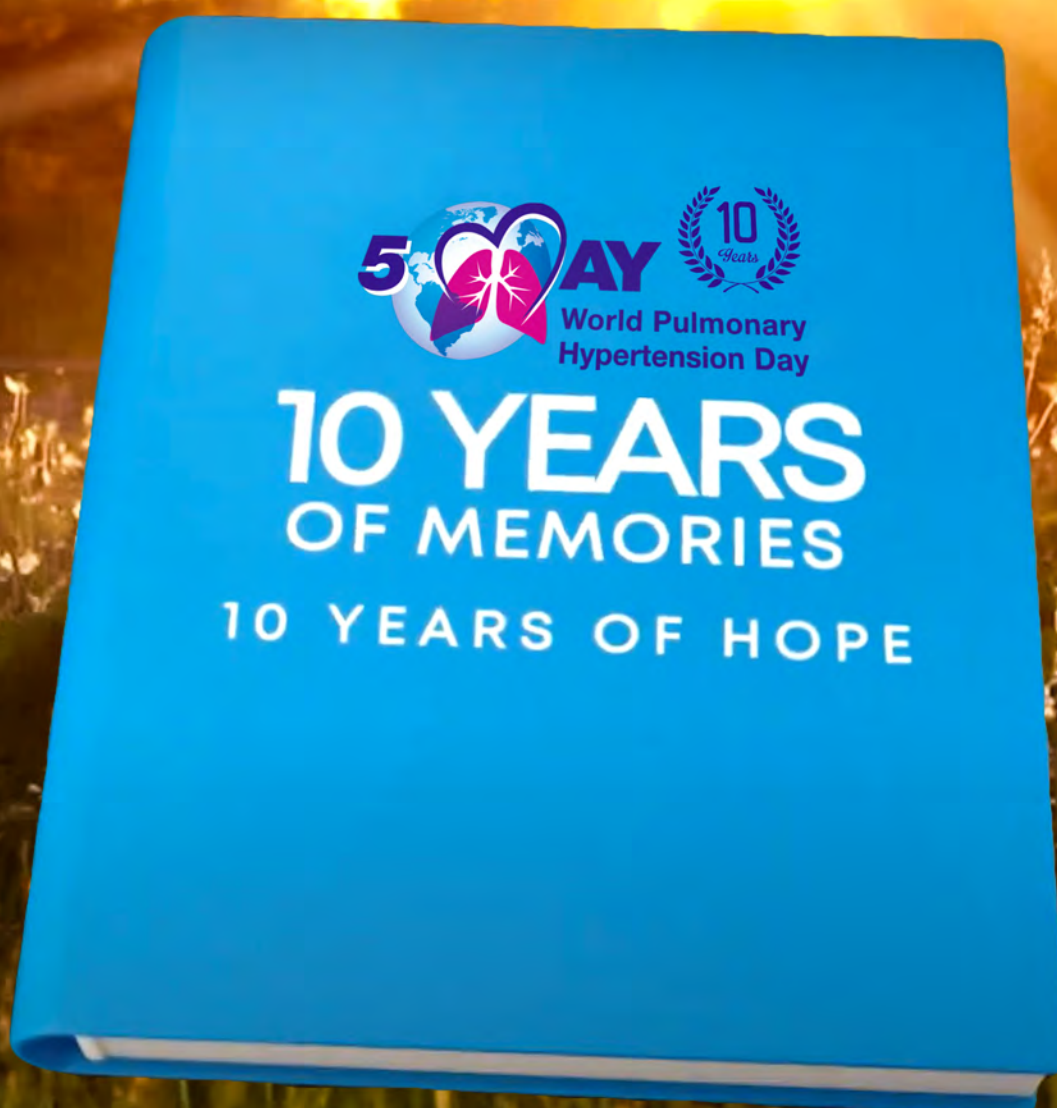


PULMONARY HYPERTENSION

Mariposa Journal

SUMMER 2022 • PHA EUROPE'S OFFICIAL JOURNAL • N. 28.



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

PHA EUROPE *for the patients*
European pulmonary hypertension association

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Editors memo

• SUMMER EDITION 2022 •

Dear Friends, Colleagues and Supporters,

It was 10 years ago when the first World PH Day (WPHD) was celebrated in Madrid, Spain in a format of a scientific symposium: key opinion leaders from the medical field and patient representatives attended that prestigious event.

A decade is a long time in a life of a series of events: World PH Day has also gone through many changes since the beginning, but we can proudly announce it becomes truly a global event. More than 80 associations worldwide celebrate WPHD on the 5th of May in various formats, but with the same message: Get breathless for PH!

In the first years World PH Day became an awareness raising event: many associations from Europe united under the same lung logo and message. More and more countries joined later on when they saw the success of the initiative.

A very fruitful collaboration with the leading global triathlon and running event organizer, Ironman gave further momentum and recognition to WPHD: triathletes all over the world proudly wear the branded suits and rang the bell during the races to attract the attention to pulmonary hypertension (PH). Many ambassadors from various sports still collect the miles, raise awareness of PH and get breathless in high mountains, long runs and swims, during kayaking and biking and many other ways.

The variety of events has also evolved: the raising awareness events have not only targeted the general public, but schools to facilitate the better acceptance of kids and youngsters living with this condition. Trainings and webinars, meetings with stakeholders, involvement of celebrities and decision-makers, negotiations with politicians, various exhibitions, organization of charity events nicely supplemented the main events and contributed to keeping pulmonary hypertension on the agenda. The PH community nicely adapted the WPHD celebrations to the COVID era as well: however mass events were canceled, millions of people were reached through social media campaigns, webinars in different languages, online petitions and online events with the involvement of members of the European Parliament (MEP) on accelerating EU research – the case of pulmonary hypertension.

The 10th anniversary of World PH Day was remarkable – both on a country and European level – with the motto of #TogetherStronger.

Many countries from Spain and Hungary to Bulgaria, from Slovakia and Czech Republic to Bosnia and Hercegovina illuminated their famous buildings on the evening of the 5th of May in the colors either blue or purple to mark this special day.

Sport events were very popular in Israel, Belarus, Serbia and in North Macedonia to mention a few.

