giant Ferris Wheel.

We took the opportunity of both World PH Day and our Milestones project to raise awareness for PH Austria and pulmonary hypertension. Through the Milestones project, individuals could personalize a plate engraved with their own message on a brick, contributing to the ever-growing Milestone Square at www.meilensteine.at. Over 18000 milestones have already been placed on the Milestone Square. This meaningful initiative has been closely associated with PH Austria and the Lung Kids Research Association for several years, capturing the hearts of all involved. The paving stone symbolized the sensation of having a heavy burden on the chest, hindering the ability to breathe. It served as a touching representation of the challenges faced by those affected by the condition.



Adding to the significance of our Milestone Square, we welcomed a special supporter: Toni Polster, the famous soccer player who achieved numerous records in the Austrian national team and played internationally for Köln and Sevilla. His remarkable 44 goals for the national team secured his permanent place in our Milestone Square.



As the graffiti took shape, beautifully revealing the World PH Day logo, we engaged interested passersby by providing information about PH Austria and pulmonary hypertension. Tony Wegas, the famous singer and two-time participant in the Eurovision Song Contest, actively supported our cause as he himself battles with pulmonary hypertension. A dedicated film crew accompanied us, capturing the process of creating the World PH Day graffiti, resulting in a captivating documentary for our social media platforms. This video will continue to raise awareness for years to come. https://www.youtube.com/watch?v=jvn_K2LQVc0



As tradition holds, we received support from the owners of the Viennese Giant Ferris Wheel around the 5th of May each year. Once again, the Ferris wheel was illuminated in vibrant blue during several evenings in May, serving as a powerful visual representation to draw attention to pulmonary hypertension.

We sincerely hope that our projects have made a lasting impression, and we eagerly anticipate each following step towards finding a cure for PH.

Monika Tschida
 PH Austria -Initiative Lungenhochdruck
www.phaustria.org
www.facebook.com/lungenkinder



BELARUS



Belarus supported people suffering from PH through a sport and game program titled „Take care of your health from childhood”, which was held at the Molotkovichi Special Orphanage School. The children prepared for the event with special trepidation and excitement: they inflated balloons, decorated the hall, tried on T-shirts, and applied aquagrim.

At the beginning of the program, an informational conversation was held for all those present about the possible causes and symptoms of PH, how people suffering from this disease feel and why it is necessary to take care of themselves and others. The presenter drew attention to the fact that, unfortunately, people suffering from pulmonary hypertension cannot play sports, or lead an active lifestyle to the fullest. They have to limit their physical activity due to the peculiarities of the disease.

After the conversation, the children, divided into two teams, took part in a sports relay race, where they had to complete all the tasks without mistakes, show dexterity, ingenuity, endurance, as well as the ability to work together in a team. The relay consisted of various competitions: „Roll the hoop”, „Snake”, „Funny balls”, „From hummock to hummock”, „Jumping on a fitball”, etc. Some of the participants managed everything easily, others needed more time and skill. The fans were very worried about their friends and classmates, so they cheered the teams on with their applause.



The holiday turned out to be great! The main thing at the event was not the victory of the team, but strengthening the health of children, fostering the love of sports, developing a sense of friendship and the ability to work in a team. The bright photoshoot in blue tones was organized for all team members, after which the children received memorable gifts and sweet prizes.

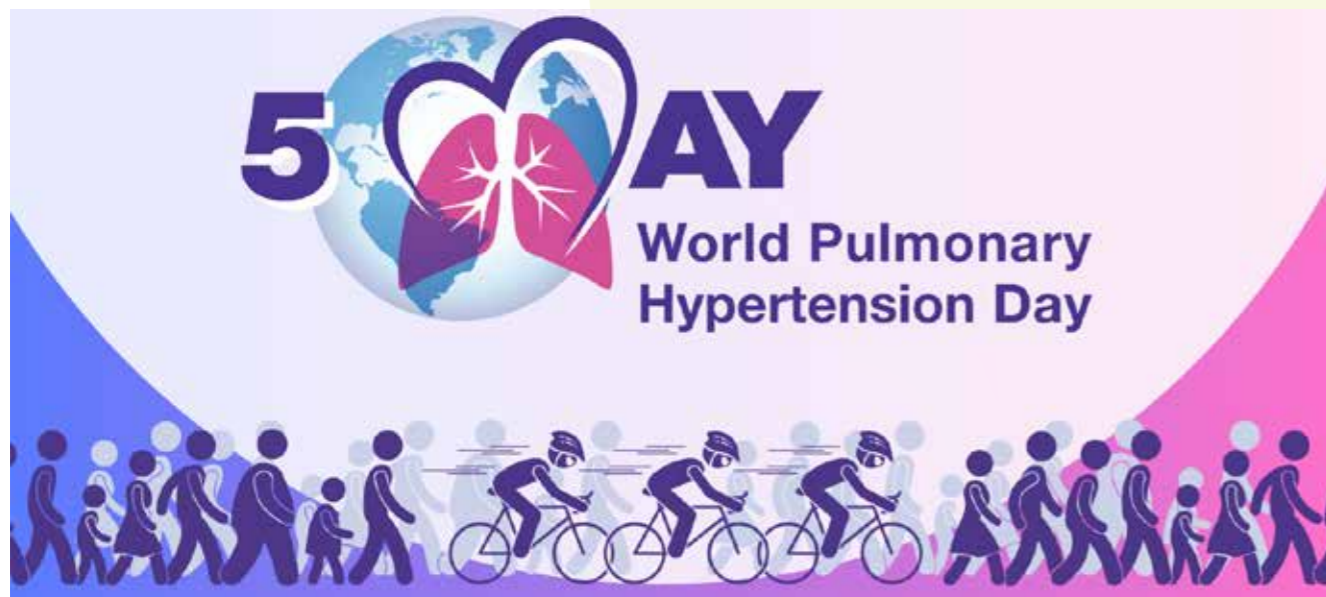
In addition to the school children and their teachers, the event was attended by the director of the orphanage school, Izotov Vyacheslav Grigorievich, the head teacher for educational work, and a teacher-psychologist. In total, more than 70 people attended, together with the students. Larisa Anatolyevna Kobrinets, the head of the Molotkovichi outpatient clinic, visited the Health Day as an invited guest. Correspondents of the popular local radio station „Svoyo Radio” told their listeners about the event dedicated to pulmonary hypertension.

<http://molintern.brest-region.edu.by/main.aspx?guid=55903>





World Pulmonary Hypertension day PH Belgium: online sporting event 'Moving for pulmonary hypertension.'



In the month of May, PH Belgium organized an online sponsoring event where people could financially support athletes, family members and PH-patients for the kilometers they collected by riding, walking, running, etc.

With this event, we wanted to achieve three goals:

1. The first was promoting a healthy lifestyle by getting people to exercise, whether they were patients or routined athletes. To help the patients, we included a link to a webinar about 'Exercising with PH', where a physiotherapist from the UZ Leuven expertise center explained how to exercise safely as a PH patient. We also organized two offline events with our members where we promoted the campaign.
2. The second goal was raising awareness by getting people to share their activity, online and offline. To help them with that, we provided materials on the two offline events and online via a toolkit with a banner, infographic, visuals, etc.
3. As a third goal we wanted to make this also a fundraising campaign, by using a fundraising platform where people could get sponsored for the kilometers they collected. We choose 'Steunactie' because it's in Dutch and not too complicated to use. To help people to set up an account, we made a step-by-step starter's guide.

To help us set up the event and make it a success, we have recruited and informed our members during two physical meetings, which were organized in late April and early May. Although patient participation was still limited, we did see that the topic about exercise with pulmonary hypertension was often discussed at the meetings with patients. There was one beautiful example of a 13-year-old patient with her mom, who walked almost 1 km daily!



To measure the kilometers, we asked people to join our Strava club, where we could see how much kilometers they have made. There were also a lot of people who only joined the Strava-club, this grew from 13 to 43 members. In total, 19.372,8 km were collected on Strava for pulmonary hypertension! Next to that, there were also the kilometers from people that did not join the Strava club or organized their own private campaign. For example, the PH-team of MSD-Belgium did their own sporting-campaign. They even shared a video of this on their LinkedIn page.



On our social media accounts (Facebook, Instagram, LinkedIn, and Strava), we shared posts of the campaign and facts on pulmonary hypertension. We encouraged people to share their progress on their socials, and we saw that the campaign was shared a lot on social media.

With the campaign, we could raise 4,525€ for pulmonary hypertension; 3,400€ through the fundraising platform and an additional 1,125€ through a company that organized the campaign internally. As a result, we almost reached our target of 5,000€!

Links:

Campaign: <https://steunactie.be/actie/beweeg-voor-pulmonale-hypertensie/-19085>

Video 'Bewegen met PH': <https://youtu.be/MbKKxOX7IFo>

Strava-club: <https://www.strava.com/clubs/PHBelgium>

Belgische patiëntenvereniging voor pulmonale hypertensie vzw (P.H. België) – Kruisbeeldstraat 28, 9220 Hamme
BE 0475 321 180 – RPR Gent, afdeling Dendermonde
BE04-0682-3239-3031 – www.ph-vzw.be – info@ph-vzw.be

BOSNIA AND HERZEGOVINA

Bosnia and Herzegovina - WPHD 2023

SPORTS AND EDUCATIONAL ACTIVITIES FOR ALL GENERATIONS

The celebration of WPHD 2023 in Bosnia and Herzegovina takes a step forward every year in terms of engaging all generations - from the youngest to the oldest.

CYCLING PH CIRCLE IN EUROPE

Our oldest collaborator is Ismet Škulj from Zavidovići, a recreational cyclist from Bosnia and Herzegovina for many years. Ismet leaves us breathless every year on May 5th. This year, he completed a 1,410 km cycling circuit with his bicycle. When we add those kilometers to those previously travelled for patients with pulmonary hypertension, Ismet covered a total of 11,690 km of cycling that he dedicated to patients with pulmonary hypertension. In late April and early May 2023, Ismet rode with Zlatko Silik for eleven days in Europe with the mark of the European PH community. In this way we once again marked the WPHD together. Despite the bad weather conditions, they managed to finish another spring cycling tour, which had a goal to raise awareness about our disease through five European countries: Bosnia and Herzegovina, Croatia, Hungary, Austria and Slovenia.



HALF MARATHONS AND MARATHONS - BREATHLESS FOR PH



Unlike Ismet, who rode a bicycle, a group of runners from Bihać, by participating in the May half-marathons and marathons in Bihać, Sarajevo, and Zagreb, ran more than 200 km; they were breathless for pulmonary hypertension. Enes Ibrahimagić, Sanel Kurtagić, Asmir Islamović, Haris Mašić, Amar Čehajić, and female runners Dženana Musić, Elza Ljubijankić, and Emina Čehajić Gradinović, members of the sports clubs BURT and SD Ultra, both from Bihać, are our constant supporters, who are tirelessly on the road together with us raising awareness about pulmonary hypertension in our country, as well as abroad. In those three cities, expanding over two countries, Bosnia and Herzegovina and Croatia, they were breathless for patients with pulmonary hypertension and achieved exceptional results.

STUDENTS AND PUPILS ABOUT PULMONARY HYPERTENSION

In addition to sports activities, we also organized two educational events about pulmonary hypertension, among students and pupils.

In Sarajevo, in the premises of HUB Homework, a presentation dedicated to pulmonary hypertension was held, the author and lecturer of which was Sabina Hodžić, a long-time activist of the Association of citizens suffering from pulmonary hypertension „Dah” - in Bosnia and Herzegovina. With the presence of Sarajevo University students, who had many questions about this difficult and rare disease, this presentation fulfilled all our expectations.

We organized the second educational event in Zavidovići with the oldest students of the „First Elementary School”. In an exceptional atmosphere, we talked about pulmonary hypertension, symptoms, therapies, the importance of early diagnosis, and we also organized a 6-minute walking test simulating a PH patient, after which we measured saturation, heart rate and lung capacity. As always, the students of this school, together with their teacher Amir Muminović, showed a lot of empathy, a lot of desire and will to help and actively participate in celebrating World Pulmonary Hypertension Day.