Portugal and Italy organized – among others – a scientific meeting and Italy as well as Austria ran a charity concert with big success. You can learn more about the activities conducted by the member associations in the following pages of this edition of Mariposa.

A special event in the European Parliament (Brussels, Belgium) kicked-off the anniversary celebration on the European level on the 26th of April. During this event the revised Call to Action on the unmet needs of patients with pulmonary hypertension position paper was presented. It was a hybrid event which helped to follow the event online for those who could not join personally and lately the recording was also shared on our channels to reach as many people as possible. Patient representatives from all over the world, key opinion leaders from the field, and last, but not least politicians (members of the European Parliament – MEP) and decision makers from European institutions attended the event. The result and the messages on access, research, screening, psychosocial support and patient empowerment, however, have effect well beyond Europe and applicable to other parts of the world. The revised position paper is an excellent advocacy tool and together with the executive summary serves as a starting point once it comes to negotiation with stakeholders. The work does not stop with the launch event: millions of people have been already reached through our social media channels with quotes from the meeting and the paper; additionally further activities are planned, including the translation of the executive summary and local events. You can get acquainted with the position paper and the launch event in this edition of Mariposa. Our online activity was not limited to the 5th of May, but we started a very successful online campaign one week earlier and our series of posts were available until the 20th of May. 17 tailor-made visuals delivered targeted messages and were translated to 20(!) languages. The posts were nicely supplemented by social media headers and were widely used, commented and re-shared showing solidarity with our common cause. All of the materials ((including the language versions) are available from our information hub

(<https://worldphday.org/toolkit/>). The total number of 10 (!) clearly shows that even a rare disease campaign can reach a huge audience! You can learn more about this campaign either by visiting the above webpage or our social media channels.

An anniversary is incomplete without a real celebration: PHA Europe organized an online event and the speakers were those who attended and were presenters at the first World PH Day conference. The event was advertised on all of our channels and we asked our partners to do so. We saw a record number of 70 attendees in the online webinar which was closed with a real surprise: an anniversary video.

Let me conclude this editorial with a big thanks to our members, patients, family members, carers, friends and also to our medical partners, physicians, surgeons and researchers, who are with us on this long journey. Without their assistance we would not be where we are now. We are very proud of World PH Day and we do hope we can continue this amazing initiative in the coming decade. A special thank goes to our industry partners, who continue to support our work and help us celebrate World PH Day!

Gergely Meszaros
Project manager • PHA Europe



CONTENTS

Editors memo	p. 2	WPHD 2022 - Italy AMIP	p. 32
Call To Action	p. 4	WPHD 2022 - North Macedonia	p. 34
Anniversary webinar and video	p. 8	WPHD 2022 - Norway	p. 35
Social Media Campaign	p. 10	WPHD 2022 - Portugal	p. 36
		WPHD 2022 - Serbia	p. 38
WPHD 2022 - Austria	p. 12	WPHD 2022 - Slovakia	p. 41
WPHD 2022 - Belarus	p. 14	WPHD 2022 - Slovenia	p. 43
WPHD 2022 - Bosnia And Herzegovina	p. 16	WPHD 2022 - Spain ANHP	p. 45
WPHD 2022 - Bulgaria BSPPH	p. 19	WPHD 2022 - Spain FCHP	p. 47
WPHD 2022 - Bulgaria PHA	p. 21	WPHD 2022 - Spain HPE	p. 50
WPHD 2022 - Croatia	p. 22	WPHD 2022 - Sweden	p. 53
WPHD 2022 - Czech Republic	p. 24	WPHD 2022 - Ukraine PHA	p. 54
WPHD 2022 - Finland	p. 25	WPHD 2022 - Ukraine PHURDA	p. 55
WPHD 2022 - Hungary	p. 26	Media clippings	p. 57
WPHD 2022 - Israel	p. 28	Sponsors	p. 65
WPHD 2022 - Italy AIPI	p. 29	Members of PHA Europe and contact details	p. 71

CALL TO ACTION

Unmet needs of persons living with pulmonary hypertension



Each association and organization need a clear strategy.

Our original call to action was launched in 2012 in the European Parliament which laid down our mission. After a decade it was high time to revisit those objectives and assess whether some of the goals are still relevant and whether some of them need more attention or resources.

We launched the reviewing process in early 2020, however it was put on hold due to COVID pandemic. One year later a roundtable was established – including a medical review committee of *Prof. Marion Delcroix, Prof. Marius Hoeper, Prof. Marc Humbert, Prof. Adam Torbicki* and *Ass. Prof. Gabor Kovacs* – which embrace all of the stakeholders on the field of pulmonary hypertension:

representatives from various patient associations and the regulatory body and representatives from the pharmaceutical companies.

The COVID pandemic changed the business-as-usual reviewing process: there were no face-to-face meetings at all, but online meetings and drafting – the position paper was reviewed part-by-part with the lead of either one of the members of the medical review committee or PHA Europe.

After many rounds of discussion, the reader can hold in their hands a heavily re-written, freshly looking and updated new call to action. We endeavored to make it easily understandable and put special emphasis on graphics to attract attention and highlight some of the key points. The call to action also



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

consists of a standalone executive summary which can be translated into various languages to facilitate discussion with stakeholders on country level.

We were waiting for the release of various COVID measures to publish our position paper. Finally, early March the European Parliament opened the door for in person meetings.

On the 26th of April the roundtable members gathered in the European Parliament, Brussels, Belgium to officially launch the new position paper.

The event of our call to action was one of the first meeting organized in the European Parliament and it was the very first and flagship event of the MEP Lung Health Group interest group PHA Europe is part of and collaborating with other lung disease patient associations and the European Respiratory Society (ERS).

The meeting was hosted by MEP *Istvan Ujhelyi* (Hungary) and chaired by *Prof. Marc Humbert* (ERS president). MEP Ujhelyi's introductory speech was followed by *Prof. Marion Delcroix* lecture which covered the rare diseases, pulmonary hypertension and EU policies. *Jose A. Valverde* outlined the role of the European Commission on the field of health and outlined some aspects of the European Reference Networks (ERNs). These general presentations led to the introduction of the call to action by *Gergely Meszaros* who also covered the patient empowerment concept of the paper.