THE YOUNGEST ONES BRING KASPER TO LIFE WITH THEIR DRAWINGS

„Kasper - the blue-lipped bear” picture book, which we printed thanks to the Bulgarian author Natalia Maeva and PHA Europe, in addition to its educational and entertaining content, also served as an inspiration for the illustration of the drawings of our youngest collaborators in raising awareness on the occasion of World Pulmonary Hypertension Day. Students I-2, III-3 and V-1 of the „First Elementary School” from Zavidovići have been our constant collaborators in celebrating this day for years. They surprised us again this year with their creative works, wanting to participate in the celebration of WPHD 2023. They sent us many of their drawings with the unforgettable message „Dear Kasper, we want you to get well!”. With great gratitude to these students who are growing by raising awareness for PH, and their teachers Fadila Suljičić, Emira Skejić-Dautbegović and Samira Isić, we hope that we have brought our disease closer to the youngest, as well as to all those who, until now, knew nothing about it. The story of Kasper the bear lives on in Bosnia and Herzegovina and carries a strong message for all small and big PH fighters - early diagnosis of our disease gives hope for a better tomorrow for PH patients.



Raising awareness about this incurable disease among all generations is our continuous task.



SUPPORT, MEDIA, VIDEO BANNER

As in previous years, during the celebration of WPHD 2023 in Bosnia and Herzegovina, words, photos, messages, newspaper articles, and other media content are continuously reaching us as exceptional public support for our disenfranchised group of patients. An increasing number of people understand the hard and hopeless situation in which patients with pulmonary hypertension find themselves in our country, which is why we are extremely proud of our work and our support. We express our gratitude to the athletes, professors, students and pupils, the media, and the associations that supported us, as well as to the company General Pro-Mark, which provided us with a video banner at the city's busiest intersection.

This year, when arranging the impressions after the celebration of the WPHD in Bosnia and Herzegovina, we must highlight the media as well. They simply left us breathless. The fact is that they have always been with us and are doing everything to help us in our fight for our lives, but this year they surpassed themselves and really did a great job on the occasion of WPHD in Bosnia and Herzegovina. Recognizing a problem and writing about it is one of the foundations on which journalism is based. Because of all their efforts, we must especially praise and mention them: Zdici.info, Fena, Fokus, Klix, Vijesti, Federalna TV, Start BiH, Bljesak.info, Centralna, Radio Olovo, Zenicablog, Radio Sarajevo, RTV Maglaj and RTV BPK.



Vera Hodžić,
president of the Assembly
Association of citizens suffering from pulmonary
hypertension „Dah” - in Bosnia and Herzegovina



BULGARIA BSPPH



PULMONARY ARTERIAL HYPERTENSION IS LIKE AN ICEBERG

On May 5th, we marked the world day of „the blue lip disease”. In Bulgaria, this rare disease affects nearly 500 Bulgarians. One of the key symptoms of this rare disease is difficulty breathing, even when doing the most ordinary daily tasks. Additionally, the blue color of the lips and limbs is a symptom of the lack of oxygen in the human body.

On May 5th 2023, from 8:00 p.m. to 11:00 p.m., the building of the National Palace of Culture in Sofia was lit in blue for the past 8 year, as a sign of empathy with the incurable, rare, and insidious disease „of the blue lips” - pulmonary hypertension. In the interval from 8:00 p.m. to 10:00 p.m. on Friday, May 5th 2023, the following buildings were illuminated: in Burgas - the Bridge in the Sea Garden; in Ruse - the building of The Pantheon of the Revivalists, in Haskovo - the Bell Tower, near the monument „The Virgin Mary”.



Pulmonary hypertension can strike anyone. The invisible disease makes you dependent on an oxygen apparatus. You can't breathe and get tired from the slightest movement. You get swelling on your legs, arms, and your lips turn blue, showing the lack of oxygen. The oxygen mask hinders you when you sleep, and climbing stairs turns from a simple action into a huge ordeal. 130 patients with a rare form of the disease fight a daily battle with it, and about 500 Bulgarians suffer from different types of pulmonary hypertension. Patients are dependent on oxygen apparatuses and costly supportive therapy. said Natalia Maeva, chairperson of the Bulgarian Society of Pulmonary Hypertension Patients.

Despite the efforts of the patient organization, the health insurance fund continues not to finance oxygen apparatuses for patients with pulmonary hypertension. Most of the patients in the third and fourth functional class of the disease need expensive intravenous therapy, which is also not available in our country. Lung transplantation is a life-saving option for them, a problem that has remained unsolved in our country for years.



TEAM „KARO” DEDICATED THEIR PARTICIPATION IN THE INTERNATIONAL PÉTANQUE TOURNAMENT TO BULGARIAN PATIENTS WITH PH

Teams from 34 countries participated in the international pétanque tournament, held from May 23rd to May 28th at the Mesongi Beach resort on the island of Corfu, Greece. The representatives of Team „Karo” dedicated their participation in this prestigious international competition to people living with pulmonary hypertension.

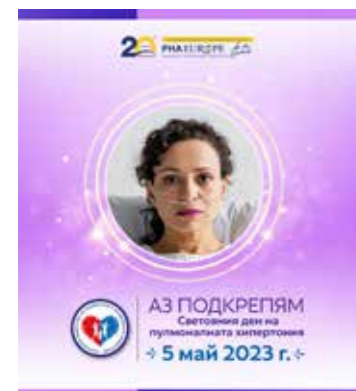
„Thank you for taking the time to donate your breath to those who cannot breathe and are dependent on their oxygen machines. Access to new therapies for PH is years behind compared to other European countries, and lung transplants remain a chimera. The training of our doctors is at a standstill, and time is of the essence for patients suffering from pulmonary hypertension,” says the chairwoman of the Bulgarian Society of Patients with Pulmonary Hypertension Natalia Maeva.

„We are delighted to support the “Donate a Breath” campaign and draw attention to the plight of vulnerable patients living with this rare and insidious disease. I hope that our partnership will contribute to more people paying attention to the symptoms, the course of the disease, and a way out of it”, added Atanas Makarov, chairman of the Karo sports club.

Pétanque has been officially played in Bulgaria since 2000. The popular French game is played on a rectangular court measuring 5 by 15 m with a hard surface of sand or clay. Balls made of a special metal alloy are used for it, weighing from 600 to 800 g, and their diameter is about 70-75 mm.



It can be played individually, in pairs or threes, but classically is played in threes, which can be male, female and mixed. When playing individually and in pairs, each competitor of a team has three balls, and when playing in threes, two balls.



PATIENT WEBINAR „LIVING WITH PULMONARY HYPERTENSION: MENTAL HEALTH”

As part of the World Pulmonary Hypertension Day campaign, a patient webinar „Living with pulmonary hypertension: Mental health” was held on 26.05.2023. Dr. Lyubomir Dimitrov, an invasive cardiologist, head of the Department of Paediatric Cardiology at the National Hospital of Cardiology and deputy chairperson of the Bulgarian Society of patients with Pulmonary Hypertension, spoke about the problems that doctors and patients with PH have gone through during the pandemic. „All these patients should receive adequate medical care. We, I am talking about the doctors, the society, and the state, should provide them adequate treatment,” the expert said.

A lecturer of the event was the psychologist Dr. Antonia Grigorova, who spoke more about the risk factors that affect the psychological state of patients with pulmonary hypertension. In addition, she offered a self-management program for patients with this rare disease- how to build useful habits, how to solve problems, how to deal with anger, and how to communicate with loved ones.

BULGARIA PHA



NATIONAL ARM WRESTLING TEAM IS SUPPORTING PH

On May 5, at 7:00 p.m., an open arm wrestling training session was held in the „Borisova Garden” park under the patronage of the Municipality of Sofia together with the National Federation of Arm Wrestling in Bulgaria. Competitors from the national arm wrestling team took part, of which 3 national champions and one European champion were distinguished.

This event was organized to promote the sport of arm wrestling and to showcase the skills and achievements of the Bulgarian athletes. The training session was open to anyone who wanted to learn more about the rules, techniques, and benefits of arm wrestling. The participants had the opportunity to challenge some of the best arm wrestlers in the country, and they were even able to receive valuable feedback and advice from them.

The event was also attended by representatives of the Municipality of Sofia and the National Federation of Arm Wrestling in Bulgaria, who expressed their support and appreciation for the initiative. They emphasized the importance of developing and popularizing arm wrestling as a sport that fosters physical fitness, mental strength, and fair play. They also announced their plans to organize more events like this in the future, as well as to provide more facilities and equipment for the arm wrestling clubs and enthusiasts in Sofia.



KOM- EMINE HIKING FOR PH

If you are looking for a challenge and a way to explore the beauty of Bulgaria, you might want to consider following the footsteps of Todor Mangarov, who is currently hiking the Kom-Emine trail. This trail is the longest high mountain hiking route in Bulgaria, spanning about 700 km along the Stara planina ridge from west to east. It takes about 25-30 days to complete, depending on your pace and the weather conditions. Todor Mangarov started his journey on May 5, and he shared some photos from the beginning of his adventure.

He also said that he was looking forward to reaching the finish line and enjoying the stunning view along the way. We wish him good luck and we will keep everyone updated on his progress. If you are interested in joining him, or even trying out the Kom-Emine trail yourself, you can follow him on Facebook.



EPFA IS SUPPORTING PH

The European Pulmonary Fibrosis Association (EPFA) was one of the sponsors of World Pulmonary Hypertension Day, which took place on May 5th, 2023. The EPFA also held its annual congress in Barcelona, Spain, from April 28th to 30th, where it discussed the latest research and developments on pulmonary fibrosis and related diseases. The congress was attended by more than 300 health professionals, patients, and advocates from across Europe and beyond.



CROATIA

WE MARKED WPHD WITH THE MZ CENER RACE AND THE II. SAVA MARATHON RACE

T-shirts with the inscription „Get Breathless for PH”, which about 280 runners ran in this year, plus children's races, aim to send the message that runners run out of breath during the race, just like sufferers of pulmonary hypertension, who also run out of breath during the slightest exertion, sometimes even while they are standing still.

A big Thank you to everyone who fights with us daily, year after year to raise awareness of pulmonary hypertension to a higher level. Many thanks go out to the runners, citizens, partners, and our doctors, who actively participated, and without whom this would not be possible!

The MZ Cener race was held under the auspices of the mayor of Zagreb.

Many thanks to Juri Buljan, the initiator and organizer of II. Sava Marathon race, under the auspices of AK Maksimir, with whom we have been cooperating extremely successfully for several years in a row.

Both races were held on the occasion of WPHD 2023.



ART FROM THE HEART

The first humanitarian art colony of the association Plava Krila was held on May 6th.

Young artists responded to our call, selflessly donating their time and talent for humanitarian purposes. The beautiful views of the Botanical Garden in May provided everyone with a quiet corner for creating beautiful works of art.

We would like to take this opportunity to say one big thank you to everyone for their participation, and express special thanks to Nika Vrbica, who connected our association with the world of artists and engaged in everything, paying attention to details. The project was financed by PHA Europe and the CBP program. The second part of the project is yet to come in the fall and will be featured in the next edition of Mariposa.



THE PROJECT „DO MORE, BREATHE TOGETHER” WAS IMPLEMENTED

The project „Do more - breathe together” was aimed at strengthening civil society organizations at the local level, as well as at contributing to the quality of life of people with disabilities. We implemented the project as the project manager with partners from the Association of Persons with Intellectual Disabilities Bjelovar, and the Sports Association Argo from Bjelovar. The project lasted 18 months in the area of Zagreb and Bjelovar-Bilogora counties. The total value of the project was around 60 thousand Euros and started on December 2nd, 2021 and was concluded on June 2nd, 2023.

One of the project activities was the creation of a manual in which we mapped the needs and services for members of vulnerable social groups within the local community, in our case people with intellectual disabilities, but also those suffering from pulmonary hypertension. The manual contains research results, important definitions, and descriptions of needs and social services with all contacts of social service providers in the treated territory, to whom the target population can turn for help and receive self-help advice. The manual can be read at this link; [chrome-extension://oemmndcblldboiebnladdacbdm-dadm/https://www.plavakrila.hr/wp-content/uploads/2023/06/Osit-Prirucnik-Cinimo-vise-disimo-zajedno_compressed.pdf](https://oemmndcblldboiebnladdacbdm-dadm/https://www.plavakrila.hr/wp-content/uploads/2023/06/Osit-Prirucnik-Cinimo-vise-disimo-zajedno_compressed.pdf)

In addition to this activity, which was the last, we carried out various other ones, as well as 3 educational activities, through which we upgraded our knowledge and skills in the area of financial management of associations, in the area of collecting funds for the work of the association, and also among the last, we had a very interesting workshop about the use of virtual tools in the business.