The next sessions followed the concept and main parts of the paper: *Ass. Prof. Laurent Godinas* talked about the importance of screening and awareness, while *Prof. Adam Torbicki* about access to treatment and special centres. *Ass. Prof. Gabor Kovacs* highlighted possible ways of research, including the use of artificial intelligence and the programme was closed by *Eva Otter*, president of PHA Europe, who talked about psychosocial support.

The event was live streamed on our social media channels – the online event collected 90 interested persons and already more than 600 views of the recording.

The meeting was a great success and bring the stakeholders closer to collaborate even more in the future.

We expect more views once the video is edited and published on our social media.

Our work with the call to action has not ended at this point: many action items have been identified and national activities are also planned.

You can learn more about and download the position paper, watch the launch event and browse amongst the presentations from: <http://lnnk.in/bHe7>

Gergely Meszaros





ANNIVERSARY

webinar and video

Follow us on Facebook for more information: www.facebook.com/worldphday

FREE
Online webinar
5th of MAY
Start at 7 PM CET



World PH Day -
10th anniversary celebration Webinar



Irene Delgado

PH patient and secretary of the
National Association of
Pulmonary Hypertension (Spain)



Rino Aldrighetti

former President & CEO PHA US



**Professor
Nazzareno Galie**

Bologna Sant'Orsola



**Professor
Gerald
Simonneau**

Université Paris-Saclay,
France

Hosted by: **PHAEUROPE**
PULMONARY HYPERTENSION ASSOCIATION

Endorsed by: **WITH THE SUPPORT OF EURORDIS**



One of the most awaited events during this year's World PH Day celebration was the anniversary webinar. As most of the PH associations leaders are very busy with the organization of their own event, decision was made to run the gathering online to attract more people also those who cannot travel for the sake of an event. The webinar was promoted on our social media platforms and many, even previously unknown people to the disease joined the session: we saw a record high number of 70 attendees. It shows the importance of the event that many medical students and physicians were among the participants (as we received a couple of requests on attendance certification), despite no credit was given.

Irene Delgado, patient from the Spanish PH association (ANHP), *Prof. Nazzareno Galie* from Bologna, Italy and *Prof. Gerald Simonneau* from Paris, France were the speakers of the event. The very common of the presenters is that they were also speakers and organizers of the scientific symposium held in Madrid, in 2012, which was the first World PH Day celebration. We could learn about the first event from Irene, who provided both the challenges of organizing the symposium like contacting the speakers, endorsement, funding and the main objectives.

Gergely Meszaros

We got to know why the 5th of May was chosen as the awareness day: the date is the anniversary of the first child's death in Spain from pulmonary hypertension as a result of toxic rapeseed oil more than 30 years ago.

The participants got insight into the program of this first symposium, the gala dinner, the accompanied press conference and many more - even backstage - information and very touching memories also came up. The next speaker of the anniversary webinar was Prof. Galie who walked through the audience in the involvement of PH (but more specifically of PAH) management in the last decade. Prof. Galie highlighted the various types of PH, the pathology of the disease and the diagnostic algorithm as per the guidelines. An informative slide on the most relevant trials and pathways were presented. The professor highlighted the evolution of the trials as well: in the beginning short and small trials were conducted, but later on bigger studies took place to focus on quality of life considerations.

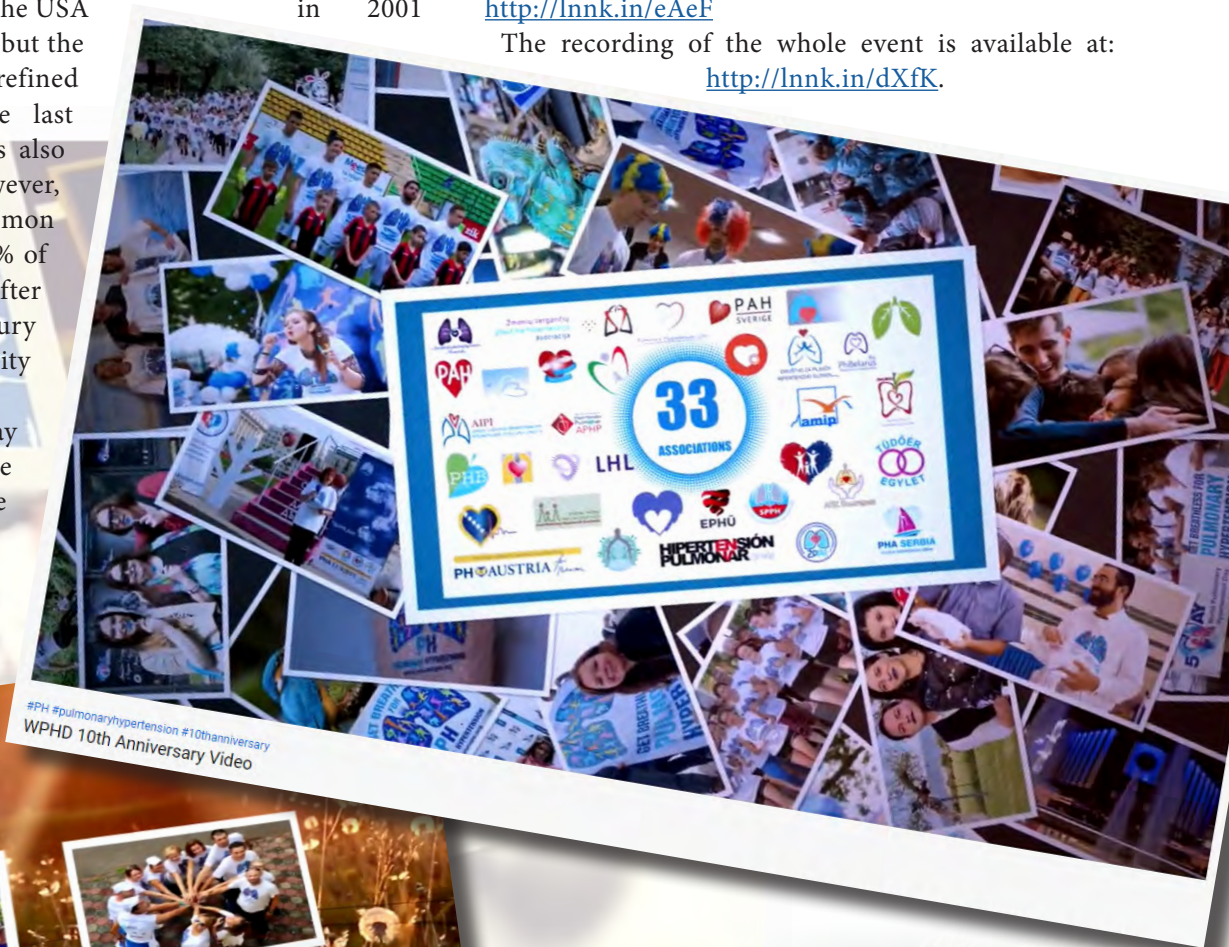
Prof. Galie touched upon treatment strategies, risk stratification and provided details regarding combination therapies. His main takeaway was that PAH management is not a simple prescription of drugs, but a continuous process including a constant re-assessment of the effects based on risk stratification. This session was followed by the presentation of Prof. Simonneau who talked about another subgroup of PH, chronic thromboembolic pulmonary

hypertension (CTEPH). CTEPH is caused by non-resolving embolism despite anticoagulation and a relatively frequent cause of PH. The professor talked about the modality of treatments: surgery (pulmonary endarterectomy - PEA), angioplasty (balloon pulmonary angioplasty - BPA) and drugs. The surgery is considered a safe intervention with 5% mortality rate and the medical treatment also offer 97 % survival rate. BPA was used in the USA in 2001 for the first time, but the technique was refined in Japan in the last 10 years – it was also mentioned, however, that the most common complication (38% of the patients) after BPA is lung injury with a low mortality rate of 0-5%. The key take-away of the lecture was that we are entering a new era for the management of CTEPH with

the possibility to combine the above treatment options in the same patient.

The webinar was closed with a surprise. Well before the event the member associations were contacted to provide their best photos and memories from their WPHD celebration. Based on this input a video was compiled and the premier was the at the end of the webinar. The anniversary video is available at: <http://lnnk.in/eAeF>

The recording of the whole event is available at: <http://lnnk.in/dXfK>.



#PH #pulmonaryhypertension #10thanniversary
WPHD 10th Anniversary Video



JOIN US IN
CELEBRATING
10TH WPHD



SOCIAL

media campaign



Gergely Meszaros

Social media campaigns are becoming integral part of our World PH Day celebrations. Such initiatives have many advantages from reaching out to many people irrespective of where they are leaving to spreading the same information with branded visuals in multiple languages.

The result of social media campaigns can be easily measured: this year's WPHD Facebook key performance indicators (KPIs) well exceeded our expectations: we achieve more than 3,1 million total impressions, record high of 2,6 million reach (solely the 10th anniversary video had a 220.000+ reach and the anniversary video of almost 1 million) and not only the number of our followers increased, but the number of fans as well. The real numbers are even higher as we were active on other platforms as well and had almost 1 million reach on Instagram.

We created an information hub at <https://worldphday.org/toolkit/> and all the visuals including more than 15 language versions, social media headers as well as a detailed timetable with additional text were made available and downloadable in order to help local associations to actively take part in the World PH Day celebration.

You cannot imagine the total reach which also include those who were reached by local patient associations with the visuals in their respective language!

The World PH Day social media campaign went hand in hand with the campaign built around our Call to Action position paper and its launch event in the European Parliament.

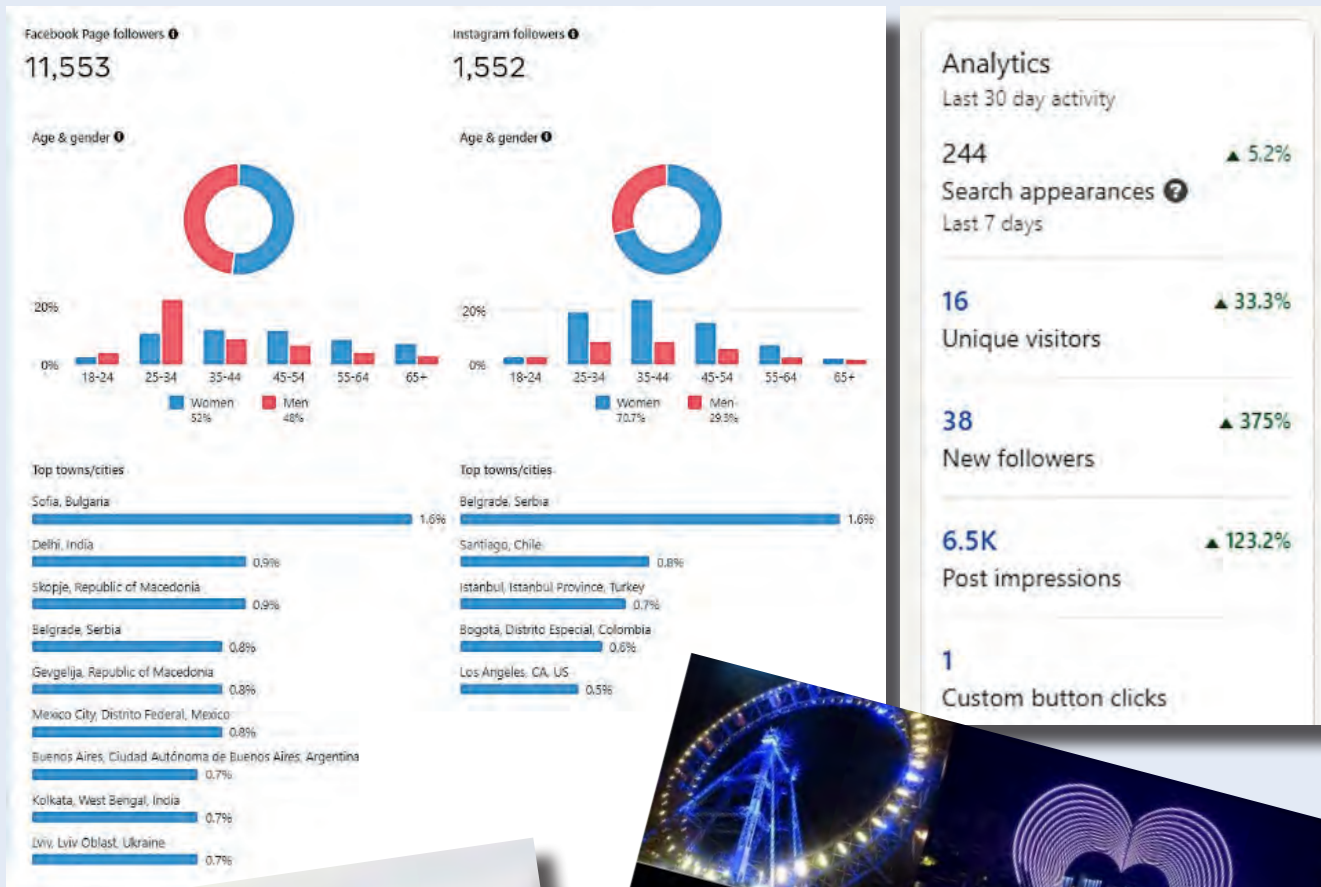
The results of this campaign on Facebook and Instagram are breathtaking and clearly shows how relevant the messages incorporated in our position paper are:

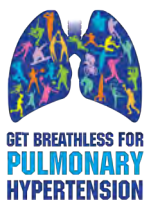
5 million total post impressions! The engagement rate was also excellent of some of the posts: we had a post which collected almost 700 likes.

We can extremely be proud of these awareness campaigns, however, on the other hand it is also a big responsibility, because our messages need to be clear, precise and relevant.

This year we achieved enormous numbers, but we will make all efforts to outstrip them next year! Stay tuned!







WPHD 2022 - AUSTRIA



10 YEARS OF WORLD PH DAY: #StrongerTogether

"History has taught us that while the world is constantly changing, by working together we can get through the toughest of times. This year we celebrate the 10th anniversary of World PH Day, which is another opportunity to further consolidate our work together." Eva Otter, President of PHA Europe, is convinced of this year's motto #StrongerTogether.

FESTIVE ANNIVERSARY IN AUSTRIA

For the tenth anniversary, around 130 supporters and friends of PH Austria celebrated a concert of Rock'n'roll legend Wolfgang Ambros and collected donations to do even more. Among the guests were many VIP's, which enabled a strong media coverage. Equipped with a lot of information and facts about pulmonary hypertension, as well as „Get Breathless for PH" T-shirts, the guests are now motivated to draw even more attention to the rare disease.

PH BREAKFAST AT AOP HEALTH AT WPHD

The international pharmaceutical company AOP Health, based in Vienna, focuses on rare and complex diseases such as pulmonary hypertension. On May 5th, World Pulmonary Hypertension Day, AOP Health organized a panel discussion. The theme of the event was dedicated to life with PH.

Participants from a wide variety of areas were given the opportunity to explain their perspective on the

disease. At the round table were Dr. Georg Fischer, CEO of AOP Orphan Pharmaceuticals, PH expert, cardiologist Priv. Dr. Nika Skoro-Sajer, Vienna General Hospital, DGKP Andreas Bichler, OrphaCare, a patient with her daughter and Eva Otter. It is particularly worth mentioning that the event was broadcast live in German, English, Spanish, Italian and Polish and attracted a very large audience.



VESPA MEETING PERCHTOLDS DORF

Have fun and do good at the same time!

Austria's Vespa drivers set out on a journey to help children with PH. Many were interested in the disease, most of the questions were about how to notice the disease, what symptoms appear and whether there is a cure in sight. Many colorful Vespas were on site, the mayor spoke the welcoming words, then the

vehicles were blessed by the chaplain, so that everyone came home safely from the trip. Start number 1 was auctioned off separately in favor of PH Austria. At 11:30 they started! What an experience! Around 500 Vespas set off, led by a safety car, accompanied by 20 security guards. At around 4.30 p.m. the participants were back in Perchtoldsdorf after the ride. There was an enormous media coverage even on ORF (Austrian major broadcast) on prime time. The media coverage had such a great impact that Eva was contacted by many viewers, including an elderly lady who donated two oxygen concentrators.



SOCIAL MEDIA: AWARENESS WITH #10Years10Facts

In addition to the global campaign, PH Austria wanted to use their social media channels around World PH Day to draw attention to the rare disease with fact-based information and create understanding for the challenges that patients have to live with. The community was invited to further spread the ten facts about PH - from historical to scientific facts to the everyday life of people with PH. Attention was also drawn to international campaigns. Between April 21 and June 9, PH Austria postings on World PH Day reached 5,742 people on Facebook and 1,534 people on Instagram and further 622 people viewed our stories.

Gerald Fischer, PH Austria - Initiative Lungenhochdruck
www.phaustria.org
www.facebook.com/lungenkinder

#10Jahre10Fakten

5 MAY 10 Years

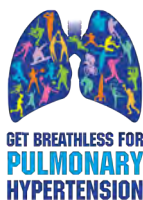
World Pulmonary Hypertension Day

Durch gezielte Behandlung und Medikation wird der Krankheitsverlauf positiv beeinflusst und die Lebensqualität gesteigert