Throughout this project, we met and got closer to people who have different difficulties than ourselves, and we consider this partnership very valuable as we became richer in great experiences.

We socialized through the activity Equality in our free time, where our partners, the sports association Argo from Bjelovar, allowed us to try rowing, which we had never had the opportunity to do before in our lives. We learned the importance of including people with disabilities in a society of equality.

We also conducted a useful rescue exercise in crisis situations with the HGSS Bjelovar branch because it is something that can happen to anyone and it is very useful to learn how to behave in such situations.



The project „Do more - breathe together” is the first project financed by ESF funds in which our association participated. We can say in the end that it was challenging and sometimes difficult. Administration required a lot of time and energy, and we encountered problems due to our inexperience. We would like to thank everyone who helped us overcome those problems step by step and successfully bring us to the end of this project. Special thanks go out to the National Foundation for the Development of Civil Society for being patient with all our questions and we hope that there will be opportunities for new projects and collaborations!



„FULL LUNGS FORWARD” PROJECT

In cooperation with professional rowers Tomislav Smrček and Nikica Ljubeka, and as part of the „Full Lungs Forward” project, a workshop was held in Bjelovar on Lake Narta with children from the 2nd Elementary School Bjelovar. It is an activity in which children aged 12 to 15 rowed with the help of professionals and held a kind of competition. At the end of the activities on the lake, a lecture was held on the importance of playing sports and adopting healthy lifestyle habits.

In addition, the children were introduced to rare diseases with an emphasis on pulmonary arterial hypertension (PAH), and T-shirts printed as part of the project were distributed to them. The children became breathless while rowing, so it was a link to how the patients get breathless. A short video clip lasting one minute was recorded at each location.

Video Đakovo: <https://vimeo.com/828280663/aa41d30415?share=copy>

Video Bjelovar: <https://vimeo.com/828280526/3d0c15281b?share=copy>

We held the same activity on May 5th in Đakovo on the lake. A workshop was held with children from Vladimir Nazor elementary school.

We are waiting for 4 more locations and socializing with children through sports and education, all for the purpose of promoting health and a healthy lifestyle, which is what this project strives for. We are coming to Karlovac, Vukovar, Sisak, and Obrovac very soon!



News links;

<https://hrvatskakucadisanja.hr/novosti/obiljezili-smo-medunarodni-dan-plucne-hipertenzije-utrkom-mz-cener/4164/>

<https://www.hzjz.hr/aktualnosti/svjetski-dan-hipertenzije-17-svibnja-2023/>

https://www.svijet.hr/hrvatski/novost_5/ostani-bez-daha-za-ph-utrka-maksimirom_229496/

<https://www.plivamed.net/vijesti/clanak/18672/Ostani-bez-daha-za-PH.html>

<https://www.jutarnji.hr/vijesti/hrvatska/utjecu-na-zakone-i-svakodneвно-pomazu-tisucama-hrvata-no-njihov-rad-i-dalje-prolazi-ispod-radara-15338371>

<https://portalzdravlje.hr/plucna-hipertenzija-bolest-koja-uzima-dah-nekad-i-godine-do-dijagnoze/>

CZECH REPUBLIC



On May 5th, we organized the event to support patients with pulmonary hypertension. The climb up the stairs to the memorial Vyšehrad was a powerful and symbolic way to raise awareness for this condition.

The illumination of buildings in Prague, Brno, and Olomouc in blue color is a meaningful gesture. The use of blue represents the characteristic blue color of the lips and skin observed in patients with pulmonary hypertension. By visually connecting these buildings with the condition, we created a striking display that helps draw attention to the challenges faced by patients.



Additionally, featuring a patient story in the media focusing on pregnancy with pulmonary hypertension is crucial for increasing understanding and empathy. Sharing personal experiences and narratives can provide valuable insights into the realities of living with the condition. It helps to educate the public and foster a greater sense of support and compassion for individuals affected by pulmonary hypertension.

Our initiative plays a significant role in raising awareness and promoting understanding of pulmonary hypertension. By bringing attention to the condition through events, symbolic gestures, and patient stories, you are contributing to a more informed and supportive society. This can ultimately lead to better care and support for patients with pulmonary hypertension.



HUNGARY



Luckily, we were able to hold our annual National Patient meeting again this year. We were warmly welcoming all interested persons, old acquaintances, and new joiners alike.

By listening to the lectures of our invited doctors, we acquired new knowledge and received tips on how to make our everyday life more beautiful, better, and easier. Empowered patient programs like this help us to understand each other better with our treating doctors and enables us to cooperate better and comply with medical protocols. We were delighted that we were able to translate the nutrition brochure of PHA Austria, and that we could hand it to our fellow patients.



Besides new knowledge, we were able to train our body with breathing exercises and our soul with the technique of our psychologist doctor.



The meeting gave us opportunity to chat and share our experiences. It is good and important to get to know each other, so that if we are in need of help, a few supporting words, or consolation, we do not have to hesitate to contact each other, and we can offer help and encouragement to our new patients.

The board of Tüdőér Egylet believes and knows that this program benefits us all and increases our endurance, because the strength of the community helps to overcome pain and difficulties.



Besides our sport ambassadors who are racing all year round to raise awareness for our disease and association, now a whole team volunteered to complete a remarkable challenge. They ran around the 'Hungarian sea', the lake Balaton. They completed 210,5 km in relay, running close to 22 hours night and day. The NN Ultrabalaton is the most popular public sport event in Hungary. The one round race circling the lake Balaton is also the longest race of Central Eastern Europe.

Breathlessness can be felt as a result of running close to 20 km sections, but for someone living with PH, sometimes it already happen after a few steps. To give the experience of circling the lake to those whose ability to perform is limited, our association has made a small Balaton, which could be ran around. We have distributed flyers and asked those who were interested to inflate a ballon and measured their saturation after. There were interesting and varying results. To some we even recommended to visit a cardiologist.



We were there when the team representing us made the start, in order to support them, and at the arrival next day, we joined the runners for the last meters. Our fellow patients arrived at the location from different parts of Hungary to cheer for those running for us. Our colourful T-shirts raised interest among the athletes and spectators, to whom we gave flyers and talked about PH. If there would have been a team beauty contest, we are sure that our awareness raising, lung decorated T-shirts would have won.



Our other sport ambassador, Antal, completed a Triatlon also taking place at lake Balaton, to raise awareness for this rare disease.

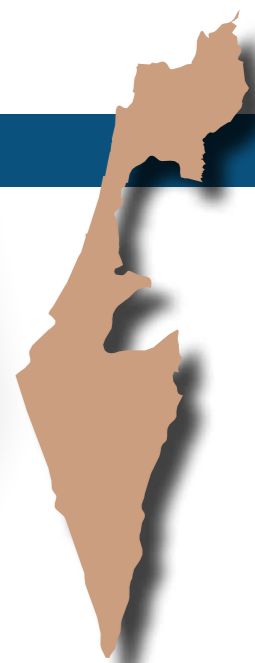
Eszter Csabuda -Tüdőér Egylet
www.tudoer.hu
<https://www.facebook.com/tudoer.egylet>

ISRAEL

This year, the Israeli Association for Pulmonary Hypertension celebrated World PH Day with an awareness campaign in a sports gym.

The Acai sport center in the city of Bnei Brak in central Tel Aviv hosts an average of 800 - 1000 visitors daily. The population in this area is generally a demographic, who is less exposed to social media, less engaged with online presence, and mostly does not watch television. One of our goals was to reach people who would likely never come across this type of campaign and who would not necessarily hear about PH if we did not draw their attention to it.

Our collaboration with this sports center allowed us to position signs strategically around the facility. Several large bright signs were placed around the facility, side by side with the exercise machines that members were using. The signs explain in clear, bold statements what patients of PH experience.





LATVIA



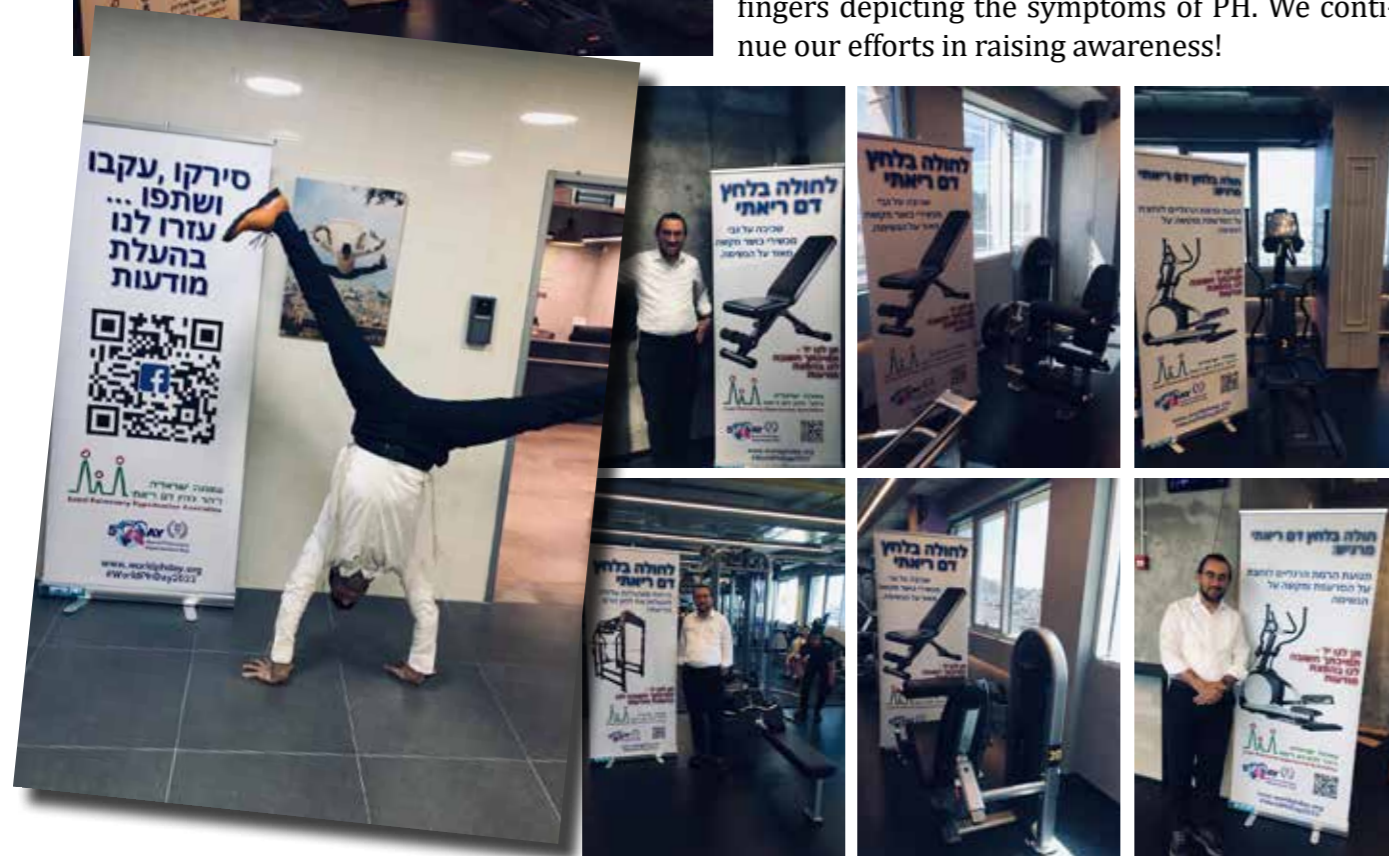
As a translated example, near the stepper machine, the sign exclaimed: For someone with PH, the action of raising one's legs creates a pressure which makes it difficult to breathe. Our second sign read: A patient with PH has to be tested every 3 months to evaluate if they are able to do a 6-minute walk – the equivalent of 400 meters. This was placed next to the treadmill. Another example featured the words: If you have PH, lying back on a weight bench significantly affects ones breathing. Furthermore, by the free weights our sign read that lifting weights would raise a person's PH symptoms.