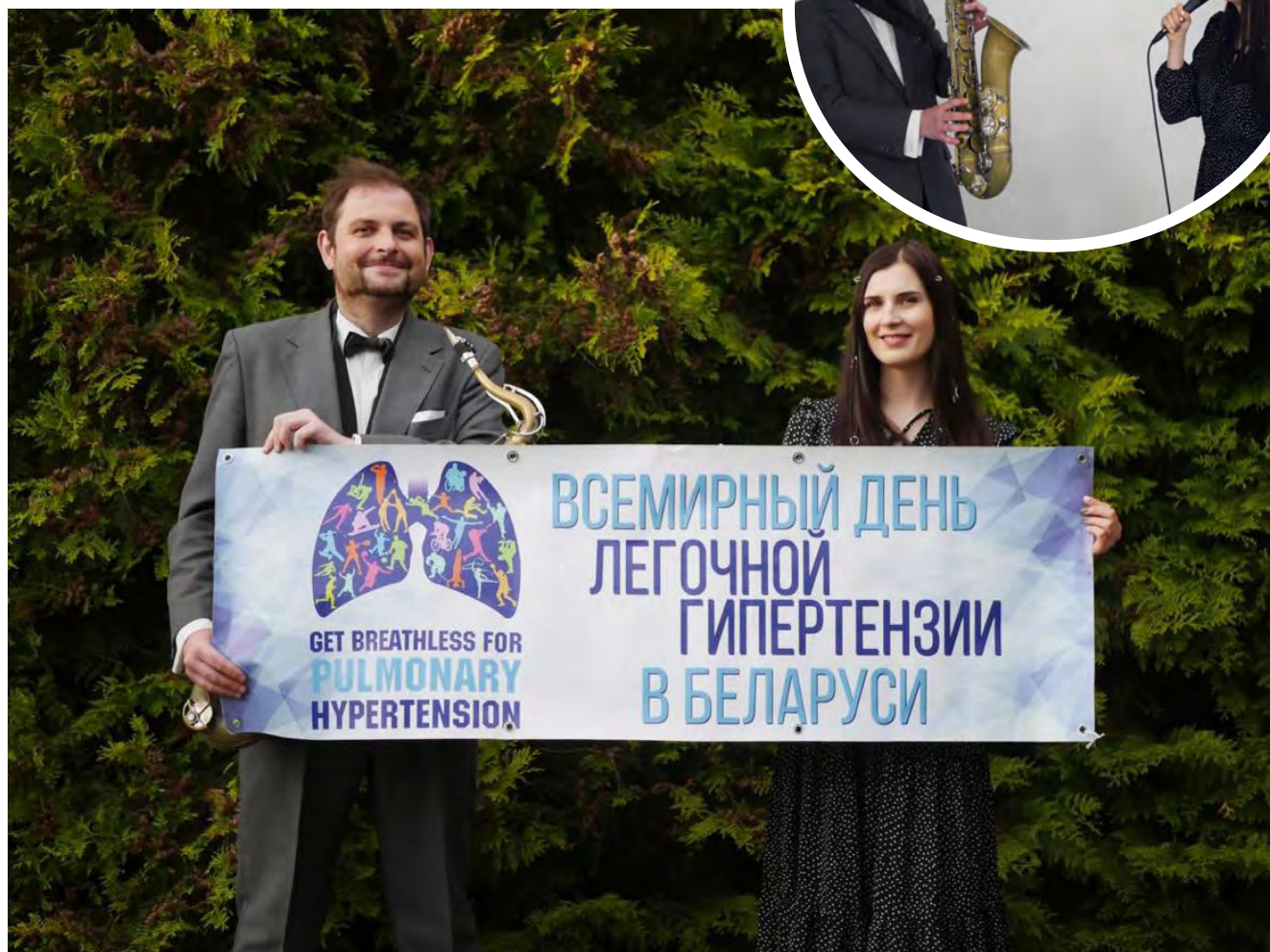
Frühe Diagnose • Beste Therapie • Lebensqualität • Heilung

PH AUSTRIA für Betroffene

INITIATIVE LUNGENHOCHDRUCK



WPHD 2022 - BELARUS



Minsk Amateur Sports Association held volleyball tournaments in support of people with PH!

Pulmonary hypertension is a rare and very serious disease. The quality of life of patients with pulmonary hypertension deteriorates significantly, and the situation is further complicated by the possibility of obtaining free therapy, not to mention the correct diagnosis. And those drugs that have been invented today do not cure, but only slightly alleviate the condition.

Therefore, it is very important to give a person suffering from this disease timely support and the realization that they are not alone, that there are people who will help, who are not indifferent to them!

Help for Patients with Pulmonary Hypertension, an association that helps patients, has been holding charity events for many years to help people suffering from this disease.

And this is not the first time that the Association of Amateur Sports actively supports this event and holds volleyball tournaments, reminding us of people - our patients, who really need this support.

Also this year, within the framework of the worldwide campaign held by the world community of pulmonary hypertension, the Jazz duet performed at the event.

We express our deep gratitude to the organizers and participants of the Minsk Association of Amateur Sports for holding the tournament, the gym of the supplementary education in Minsk. And also to the friendly and cheerful activists of this event!

P.S. The most important thing in this life is not to remain indifferent. As long as a person feels someone else's pain - they are human!

*Alina Katsubinskaya
PH Belarus*



10 ИЮНЯ

в 11:00 по Москве
онлайн встреча на тему
**Рекомендации пациенту
для эффективного начала приема
ЛАГ-специфических препаратов**

Рассказывает и отвечает на ваши вопросы

Зарина Солтановна Валиева,
к.м.н., старший научный сотрудник, доктор медицинских наук, профессор
«Института кардиологии им. А.Н. Мясникова» ВГМУ,
национальный медицинский исследовательский центр кардиологии,
Министерство здравоохранения Российской Федерации

А также пациенты с ЛАГ поделятся личным опытом на тему встречи.

Трансляция встречи состоится на YouTube канале АНО «Дом Редких»
<https://youtube.com/channel/UCPwXNqsQSVm337xq891rqPQ>

Я живу с ЛАГ
ИНФОРМАЦИЯ. ЗНАНИЕ. УМЕНИЕ. ОПЫТ.

«ЛАГ» Жизнь

Я живу с ЛАГ
ИНФОРМАЦИЯ. ЗНАНИЕ. УМЕНИЕ. ОПЫТ.

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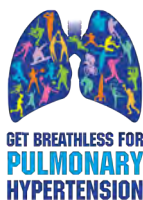
Простациклин

- Нормальный уровень простациклина помогает поддерживать здоровье кровеносных сосудов, поддерживая их открытыми и обеспечивая нормальный кровоток. У пациентов с ЛАГ может не производиться достаточное количества простациклина.

Что делают лекарства, воздействующие на путь простациклина?