Each of these signs feature a large QR code with bright red messaging "Show your support for PH" and "Help us raise awareness". Members of the gym were then asked to follow us on social media, where we hope to continue sharing information about the symptoms and PH in general.



The campaign is ongoing and people are engaging and asking questions about PH. We are confident that the vision of the signs and the conversation around the illness will create greater awareness. In addition to the above-mentioned awareness efforts, flyers were given to each person who came to the sports center over the span of a month- the flyers, as seen in the photos, feature a hand with 5 fingers depicting the symptoms of PH. We continue our efforts in raising awareness!



Spring 2023 comes with new plans and activities to highlight awareness for PAH in our society in Latvia. One of them was the **Media campaign "TalkPH"**, which started March 10th on all PHA Latvia social media accounts: we invited PH patients and their family members (carers) to share their stories through handwritten letters about what it's like to live with pulmonary hypertension. The letters were published on our social media accounts to share our experience with a broader society.

4TH BALTIC PULMONARY HYPERTENSION CONFERENCE

We are very proud that the 4th Baltic Pulmonary Hypertension Conference was held in Riga Stradiņš University, on the 21st of April. The conference was organised with the cooperation of all three Baltic states – Latvia, Lithuania, and Estonia – Assoc. Prof. Andris Skride, PhD Ainars Rudzitis, Prof. PhD, Aivars Lejnieks (Latvia), PhD, Lina Gumbiene, MD Egle Paleviciute, Prof. PhD Skaidrius Miliauskas, Prof. PhD Egle Ereminiene (Lithuania), Prof. PhD Alan Altraja, PhD Ly Anton (Estonia). The conference offered the opportunity to hear the latest in treatment of PAH and CTEPH from international experts Prof. Marcin Kurzyrna from Poland and leading experts from Baltic states. The programme included case reports, individual approaches to new therapeutic targets and better quality of life goals for patients living with PAH – those were the topics in 4th Baltic Pulmonary Hypertension Conference in Riga. The conference was attended by specialists, GP doctors, students, pharma companies, and the patient organizations of the Pulmonary Hypertension Association Latvia and PH Europe. Ieva Plume, President of PHA Latvia, gave a brief opening speech at the conference.



WPHD 2023

The most important day of the year for our PH society is World Pulmonary Hypertension Day on May 5th when we gathered for an "Adventure walk" with cardiologists, writers, psychologists, and physiotherapists. The walk near the Baltic Sea included some tasks to complete as well as sharing stories and experiences while, having great time reuniting and taking in deep breaths of fresh air in a pine tree forest.

Within all activities, we also created a social media fundraising initiative called **“We catch every breath”** to support patients with PAH living at home due to illness, so they can meet some acute needs in their life.

Together we are stronger – stronger to raise awareness in society and to reach the goals of a better life for each PAH patient in Latvia and world! By receiving caring comments, we see that we are heard and not alone.



Mana pieredze
 Viena pneimonija, otra, trakais brauciens pa slimnīcas koridoriem uz reanimāciju un sanitāres replika: “Viņa mirst!”. Tad sekoja vārds neaprstāms stāvoklis starp šo Sauli un Cītu pasauli, kurā es nepārtraukti melnā, melnā tumsā meklēju savu zaļo Audi. Un tikai tajās sekundēs, kad kaut kur tālumā atradu mašīnu, uz īsu mirkli atgriezios realitātē.
 Zinaida no Jēkabpils



Related links:

National TV1, Day news, 21.04.2023., 18.00
 Interview with Prof. Dr. Andris Skride, PHA Latvia President Ieva Plume, lung transplant patient Zane Lazdina.
<https://replay.lsm.lv/lv/ieraksts/ltv/291896/verte-jau-nakas-metodes-pulmonalas-hipertensijas-arstesana>

National online newspaper Neatkariga Rita Avize 09.05.2023. – Article from press realize.
https://neatkariga.nra.lv/veseliba/413514-pulmonalas-hipertensijas-pacientu-vestules-atklaj-cik-svarigi-slimibu-atklat-laikus?_gl=1*1hcagbz*_ga*MzQ4Mzk0ND-MxLjE2NDEyMTYxMzg.*_ga_LTMBW853YH*MTY4M-zYxNjY0OC4yMS4xLjE2ODM2MTY2NTQuMC4wLjA

National news portal LSM.lv – article about pulmonary hypertension 21.04.2023.
 Article due to 4th Baltic PH conference
<https://www.lsm.lv/raksts/dzive--stils/veseliba/21.04.2023-slimiba-kas-nosmace-konferen-ce-spiez-par-pulmonalas-hipertensijas-arstesanu.a505831/>

4th Baltic Pulmonary Hypertension Conference
<https://www.bphconference.com/>

THE NETHERLANDS



REPORT ‘VESTINGLOOP ’S-HERTOGENBOSCH’ MAY 14TH 2023

This event was held for the 17th time. Participants can choose between hiking (10 – 25 km), running (5-10 km), or a trailrun. For kids, a special kids run (1 km) was arranged.

This year, pulmonary hypertension was the charity of this event. We collaborated with the fundraiser ‘Heb hart voor longen’, who have the right contacts in this area.

The main goal was to raise awareness for pulmonary hypertension amongst the general public. This event is very appropriate for this goal: 9000 participants and loads of people lined the streets to cheer them on. The subgoal was raising funds for research.



On the website of ‘Vestingloop ’s-Hertogenbosch’, information about PH could be found. They shared a lot of content on social media about PH and living with this disease. They also shared a lot of our social media posts. Furthermore, a lot of attention was put on this event and PH through the local newspapers and social media accounts of local media companies. During the registration on the website, participants could choose to pay extra money to donate to pulmonary hypertension.



The 14th of May started with a big present: sunshine and no clouds! A beautiful day for hiking, running, and cheering. The starts took place in a nice, big park, where people could pick up their start numbers and T-shirts. PHA the Netherlands and Heb hart voor longen have arranged a group of participants that hiked (including some runners too) with bright yellow T-shirts, with special attention for PH. The trail run started around 9 o’clock, and the hikers started at 10.30 o’clock. The kids run started at 12 o’clock and the 5 and 10 km running event started in the afternoon.



The finish line was at the center of the city on a very big and famous square. A huge crowd was cheering! On the square was a large screen, where sponsors were mentioned, and a short movie about PH was played. The atmosphere was fantastic and many people gathered in the square and stayed until the evening.

The goal with this event was achieved, as the PH awareness message reached many people and funds were raised: more than 10,000 Euros.



NORTH MACEDONIA



Association for pulmonary hypertension
Moment plus

Every year, we do our best to spread PH awareness and fight for a cure for patients. While we create awareness every day, every week, and every month of the year, we specifically dedicate a lot of our efforts to the World PH Day.

CONCERT

We organized a concert in which many local bands and singers from the vicinity of Gevgelija participated. We had fun playing and singing together with the audience that gathered with us that day to support the patients who are fighting this serious disease every day. Furthermore, our folklore ensemble performed with a few dances featuring our traditional music—this was exciting for the crowd and put everyone in a good mood. In addition, we also had several performances by young female dancers from our local hip hop group, who entertained the audience with a more modern dance style. People were taking pictures, filming, and they started asking why all this was happening. Some attendees already knew about the cause, however, as they came again to support our goal to create awareness. It was a wonderful day filled with lots of activities and fun, and it was shared by several newspapers, as well as broadcasted on Gevgelija's local radio station.



RACE

In addition to the concert, a 5 km race was organized in the name of Gjurgica and all patients, who lost the battle with PH. Runners from all over Macedonia, including top marathon runners, ran for a good cause. They raced and ran out of breath in order to give their maximum support for PH awareness.

OTHER ACTIVITIES

We also had runners all over the world running under the motto „Get Breathless for PH”, waving flags everywhere and wearing support shirts and jerseys.

Ratko Kjaev
Reporter



NORWAY



The World PH Day was marked in Norway over the span of two days with a round table conference on the 4th of May, and a stand at the Lovisenberg heart and Lung hospital on the 5th of May.

Additionally, Sølvi Molnes, our leader, was interviewed by one of our large newspapers, and her story was posted by several newspapers and large Norwegian magazines, as well as published online.

LHL, our heart and lung organisation, had a podcast with our board member Ina Lill Øvre Torp, and our consultant at the heart and lung hospital Dr Med Jostein Grimsmo. The link to the podcast is: www.lhl/pah.no



The Round table Conference was organized by Janssen PH Nordics at their venue at Lysaker in Oslo. It was the 4th annual round table conference held by Janssen.

The theme and goal setting for the meeting was to raise awareness for PH, particularly for PAH, Pulmonary Arterial Hypertention.

Our goal was also to discuss how, together, we can contribute to an increase in Quality of Life and help people who already have gotten the diagnosis to be able to live a good life with PH/PAH in Norway.

Charlotte Myrdal Østby, PAH nurse and contact hospital nurse from Rikshospitalet in Oslo cardiological department, informed us about the new PAH register in Norway. She is the coordinator for mentioned register for all of Norway.

The goal is that all PAH patients in Norway are included in this register by May 2024.

Charlotte told us that the majority of PAH patients are women.

We also discussed the importance of getting PAH into the Rare Disease Registry in Norway.

It is still hard to find and diagnose patients early, as patients still are in the functional class III or IV by the time of diagnosis. That results in late diagnosis and more severe cases. Hopefully, the new register can help with that.

Furthermore, the new international Guidelines on PAH will be followed by all centres in Norway. A follow-up consultation approximately 3 or 6 months after diagnosis is important, so that we can find the best medication and combination of treatments for each individual patient as early as possible.

We have one central rehabilitation centre for PAH at Lovisenberg Rehabilitation in Garderen in Oslo for the entire country. They are very experienced with training and rehabilitating patients and takes place for 4 weeks once a year, for each patient.

The importance to get a PAH contact nurse at each regional centre, in addition to the centre in Oslo, was also discussed.

Our stand at Lovisenberg Rehabilitation Centre was in the reception area of the hospital on the 5th of May.

We had a roll up, leaflets, coffee, and chocolates to attract people.

We talked to both patients and staff and informed about PAH, and the World PH Day.



GLAD FOR Å LEVE: Sykdommen hennes var tidligere som en dødsdom å regne, men forskning og nye medisiner har reddet livet til Sølvi. Foto: Gry Traaen



PORTUGAL



To celebrate World Pulmonary Hypertension this year, APHP - the Portuguese Association, held a weekend retreat on the 6th and 7th of May, in the pretty Spa town of LUSO. It was a weekend filled with many and diverse activities for patients, families, caregivers, friends, health professionals, and many athletes.

Patients and their families and friends from various parts of the country united and were accommodated at the Luso hotel, where a meet and greet took place, followed by fun, creative, and educational games. Patients got to know each other on a more personal level, learned more about their disease, and had the opportunity to share their PH journey.

We completed the first day with a walk downhill to visit the local Luso Museum, a space that features several exhibitions relating to the famous natural mineral water, with its spring coming from the mountain, and finally a group dinner, enjoyed by all.

A sunny Sunday brought more than 500 participants to take part in the organized trail/walk by “Trilhos do Luso”, who were wearing our “GET BREATHLESS FOR PULMONARY HYPERTENSION” T-shirts, and walked the 10km trail, in the beautiful, luxurious mountain forest of the Luso-Bussaco, with its uphill entwining pathways. The Portuguese Pulmonary Hypertension Association was awarded 1st place for having the largest number of participants in this event.

The Luso Stadium was the stage for all activities, as this was the starting and finishing point for all participants taking part in the walk. Simultaneously to the trail, a yoga class was conducted by Dr. Graça Castro – a cardiologist and Pulmonary Hypertension specialist at the CHUC- Centro Hospitalar e Universitário de Coimbra (one of the largest PH reference centres in Portugal), and was attended by more than 30 people.