Данные препараты имитируют некоторые эффекты природного простациклина:

- Расширение суженных кровеносных сосудов
- Замедление утолщения кровеносных сосудов
- Предотвращение свертывания крови



WPHD 2022 - BOSNIA AND HERZEGOVINA



MAY IN THE SIGN OF PULMONARY HYPERTENSION

The Association of Citizens Suffering from Pulmonary Hypertension "Dah" - in Bosnia and Herzegovina, under the slogan *"Together we are stronger"* and the leitmotif of dandelion, throughout the month of May celebrated World Pulmonary Hypertension Day – WPHD with many activities. The number of participants and activities did not allow us to organize and realize or participate in everything in one or several days.

WE HAVE CELEBRATED WPHD IN MANY CITIES, VARIOUS ACTIVITIES

On the date of May 5, the pedestrian Jalijski bridge and the Sports and Recreation Center "Arena" in Zenica were coloured blue. Both buildings are very frequent and are located in the center of Zenica, a city whose administration has given full support to the association "Dah". In addition to this activity in Zenica, we were also part of the "Zenica Night 10k". Thanks to the organizer of this race, but also to the participant runner Enes Ibrahimagić from Bihać, pulmonary hypertension was one of the topics that appeared and was discussed at this traditional night race.

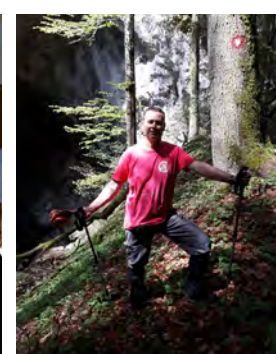
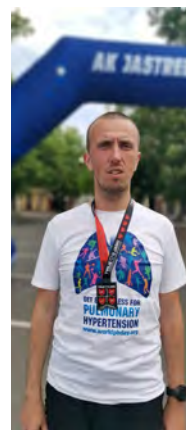
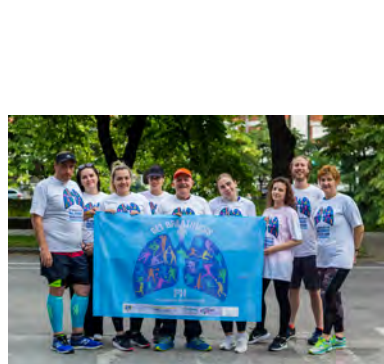
Apart from Zenica, the World Pulmonary Hypertension Day was marked in two other cities, in Sarajevo and in Zavidovići, and the Association "Dah" received online support from all over the world. Support has come to us from all generations, from the youngest to the oldest. Among the events that need to be mentioned is the traditional international Krivaja rafting in Zavidovići, where rafters from the region take part. Rafting club "Krivaja - Zavidovići" is the organizer of this great sports and recreational event and is very happy to participate in all activities that ultimately have a humanitarian character, so that rafters in the region also participated

in raising awareness about pulmonary hypertension. Also, recreational cyclist Ismet Škulj set off on a 1920 km long bicycle ride from Zavidovići for people who are in a very difficult position and often without adequate medical care and medication. With this ride, Ismet Škulj has covered a total of 10,000 km with the markings of the European PH community, as he has been our permanent partner in the celebration of WPHD in the past few years. We are very happy and proud that Ismet Škulj is with us, among the PH fighters.

The seriousness of the situation regarding the situation of people suffering from this disease in Bosnia and Herzegovina was understood by the students of the Prva osnovna škola (primary school) in Zavidovići, who are constantly developing empathy for the sick and all who need help, and have been involved in celebrating this date. Drawings, photos, videos, songs, were used to raise awareness and show their compassion to PH patients. They are the key for making PH not as unknown in the future as it is now.

World Pulmonary Hypertension Day in Sarajevo was celebrated by a very constructive meeting with students gathered at the Homework Hub, who had an opportunity to learn more about PH through interviews and information leaflets of the Association. In addition to this meeting, a street performance was organized with a group of young Sarajevo runners "Trčanje i To", which included training and running along the famous and busy Wilsnovo promenade. Apart from the participants in this activity, passers-by also showed interest in what this group of young runners is doing together with the Association "Dah", but especially in the information about pulmonary hypertension.

In addition to activities in cities, we recorded a short video called *"Do you see me now?"* which pointed out the fact that pulmonary hypertension is an invisible disease.



The video has attracted attention among our partners in the WPHD celebration project and followers on social media because it symbolically brings them closer to what kind of disease it is.

We must also mention the cooperation with the company "Graficom" from Maglaj, which installed video banners dedicated to the World Pulmonary Hypertension Day 2022 in two cities in Bosnia and Herzegovina, Maglaj and Zavidovići.

WE ARE STRONGER TOGETHER

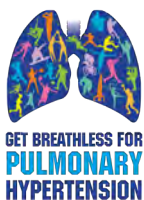
In addition to all the listed live events, the online campaign also started spontaneously. Followers of the pages of our Association on social networks sent their messages and photos in support of patients with pulmonary hypertension from all over the world. More than a hundred messages were received from Bosnia and Herzegovina, Germany, Austria, Sweden, Denmark, Croatia, the Netherlands, France, Italy, Switzerland, Slovenia, USA, Finland, Spain, Norway, Turkey and the UAE (United Arab Emirates) for what we are especially proud.

Finally, we must point out that we are immensely happy at the enormous support we felt this year during the celebration of WPHD 2022, because it is proof to us that we are doing a good job. It is especially important to us that we have been supported by many other associations and organizations in Bosnia and Herzegovina that bring together people with disabilities and other disadvantaged patients.

Where we still need support and cooperation are the institutions of the system in our country that deal with health, in order to provide a cure for all PH patients in Bosnia and Herzegovina, and thus a better position of our members. We are on the right track and it goes slow and steady. We are persistent and patient enough to believe that together we are stronger and that the problem of treating PH patients in our country will be solved systematically.

*Vera Hodzic, President
Association of Citizens Suffering from Pulmonary
Hypertension „Dah” - in Bosnia and Herzegovina*





WPHD 2022 - BULGARIA BSPPH

FOR THE 10TH TIME, WE MARK THE WORLD PULMONARY HYPERTENSION DAY WITH A CAMPAIGN "GET BREATHLESS FOR PH"

On the 5th May, we mark the world day of "the blue lip disease". In Bulgaria, the rare disease affects nearly 500 Bulgarians. One of the key symptoms of this rare disease is difficult breathing even when doing the most ordinary daily tasks; in addition the bluing of the lips and limbs is a symptom of the lack of oxygen in the human body.