We were pleased to hand out our new patient kit to members and brochures to the general public, raising awareness for Pulmonary Hypertension. Our wheel of fortune was a success amongst young and old participants, as they all took their turn in spinning the wheel, which turned out to be a fun way to raise funds. More funds were raised with the selling of personalized merchandise, such as pens, notebooks, anti stress hearts, and 3 paintings, which had been donated to the Association. For the little ones, face painting was available, and our mischievous Zebra Mascote - HOPEY, who was very active, delighted everyone present at the event.

A very special moment was held to pay tribute to Maria João Saraiva – founder of the patient association almost 20 years ago, who sadly passed away last September. A touching speech was given by Teresa Carvalho, and 50 balloons were launched into the sky, in remembrance of someone so special to all, and who lived faithfully and true to her motto - CARPE DIEM” – Seize the day! On a more intimate note, for those who walked along her side and shared her PH journey, a lunch was held, followed by the screening of a beautiful autobiography video, and the testimonials of family and friends. Our WPHD ended with a very special talk by Dra. Graça Castro, who pointed out the importance of Pulmonary Hypertension support groups, which are an excellent resource for help and encouragement, and the signing of our LUNG canvas with our messages of HOPE!

Our main aim was for all participants to have fun, enjoy the day, and leave inspired by what they had seen or learned.



Our social media campaign started on the 21st of April, and ran throughout the month of May. Four PH patients were on national tv programmes, to talk about their personal experiences with PH. More than 30 articles were written and disclosed in various means of communication – newspapers, magazines, and internet. A PH member was invited to take part in a podcast, produced by the National association of Portuguese pharmacies. Our first webinar was held on the 31st of May (we have 4 planned), in which our panelist, Dr. Antonio Marinho, pediatric cardiologist, spoke about Pulmonary Hypertension in infants and adolescents.

On the 21st of May, the Portuguese Pulmonary Hypertension association was invited to participate in the event entitled “Navigating with your Heart”, which took place in Lisbon. The main objective, besides interacting and sharing enjoyable moments, - “is to build bridges between patient associations”. Members from another 3 different patient associations – ATPP (lung transplant association), AADIC (cardiac insufficiency association), Coração Feliz (children and adults with congenital heart disease), enjoyed a boat trip along the main river in Portugal, which included snacks and a very relaxing and zen moment with breathing and stretching exercises conducted by Ana Monteiro. Aboard the sailboat, we were honoured with the presence of two health professionals, Dra. Filipa Ferreira, cardiologist and Pulmonary Hypertension specialist, and renowned portuguese heart and lung transplant doctor, Prof. Fragata, who presented us with a very informal, pleasant speech, congratulating the various groups for the initiative, and highlighting the importance of patient support groups for all those living with an illness.



We thank all our sponsors, who supported our events, and all our members who contributed to raising awareness, and acknowledging that standing together makes us STRONGER, and our voices are LOUDER. Our HOPE is that Pulmonary Hypertension soon becomes Past History !





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Pulmonary Hypertension Serbia (PH Serbia) has prepared a slightly different way of marking World Pulmonary Hypertension Day 2023 this year. With the enormous support of our honorary ambassador and famous European actor Goran Bogdan, we have implemented a video project titled „Talking about PH,” which was broadcasted in the form of a news/information program on four national television channels. Goran Bogdan and the president of the PH Serbia Association, Danijela Pešić, presented facts about PH in the form of an informative television program (news), and then showed that reality is much more complex than the information viewers had the opportunity to hear while watching the news during prime time on the four most-watched television channels in Serbia. An appeal was made to decision-makers for broader and adequate support of patients suffering from PH, and awareness of this disease among the wider population was raised in an effective and impactful way. This approach to raising awareness is something that PH Serbia has not done before, and our goal was to reach as many people as possible in a viral manner.



As part of the World Pulmonary Hypertension Day 2023 commemoration, and with the support of our Inspired by HOPE team runners, for whom we prepared specially designed shirts featuring all our logos and marks, we wanted to make history again and further commemorate May 5th in the best possible way at this year's Belgrade Marathon, which coincides with WPHD. Our runners, led by Slaviša Vesić, completed the entire marathon while pushing a wheelchair-bound girl who, due to her illness, Friedrich's ataxia, could not do it herself. This achievement was just a dream for her. PH Serbia, our runners, and Ana have made history at the Belgrade Marathon with this incredibly humane act and action we named „On May the 5th - Dreams Become Reality.”

While our Inspired by HOPE team runners write history at marathons and conquer peaks throughout Europe, dedicating their achievements to us, PH patients and association representatives have given their maximum efforts to highlight the progress made and emphasized the numerous unresolved problems that we need to solve together at various conferences organized in honor of World Pulmonary Hypertension Day 2023. We would like to highlight the conference organized by the pharmaceutical company MSD as an important events for us, as pharmacists and company representatives from the region had the opportunity to hear from PH patient Danijela Pešić directly, what life was like without therapy in the past and how life with therapies today is closer to the dream that many still have.

With the support of PH Europe, by sending a cover letter to relevant decision-makers and government bodies, as well as by providing translations of the „Call to Action” document on the status and needs of PH patients, we have succeeded in organizing several meetings that will be decisive for improving the position of our patients. We had the opportunity to print this important document in larger numbers and deliver it to everyone who can help. All of this served as a kind of preparation for the major PH conference that PH Serbia will hold in October 2023, where we will attempt to push all boundaries when it comes to raising awareness, improving the quality of life, and overall position of our patients. Many international invitees have already confirmed their participation.



One regular segment that we will strive to include in our association's work is the organization of workshops for psychological support for our patients, where we interactively discuss open questions important for every PH patient, from daily life, activities, topics related to nutrition, and the impact of the disease on psychological status, to societal attitudes and the position of PH patients in the workplace, self-treatment, and more. These workshops are conducted in collaboration with our prominent psychologist, Aleksandar Šibul, and other expert collaborators of the association.

This year's World Pulmonary Hypertension Day has been recorded on all our social media platforms. On our Facebook page alone, the video featuring Goran Bogdan, which we translated into five different languages, was viewed by over 50,000 people, while on other platforms, our message reached over 10,000 people who had the opportunity to learn about all aspects of PH through informative and engaging content from PH Europe, which we translated into our language. We express our gratitude to the Spanish association and Turkish PH association.

We are looking forward to this year's success with hope that the highlight will be our major international PH conference in October, which will not only restore hope for patients that PH will become a thing of the past, but also bring us closer to that moment. We would like to express our gratitude to all our partners, PHA Europe, our friends, and sponsors for their selfless support.

VIDEO LINK: <https://www.youtube.com/watch?v=e6yPevh4Ew0&t=10s>

Danijela Pešić and Uroš Antonijević
 PH Serbia Team

SLOVAKIA

In Slovakia, we started the campaign for World PH Day at the end of March with invitations on our social networks to our upcoming activities. At the end of March, runners participated in three running competitions - Šamorín running league, ČSOB marathon, and the Jabulani challenge (Australia). Due to the initiative of the runners, three patients from our association joined the Wings for Live World run on May 7th to support research in the treatment of spinal injuries. On May 13th and 14th, our team of PH patients took part in the challenging Vltava Run relay race in the Czech Republic. Their activities will continue throughout the year. A great success is that our team has grown to include new runners from the younger generation as well.

On April 29th, we cheered on the volleyball players, who gave us their breath throughout a ten-hour volleyball tournament. It was organized for us again after 10 years by the Polar volleyball club in the sports hall in Veľký Krtíš. Eight mixed teams competed for the title like lions, and we gave out a special cake with the WPHD logo to the winner. The event was covered by the mayor of Veľký Krtíš and was promoted in the Rádiožurnál program of Slovak Radio and in the regional newspaper.

<https://www.youtube.com/watch?v=v6burqXsgY4>



A member of our association Zuzka Čižmanská, collected proceeds from an entire week's sale of mini Pavlova cakes in her pastry shop. She contributed to the campaign not only by distributing information about PH, but also with a donation of €120 for the association.

Our campaign on social networks also reached out to the civic association „Rare Diseases“, which contributed to the campaign by creating a video about the symptoms of PH, as well as an interview with Slovak PHA president Iveta Makovníková. She contacted the commercial TV Markiza, which led to broadcasting the interview in two editions of the main news on May 5th.

This year, we again prepared the traditional, already 7th year of hiking event for patients with PH. This time, we chose the Orava region. Patients, doctors, health professionals, family members, and hiking enthusiasts all gathered in the beautiful surroundings of the hotel resort Oravský haj. On the eve of the climb, an information seminar was held with expert doctors from the Center for PH in Bratislava. T. Valovičová and M. Luknár focused on different types of PH, their diagnosis and treatment. We specifically dedicated it to type of PH caused by congenital heart defects. Patients also participated in the seminar with their stories.



On May 27th, a total of 120 hikers climbed to the top of Skorušina mountain (altitude 1314 a.s.l.) with photos of patients on their back. We were joined by local residents, who also prepared a few surprises for us. For the first time, patients were taken out by firemen in cars and reached the top of the mountain. Everyone appreciated the beautiful view from the observation tower, but also the excellent hunting stew, which was cooked by local residents since the early morning hours. We took a photo together, handed out badges and medals to the participants, and returned to the valley. In the evening we met in the conference room for the raffle. A number of gifts were distributed. The Folklore ensemble from Brezovica enriched the evening with their performance. The hospitality, willingness, and respect of this region, as well as the beauty of nature and pleasant peace, brought out all the positive energy within every participant. The mayor of Brezovica also supported the event.



SLOVENIA

ONLY WHEN YOU CAN NO LONGER BREATHE WITH FULL LUNGS, YOU REALIZE THAT EVERY BREATH REALLY COUNTS

On May 24th, 2023, the Association for Pulmonary Hypertension of Slovenia organized the event „Every Breath Counts” on Prešeren Square in Ljubljana, where passers-by were made aware of the disease pulmonary hypertension and its symptoms. „With the event and stand in the middle of Ljubljana, we wanted to attract as many people as possible to try the adapted six-minute test of walking with straws and thus see what it’s like to breathe with the lungs of a patient with pulmonary hypertension,” emphasized the president of the association Tadeja Ravnik.

The breathing of the patient is similar to the breathing of a healthy person with a nose clip and two straws in the mouth. This makes it difficult for oxygen to enter the lungs, so the individual breathes faster and is less able to exert physical effort.

About a hundred people took part in the adapted walking test. But the feelings and experiences were very similar for everyone - a feeling of surprise at how hard it is to breathe, and how anxious you feel when you just can’t inhale with full lung capacity.



Statements from passers-by who have tried the adapted six-minute walk test include:

„I thought it would be easier, but it wasn’t. What oppresses you is not pleasant if you cannot breathe. I have never experienced such a feeling of not being able to breathe in my life. I can’t imagine having to live like this.”

„The six-minute walk test is quite demanding. Personally, it was already a challenge to hold straws in my mouth and really only breathe through them. I also tried walking up stairs with straws and a nose clip, it’s a bit harder than walking up a flat one. If I had to walk up the stairs for longer, I would definitely need a break. I believe that for someone who has to breathe in this way all their life, it is very challenging to live with it.”

Cene Prevc, former ski jumper

„This is an interesting test. Especially this feeling of strain on the lungs, because they are not getting enough oxygen and then somehow you constantly feel a lack of oxygen or the amount of air in the lungs. I also felt pressure in my chest and lungs. It’s hard, really hard.”

„Since walking with straws and a nose clip didn’t seem so difficult to me, I was interested in how it is if you have to watch a child next to you, show him something, for example, how to jump from one small step. Well, that turned out to be very difficult. It starts to feel tight in your chest and you immediately feel tired. It’s not easy.”

We are glad that many individuals who wanted concrete information about the disease and its symptoms came to our stand. Of course, we don’t want the number of people suffering from pulmonary hypertension to increase, but we are happy that our long-term efforts have borne fruit and people with symptoms similar to those of pulmonary hypertension - i.e. shortness of breath, excessive fatigue, blue lips, swelling of the legs and dizziness, now actually think about this disease.



SPAIN ANHP

ACTIVITIES WE HAVE ORGANIZED FOR WORLD PULMONARY HYPERTENSION DAY

The activities that the National Association of Pulmonary Hypertension has organized within the Campaign for World Pulmonary Hypertension Day under the slogan "Hypersensitize yourself, we are Pulmonary Hypertension", have had the objective of raising awareness about pulmonary hypertension, not only among people who suffer from it or their families, but also in society in general.

The campaign, during which updated information on pulmonary hypertension has been provided thanks to the collaboration of several socio-sanitary specialists, who have participated in the workshops and Webinars organized by the association, has had a great impact on social networks. This has allowed us to reach all corners of the world, transferring the reality with which people with pulmonary hypertension, their families, caregivers, and professionals live. We have collaborated with entities from around the world of pulmonary hypertension with informational materials and the following hashtags:

#SeguimosLuchando#InhalaEsperanza#InhalaValentía #VenzamosHP#Ponletumejorsonrisa
 #FilosofíadePHantasticals#PuraEsperanza#LaPacienciaCura #WorldPHDay2023
 #DíaMundialHP2023#HablemosHP #UnAlientoPorHP#hipertensiónpulmonar#LuzAzul
 #enfermedadrara #Concienciación#WPHD #IniciativaGlobalHipertensiónPulmonar#PHAEurope



We leave you more information about the activities carried out during this intense but productive month:

On May 2, CUPON DE LA ONCE commemorating World Pulmonary Hypertension Day. Five million ONCE coupons helped us raise awareness about pulmonary hypertension. <https://www.once.es/noticias/el-dia-mundial-de-la-hipertension-pulmonar-en-cinco-millones-de-cupones-de-la-once>

On May 5th we collaborated in the I Conference on Pulmonary Hypertension at the Miguel Servet Hospital in Zaragoza, coinciding with World Disease Day. We had the hospital manager, stress the importance of the Hospital's pulmonary hypertension unit, coordinated by Dr. Juan Antonio Domingo, which has recently been accredited as an intermediate pulmonary hypertension unit by the Spanish Society of Thoracic Surgery and Pneumology (SEPAR).

On May 4th, 18th and June 1st, we have carried out the respiratory exercise workshop in a virtual format given by D. Juan Izquierdo, physiotherapist of the Cardiac Rehabilitation and Pulmonary Hypertension Unit of the University Hospital October 12. During these sessions we have learned to perform certain breathing and strength exercises for people with pulmonary hypertension.

On May 11th, we organized a psychoeducational workshop for patients with pulmonary hypertension and their families under the title „What is not visualized: emotional exhaustion in pulmonary hypertension” taught by Jennifer Moreno, a psychologist who collaborates with the entity.

On May 24th, we held the ANHP breakfast “Encounters that Hyperconnect” in a virtual format, where we offered a space for exchange between patients and welcomed people, who have joined the entity in the last six months.

On May 5th, different emblematic monuments of some towns and cities in Spain were illuminated in blue in support of World Pulmonary Hypertension Day.

- o *La fuente de Neptuno en Madrid*
- o *Estadio San Mamés del Athletic Club de Bilbao (Bilbao)*
- o *Los 4 postes de Ávila*
- o *La Casa de la Cultura de Gandía (Valencia), iluminación y pancarta de la campaña en la fachada.*
- o *El Ayuntamiento de Lorqui (Murcia)*
- o *La fuente de la Plaza de España y de la plaza de D. Juan de Austria de Sevilla*
- o *Palacio de Aljafería de Zaragoza*
- o *Ayuntamiento de la ciudad de Santander*
- o *Ayuntamiento de El Espinal (Navarra)*
- o *Ayuntamientos de Otañes y Castro Urdiales (Cantabria)*

In addition, throughout the month, we publish on our social networks about the disease and what it means to live with it.





1. The Foundation against Pulmonary Hypertension illuminates the most representative buildings of the most important cities in Spain

On World Pulmonary Hypertension Day, many Spanish cities have lit up their most characteristic buildings in blue to raise awareness for this disease. We would like to thank all the city councils that have collaborated in this gesture of solidarity.



2. Inauguration of the reform of the reception flat for patients with Pulmonary Hypertension, who are going to undergo a transplant

Inauguration of the refurbishment of the reception flat for people affected by Pulmonary Hypertension, who come from other Autonomous Communities to undergo a transplant or long-term treatment. In the photo we see Ramón Jurado, Mayor of Parla, María Curiel, councilor for Health, Enrique Carazo, and Laura Ranz of the FCHP.



3. Inauguration and financing of a cycle ergometer in the hemodynamics room of the Ramón y Cajal University Hospital (Madrid)

On World Pulmonary Hypertension Day, we inaugurated and financed a cycloergometer in the cardiology haemodynamics room of the Ramón y Cajal University Hospital. The cycloergometer is used to perform catheterisations on the fly and to be more precise in the diagnosis. In the photo we are joined by Dr. del Cerro, Dr. Jesús Álvarez, Dr. Ignacio Hernández, Dr. Elvira Garrido, Dr. Andrés Tenes, Dolores Rivas, Ismael Cerro, Enrique Carazo, and Laura Ranz. We are very proud that patients with Pulmonary Hypertension and congenital heart disease can benefit from it. Special thanks go out to the Enrique Flores Foundation for trusting us.



4. Pulmonary hypertension goes to school

It is important to know about Pulmonary Hypertension from a very early age. Not everyone has the same conditions and, therefore, we should all be aware of the problems that our classmates may have. That is why we bring Pulmonary Hypertension to schools. Here are some images of a class with one of our girls with Pulmonary Hypertension, teaching her classmates and teachers about her illness. Laia is a champion! Thanks go out to CEIP Rafael Altamira in Alicante for these inclusive activities.



5. Signing of the agreement with Madrid City Council

An exciting agreement with the Madrid City Council was signed at the Palacio de Cibeles by Borja Carabante, Delegate for the Environment and Mobility, and Antonio Prieto, Manager of Madrid Salud. On behalf of the Fundación Contra la Hipertensión Pulmonar, we were joined by President Enrique Carazo, Carlos Garcia-Hirschfeld, and Laura Ranz. This agreement will serve for the development of actions in the field of health and environmental education for patients with Pulmonary Hypertension. Thank you for all the work that has seen the light of day.



6. Meeting with Cristóbal Belda, director of the Instituto de Salud Carlos III.

We continue working to promote research in Pulmonary Hypertension with **Cristóbal Belda**, director of the Instituto de Salud e Investigación Carlos III, and our president **Enrique Carazo Mínguez**. We have held very fruitful meetings that make a difference.



SPAIN HPE

Hipertensión Pulmonar España ORG pacientes



7. Solidarity Flashmob for research into Pulmonary Hypertension

A solidarity Flashmob was held at the Ajuntament de Santa Margarida i Els Monjost (Barcelona). This was a very special day of dances and smiles that the Associació Alma Calí organised with a lot of love. We would also like to thank our friends from the Sagas LegiónST 501, Spanish Garrison 50th Legion, and the Spanish Base of the Rebel Legion for being so generous. All proceeds will go towards Pulmonary Hypertension research.



8. Conference for patients with Pulmonary Hypertension

A conference for patients with Pulmonary Hypertension was held at the Hospital Universitario Costa del Sol in Marbella. This was an incredible conference, in which the information was transmitted in a pleasant way, being understandable and useful for everyone. A great team of professionals works in the multidisciplinary unit, and special recognition goes out to Dr. Bravo for taking care of his patients in every way. Thank you for counting on our foundation and making known our resources for patients, families, and transplant recipients with PAH.



9. Meeting at the Virgen de la Macarena University Hospital (Seville)

Another meeting was held at the Virgen de la Macarena University Hospital (Seville) with Dr. Alejandro Recio, head of the hospital's Pulmonary Hypertension Unit and head of nursing. We were able to meet all the professionals working on the disease, and all the areas (medical, surgical, diagnosis, clinical support, nursing...). It was a very interesting meeting, in which collaboration ties were formalised.



10. 1st Conference at the Tajo University Hospital (Aranjuez).

The 1st National Organ and Tissue Transplant Day Conference was held at the Hospital Universitario del Tajo (Aranjuez). On such an important day, a patient with Pulmonary Hypertension on the waiting list for a transplant, who is living in the reception flat of the Foundation against Pulmonary Hypertension, wanted to participate. We would like to thank the medical management, and all the professionals for organising this event.



MAY 5TH WORLD PULMONARY HYPERTENSION DAY 2023

As every year in May, we launched a campaign to raise awareness for Pulmonary Hypertension to mark the World Pulmonary Hypertension Day on May 5th.

HPE-ORG also joined the campaign that has been carried out worldwide through social networks along with the entire community of Pulmonary Hypertension, sharing visuals about the reality of pulmonary hypertension with the hashtags [#StillPHighting](#) [#InhaleHope](#) [#InhaleCourage](#) [#BeatPH](#) [#PutAHappyFace](#) [#PhilosophyofPHantasticals](#) [#PureHope](#) [#PatienceHeals](#) [#WorldPHDay2023](#) [#TalkPH](#) [#OneBreathForPH](#) [#pulmonaryhypertension](#) [#BlueLight](#) [#rareisease](#) etc. [#RaiseAwareness](#) [#WPHD](#) [#GlobalPulmonaryHypertensionInitiative](#) [#PHAEurope](#).

In addition to the social media campaign, we have carried out our own campaign and activities. As in previous years, we involved HPE-ORG members in working committees, so that with the help of their immediate environment they could organize different activities linked to sports under the slogan „Be Breathless for Pulmonary Hypertension”, always with the support and supervision of HPE-ORG.

Thanks to this initiative, we have involved different city councils to illuminate buildings in blue in several cities in Spain, including the Central Market in Alicante, the Miner's Fountain in Guardo, the façade of the Municipal Palace in Tarragona, Torre dels vents and the Kesse Youth building, the Cathedral of Sant Feliu de Llobregat City Hall, and the house of culture in Churriana de la Vega and Hospital Universitario Virgen de las Nieves de Granada. In all these cities, posters have been put up around the buildings lit up in blue indicating the reason for the illumination to raise awareness of Pulmonary Hypertension. At the same time, we have organized Pilates classes in the Victory center in Guardo, and in Salamanca together with the AVIVA Foundation. At the Guardo Language School, our member Carmen Buján gave a presentation in English about Pulmonary Hypertension, what it means to live with this disease, and the work we do in our association.

This year, we also organized our General Assembly of members as part of the celebration of World Pulmonary Hypertension Day. In this Assembly, besides sharing moments with the members of the entity, we had the opportunity to receive a first-hand talk of the physiotherapist in charge of giving our Postural Training workshops, Nuria Codina, from Corporación Fisiogestión, who informed us about the benefits of moderate and controlled exercise for patients with pulmonary hypertension.

To Donate Is to Love

For those who were unable to attend in person, we held an online nutrition workshop with Alimenta, in which we learned how to introduce sweets into our diet while at the same time taking care of our diet.

In the city of Sant Feliu de Llobregat (Barcelona), where our headquarters is registered, as part of the activities of the 65th National Exhibition of Roses held from May 12th to May 14th, we were present at the stand of Minority Diseases where we were visited by Pere Aragonès, President of the Generalitat de Catalunya; Oriol Bossa i Pradas Mayor of Sant Feliu; Loren Rider, councilor of health; Aitor Rivera, councilor of Commerce, Lourdes Borrell current mayoress, Nil Moliner musician, composer and Spanish singer-songwriter and many more who were involved in raising awareness, as well as being photographed with the WPHDay T-shirt.



As a novelty this year, we got in touch with the graffiti association Kaligrafics from Sant Feliu de Llobregat who made a graffiti from one of the visuals shared by PHA Europe to make the people of Sant Feliu aware of the reality that people affected by pulmonary hypertension live. We encourage people to get involved in the campaign by uploading their photo to their RRSS with the hashtag: #WorldPHDay2023.



Additionally to the activities carried out in person and online, our president María Rodríguez was interviewed on two occasions, once for the Plataforma de Malalties Minoritàries, in which she shared a video with Dr. López Meseguer, head of the Pulmonary Hypertension unit of the hospital La Vall d'Hebrón in Barcelona, and also for the digital magazine ConSalud.es, an interview in which María Rodríguez spoke about her experience with pulmonary hypertension throughout her life.



Thanks to the dissemination work carried out in the municipality of Guardo, we have received the recognition of the Social Entities of Alto Carrión in the Gala „Construyendo Comunidad” organised by Radio Guardo AMGU, which was collected by our member Carmen Buján.

Together with the support of the association organizing the activities, the result has been a success, both in the organization and participation of the activities, and in the dissemination of these activities.

As the last activity carried out in the framework of World Pulmonary Hypertension Day, on June 15th we organized the 2nd PAH Needs Conference in the Autonomous Community of Castilla y León with the aim of continuing to detect areas of improvement in care for patients with Pulmonary Hypertension.



UKRAINE PHA



We have also joined Ferrer Spain with the PHantasticals awareness campaign, an initiative that seeks to raise public awareness of rare and chronic diseases.

With this World Pulmonary Hypertension Day campaign, we have achieved great growth in all our social networks, especially in terms of interactions with our publications, which means that we have been able to reach many people who have learned first-hand what it means to live with Pulmonary Hypertension.

In addition, other entities have echoed our publications and have supported us on their social networks by sharing our content to give more visibility to this disease.

Finally, we are very satisfied with the results obtained, and with the involvement of the people who have participated in different cities. With yet another year we have managed, by the end of May, to make more people aware of Pulmonary Hypertension, raising awareness of the importance and seriousness of this pathology, as well as making our organization and the services we offer more visible.



This year's World PH Day was held in Ukraine despite the current war activities in the country. Many patients had to leave their houses, some of them moved to more safe places, 20% of patients moved abroad. However, our community remains strong! Regardless of our location, we feel the support of one another!

The main event for Ukrainian patients was the online conference with doctors from the PH Centers, Lung Transplant Centers, and representatives of organizations involved in supporting programs for Ukrainian patients. The interactive meeting with patients who are currently in different countries was especially interesting. Furthermore, we have discussed important questions related to social and psychological stability during the war times—these meetings were intense, yet also very interesting. We also had an opportunity to do some breathing exercises that help with managing anxiety together with our yoga teacher, who is also a PH patient.



In Kyiv, we had the chance to have an offline meeting with PH patients, where we greeted each other and discussed topics and questions that bothered our members.



During these difficult days, we received much support from so many people in various ways. For example, the "Meridian" dance studio prepared a special dance called "The light through the darkness", dedicated to PH patients.



During the entire month, our volunteers and patients have been taking part in different sports events in order to raise awareness regarding the disease.

Once again, we have felt the support from one another and our close ones.

Together we are stronger!

UKRAINE PHURDA



This year marks the fourth year in a row during which we celebrated WPHD online. For this year, we organized a variety of activities to mark WPHD. A few weeks before the main event, we gathered with patients and held a photoshoot. We had fun and enjoyed the special moments for the first time in-person after a long break. The pictures from the photoshoot were used in our awareness campaign, during which we produced billboards and city lights to place around the city of Lviv. The billboards feature a hotline number and a call to action – “*Spread awareness about PH*”. During June, these billboards and city lights were placed on the streets.

On May 5, PHURDA and CF „Sister Dalila” held an online patient meeting on Zoom under the topic: „World PH Day 2023”. We spoke about new opportunities for PH patients in Ukraine. PH specialist from the PH center in Kyiv, Olena Torbas, shared the specifics of work during war, the situation with medicine, diagnosis, treatment, and plans for the future. Furthermore, Oksana Kulish Skaara presented information about the cooperation between PHURDA and other European organizations, which is particularly important during a time of war. We also remembered the history of WPHD, especially our previous amazing activities, when we celebrated together at beautiful and relaxing places.



To develop another part of our awareness campaign, we invited educational institutions to join us on WPHD and spread information about pulmonary hypertension using #blue_butterfly. Approximately 100 schools and kindergardens joined the initiative and hand-crafted blue butterflies, took pictures and posted them on Facebook, making a cool #blue_butterfly online flashmob. Such support is very precious for us!



To continue the awareness campaign to celebrate WPHD, we created an animated cartoon about PH called „Not the best friend”. On May 5, the cartoon was broadcasted on a TV channel during the evening news program. We also added English subtitles to the cartoon. We thank everyone who joined us in the creation of this cartoon: illustrator - Myhailyna Vaksman, voice artist – Maya Boichenko (Art school NKIDS), technical support - TRC “Pershyi Zakhidnyi” with the support of Natalia Kutsyniak, and Olha Tsap.

Our PH community thanks the European Lung Foundation, CF „Patients of Ukraine” and TRC „Pershyi Zakhidnyi” for media support of our activities.

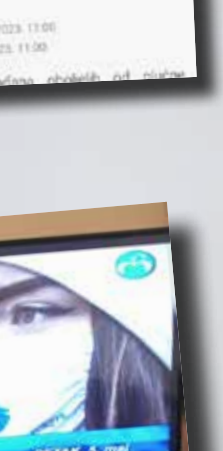
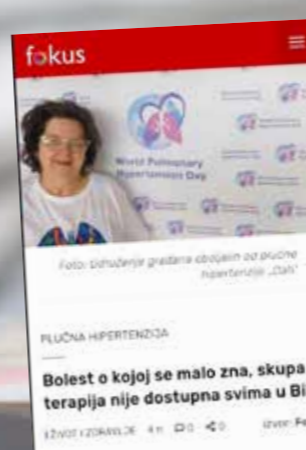
We express our sincerest thanks to PHA Europe for the support of our activities during WPHD.



AUSTRIA



BOSNIA AND HERZEGOVINA





U glavnom gradu Zagrebu nalazi se sjedište Europskog udruženja oboljelih od plućne hipertenzije „Pulmonary hypertension association Europe“, odnosno PHA Europe. Udruženje okuplja 27 članica diljem Europe i šire, a jedna od njih je i Hrvatska u kojoj je 2015. osnovana udruga Plava krila s ciljem potpore i edukacije oboljelih od plućne hipertenzije.

Plućna hipertenzija
Bolest o kojoj se malo zna
Izjednačiti prava oboljelih od plućne hipertenzije
Lifestyle / Zdravlje | 05. 03. 2023. u 09:03 @ljusak.info

Projekt „PUNIM PLUĆIMA“ ili kako podići svijest o plućnoj arterijskoj hipertenziji
Projekt „PUNIM PLUĆIMA“ ili kako podići svijest o plućnoj arterijskoj hipertenziji

Novi 1.410 km izmetove vožnje je uz ranije pređene kilometre 28 PH, rezultiralo ukupnim brojem od 11.690 km vožnje koje je izmet posvetio oboljelima od plućne hipertenzije.

Zavidovićanin Ismet Škulj na još jednoj biciklističkoj turneji
Kraj aprila, početak maja 2023. obilježila je nova biciklistička turneja Zavidovićanina Ismeta Škulja. Naime, ovaj bh rekreativni biciklist je i ove, kao i prethodnih godina, svoju proljetnu evropsku vožnju posvetio oboljelima od plućne hipertenzije i na taj način dao svoj doprinos u obilježavanju Svjetskog dana plućne hipertenzije – WPHD 2023 koji se obilježava 05. maja. Ismet Škulj je ovom prilikom prešao 1.410 km na svom biciklu sa obilježima evropske PH zajednice.



Kvalitetna terapija
- Kad osoba sazna da boluje od plućne hipertenzije pa zatim na internetu pročita poražavajuće podatke i crne prognoze, nerijetko padne u depresiju. Tad je najvažnije da ostvari kontakt s osobama koje su u istoj situaciji kao oni sami. Koliko god da vas razumiju i podržavaju obitelj i prijatelji, samo osoba koja ne može disati isto kao vi sami može shvatiti kako vam je zaista - navodi Zdenka Bradač, predsjednica udruge Plava krila.

Utječu na zakone i svakodnevno pomažu tisućama Hrvata, no njihov rad i dalje prolazi ispod radara
Razgovarali smo s vodećim ljudima tri važne zdravstvene udruge, ali i kako bismo saznali više o njihovom radu te izazovima s kojima se svakodnevno suočavaju



Plućna hipertenzija - bolest koja uzima dah, nekad i godine do dijagnoze

ENERGIJA POVEZUJE
Prevenција bolesti: Ostani bez daha za PH utrkaj Maksimovom

Projekt „Punim plućima“ ili kako podići svijest o plućnoj arterijskoj hipertenziji

Svjetski dan hipertenzije - 17. svibnja 2023.

OSTANI BEZ DAHA ZA PH

HUNGARY



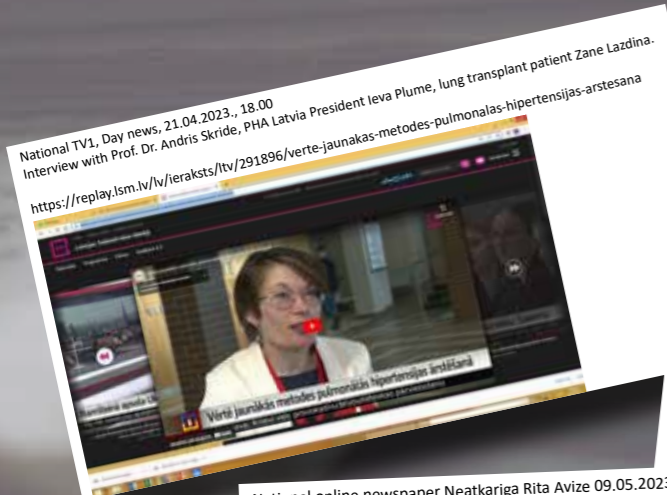
PORTUGAL



A few Online News

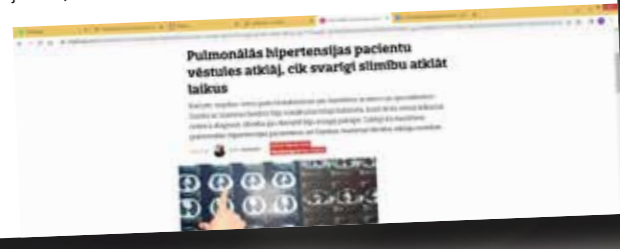
- <https://www.newsfarma.pt/noticias/13116-associacao-portuguesa-de-hipertensao-pulmonar-alerta-para-a-urgencia-do-diagnostico-precoce>
- <https://gicnoticias.pt/especiais/olhar-pela-saude/2023-05-05-Hipertensao-pulmonar-uma-doenca-rara-incuravel-e-por-vezes-fatal-aaebc9a>
- <https://www.bairradinformacao.pt/2023/05/05/evento-em-luso-assinala-dia-da-hipertensao-pulmonar-e-recorda-maria-joao-saraiva/>
- <https://saudebemestar.com.pt/hipertensao-pulmonar-doentes-e-especialistas-alertam-para-a-urgencia-do-diagnostico-precoce/>

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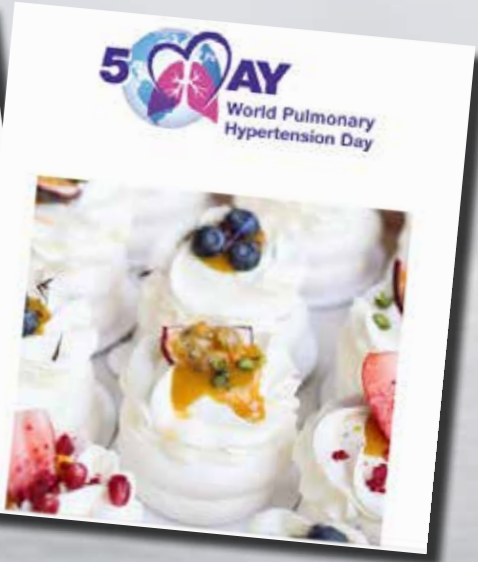


National news portal LSM.lv – article about pulmonary hypertension 21.04.2023.
Article due to 4th Baltic PH conference
<https://www.lsm.lv/raksts/dzive--stils/veselibu/21.04.2023-slimiba-kas-nosmace-konference-spriez-par-pulmonalas-hipertensijas-arstesanu.a505831/>

National online newspaper Neatkariga Rita Avize 09.05.2023. – Article from press realize.
https://neatkariga.nra.lv/veselibu/413514-pulmonalas-hipertensijas-pacientu-vestules-atklaj-cik-svarigi-slimibu-atklatai-laikus?_gl=1*1hcagbz*_ga*MzQ4Mzk0NDMxLjE2NDEyMTYxMzg*_ga_LTMBW853H5Y*MTY4MzYxNjY0OC4yMS4xLjE2ODM2MTY2NTQuMC4wLjA



SLOVAKIA





Výstup na vrch Skorušina „Vystúpim za teba“

Združenie pacientov s pľúcnou hypertenziou o.z. v spolupráci s obcou Brezovica organizujú v sobotu 27.5. výstup na vrch Skorušina „Vystúpim za teba“

Bližšie informácie a prihlásenie sú zverejnené na stránke: <https://www.pnaclova.sk/>

Národný ústav srdcových a cievnych chorôb, a.s.

Aj ten rok sa organizovala krásna aktivita ku Svetovému dňu pľúcnej hypertenzie. Spojenie občianskeho prostredia s aktívnym oddychom, empatia a podpora pacientov patrí každoročne k obľúbeným činnostiam zdravotníckych pracovníkov lekárov a NUSCC, a.s. pacientov ich príbuzných a priateľov.



Benefičný volejbalový turnaj. Pes žije. Závažná choroba. Pozor, na otrávené návnady.

POKROK. Daruj dych. Nový supermarket v M. Tameni. JARNÁ AKCIA.

Šele v odsotnosti polne kapacite pľuč prepoznate pomen vsakega vdiha

'Da nekaj ni v redu, so mi povedale stopnice'

Šele v odsotnosti polne kapacite pľuč prepoznate pomen vsakega vdiha

Vsak vdih šteje

'Da nekaj ni v redu, so mi povedale stopnice'

"Nina, oprosti. Zmotili smo se."

Daruj dych pre pacientov s pľúcnou hypertenziou

TN Keď dochádza dych

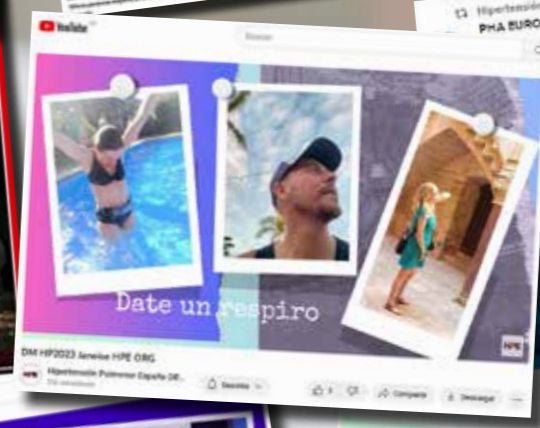
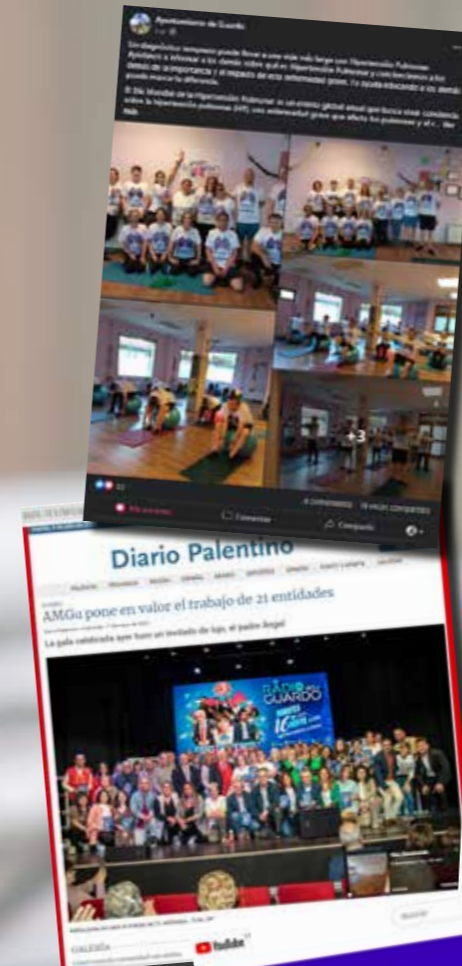
Pľúcna hypertenzija nima starostne omejitve, ima pa lahko hude posledice

Težka in dolga pot do prave diagnoze

Pľúcna hipertenzija - bolezen, na katero ne pomislijo niti zdravniki

Môžete byť našim hlasom

SPAIN FCHP



SPAIN HPE



UKRAINE PHA



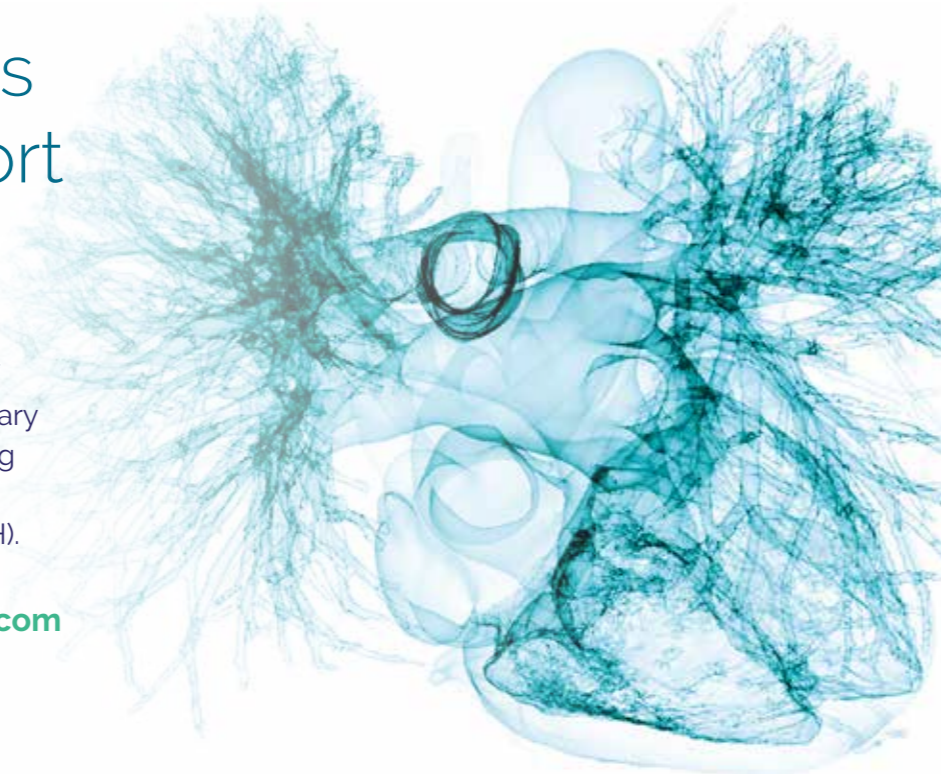




Aerovate Therapeutics is proud to support PHA Europe

We are committed to developing new therapies to improve the lives of people living with rare cardiopulmonary diseases. We are currently developing an investigational therapy to address pulmonary arterial hypertension (PAH).

Learn more at www.aerovatetx.com



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At Janssen, we understand that pulmonary arterial hypertension (PAH) comes with many challenges, and not all are physical.

That's why we've created **PH Human** – an educational programme dedicated to empowering people living with PAH to help understand their condition and engage in their care, bringing loved ones and caregivers along on their journey.

Whether you are looking for tools to support productive conversations with your healthcare team like our **Breathe In, Speak Out Conversation Kit**, interested in understanding the standards of care you should expect to receive through our **PAH Patient Charter**, or you are simply searching for tips and tricks to **live well with PAH** – PH Human has a variety of resources and real-life experiences available to empower you to play an active role and make informed decisions in your care.

Find out more on **PHuman™**



EM-102191 | June 2022



Hollie, 37
United Kingdom
Entrepreneur
Living with pulmonary arterial hypertension



Janssen Pharmaceutica NV © JP NV 2022.



Vision • Connection • Innovation

Gossamer Bio was named in symbolism of the gossamer thread, the connection that binds all relationships in life.

The goal of Gossamer Bio is to improve the lives of patients through meaningful advances in scientific development and an unwavering commitment to supporting patient communities across the globe.

Gossamer Bio is proud to support meaningful and engaging awareness and education programmes that are created and led by PAH patient advocacy groups.

Please follow this thread to learn more about us: www.gossamerbio.com

@GossamerBio

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Sumitomo Pharma America, Inc. (SMPA) is dedicated to improving the health and well-being of people around the world.

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* EU Medical Device Regulation (MDR) 2017/745
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CLINICAL TRIAL

**Do you know
someone with PAH?**

Become a part of the clinical trial for people living with pulmonary arterial hypertension (PAH)*

For more information on the trial, visit:

www.vipah-prntrials.com



*The treatment that Respira is researching in the VIPAH-PRN2B trial is investigational and has not yet been approved for doctors to prescribe. The VIPAH-PRN2B trial is sponsored by Respira Therapeutics, Inc.

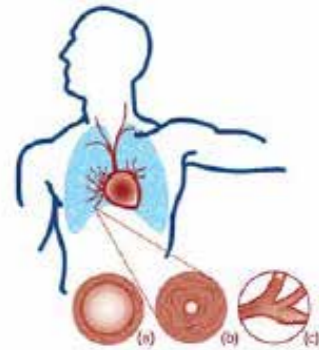
ClinicalTrials.gov Identifier: NCT04266197; RT234-PAH-CL202

AIMS OF PHA EUROPE

Pulmonary arterial hypertension causes breathlessness and is a rare, progressive and currently incurable lung disorder. PHA EUROPE, European Pulmonary Hypertension Association, was founded in 2003 and is registered in Vienna, Austria as an international nonprofit organisation. PHA EUROPE is an umbrella organization bringing together Pulmonary Hypertension patient associations across Europe. The primary objective of PHA EUROPE is to establish a narrow cooperation between the members and the European institutions, international organizations, and public institutions worldwide and work towards achieving the best possible standards of care for all European pulmonary hypertension patients.

WHAT IS PULMONARY ARTERIAL HYPERTENSION?

In patients with Pulmonary Arterial Hypertension, characteristic changes occur within the pulmonary circulation, which include thickening of the linings and obstruction of the small pulmonary blood vessels. They are both structurally and functionally abnormal. In severe cases, up to 80% of these very small blood vessels are rendered non-functional. As a result, the pressure in the pulmonary circulation rises well above normal, and this places strain on the right side of the heart. This strain can cause the heart to enlarge, and the patient may develop heart failure. This is a disease that can affect all ages and is more commonly seen in females. Pulmonary arterial hypertension has an estimated prevalence of about 50 per million population.



a) Cross section of normal pulmonary artery

b) Reduced lumen of pulmonary vessels due to cell proliferation and remodelling in advanced pulmonary arterial hypertension

c) Longitudinal section with pathological changes within the vessels (proliferation, deposition of blood clots, thickening) causing difficulties for the heart to pump blood through the lungs

TREATMENT OF PULMONARY ARTERIAL HYPERTENSION

Over the past decade, a number of evolving therapies that either use complex delivery systems such as 24-hour intra-venous or subcutaneous drug infusion, drug inhalation and, more recently, oral medications, have transformed the outlook for PAH patients. PAH is a condition that can be rapidly progressive and needs careful, ongoing expert care and management. The disease can be insidious in its onset, with unexplained breathlessness and tiredness as its two main symptoms. If undiagnosed and/or inappropriately treated, the average life expectancy for these patients is estimated to be around 2-3 years. For those patients who fail to respond to medical therapies, double lung, or in some cases, heart and lung transplantation, may be appropriate.

THE FUTURE FOR PULMONARY ARTERIAL HYPERTENSION

While a cure for this aggressive and life-threatening disease is still some way off, there is much to be optimistic about. There are an ever-increasing number of therapies available for the effective treatment of pulmonary arterial hypertension, which improve the quality and length of life. The aim for the present should be to ensure that all patients with pulmonary arterial hypertension have access to centres of excellence in the diagnosis, management, and ongoing treatment of this disease.

Members of PHA Europe and contact details

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HUNGARY



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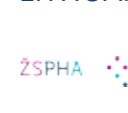
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LITHUANIA



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