On 5th May 2022, from 8:00 p.m. to 10:00 p.m., the building of the National Palace of Culture in Sofia will be lit up in blue for the seventh year, as a sign of empathy with the patients who struggle 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 Thursday, 5th May 2022, were illuminated: in Burgas - the Bridge in the Sea Garden; in Ruse - the building of the municipality, in Haskovo - the Bell Tower, near the monument "The Virgin Mary".

The towns of Blagoevgrad, Pleven and Stara Zagora supported the initiative by hanging on the building of the respective municipality a specially created for the World Pulmonary Hypertension Day "Flag of Support".

"Pulmonary hypertension can strike anyone. The invisible disease makes you dependent on the oxygen apparatus. You can't breathe and get tired at the slightest movement, you get swelling on your legs, arms, your lips

turn blue, you suffocate. 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 this rare disease, and about 500 Bulgarians suffer from different types of the disease. Patients are dependent on oxygen apparatuses and costly supportive therapy. Unfortunately, in a post-pandemic environment, many patients infected with COVID-19, often confuse the symptoms of the rare disease with that of post-Covid syndrome," 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.

PATIENT WEBINAR "CHALLENGES FOR PH PATIENTS IN THE POST COVID-19 ENVIRONMENT"



As part of the World Pulmonary Hypertension Day campaign, a patient webinar "Challenges for Pulmonary Hypertension Patients in a Post Covid-19 Environment" was held on 25.05.2022. 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, the state, should

provide them adequate treatment," the expert said. A lecturer of the event was the psychologist Dr. Antonia Grigorova, who told 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, how to communicate with their loved ones.

30 ENTHUSIASTS RACED DRAGON BOATS IN SUPPORT OF PH PATIENTS

Two teams with pulmonary hypertension patients, their friends and professional rowers raced in Pancharevsko Lake on the occasion of the World Pulmonary Hypertension Day. The race "Give a Breath for Pulmonary Hypertension" was organized by the Bulgarian Society of Pulmonary Hypertension Patients and was held near Pancharevo. The initiators relied on the professional support of professional rowers, and the teams were led and mentored by conditioning coach Stefan Terziyski, who has helped more than 700 people with their healthy lifestyle through his platform Bestefficient, as well as by professional rowers - national and Olympic rowing champions.

The race was amateur and was held with so-called "dragon boats". The only boats of their kind in Bulgaria are decorated with the heads of dragons adorned with

red ribbons, symbolizing joy, happiness and success. Each team included 15 participants, a steersman and a drummer who set the rhythm of the paddling.

"Thank you for giving of your time to donate your breath for those who cannot breathe and are dependent on their oxygen apparatuses. Sadly, despite a promising start to solving the lung transplant problem after the patient crisis years ago, the situation remains undeveloped. The training of our medics is at a standstill and the situation of patients suffering from pulmonary hypertension is worsening," Natalia Maeva, the chairperson of the Bulgarian Society of Pulmonary Hypertension Patients, told the participants of the sports event.

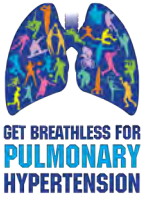
"Once again, we are coming together to pay attention to the problems of vulnerable pulmonary hypertension patients. It is sad that there are no developments in addressing the health challenges of those in need. I hope that with our initiative today, we will once again draw attention to the symptoms, the course of the disease and the outcome," added Stefan Terziyski, founder of Bestefficient and host of the sporting event.

Natalia Maeva, Bulgarian Society of Patients with Pulmonary Hypertension - BSPPH

www.bspph.net

www.facebook.com/BSPPH.Bulgaria?ref=h



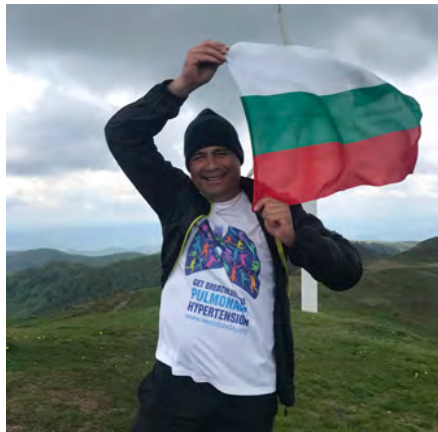


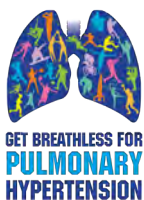
WPHD 2022 - BULGARIA PHA

For the World PH Day this year PHA Bulgaria organized and participated in a conference together with few other rare disease patient organizations. We were able to speak about the news and challenges for people with PH and other rare disease.

PH Bulgaria organized also patient meeting and mountain climbing. Until the end of the year we plan another event plus patient meetings.

Todor Mangarov, PHA Bulgaria
<http://www.phabulgaria.eu/>
www.facebook.com/aph.bulgaria





WPHD 2022 - CROATIA



The year 2022 is the tenth in a row that the World Pulmonary Hypertension day is celebrated all over the world, and in Croatia for the seventh year in a row, since the association "Blue Wings" was founded. Every year we implement projects to mark this important day. World Pulmonary Hypertension Day is May 5th.

Throughout May, we strive to raise awareness through various activities about this rare disease of the pulmonary circulation. In addition to the online campaign on their website, we participated in the 1st Sava Marathon (The race of the eight bridges) in Zagreb held on May 14. At dawn, at 6 am, the strongest runners gathered on the Sava embankment - they weren't sleepy, the adrenaline had lifted them out of bed and they had no problem running 42 kilometers. Many of the above are not from Zagreb; thus, the whole story is gaining weight because who knows when they got up to be at the start at 6 o'clock in the morning. About 60 runners took part in the marathon.

T-shirts with the inscription 'Get breathless for PH' sent a message because marathoners were left breathless during the race the way people with pulmonary hypertension stay with the slightest effort, even while at rest.

As an introduction, we organized the MZ Zener race in April to mark World Health Day, and for the third year in a row, this race is dedicated to pulmonary hypertension. In addition to informing about pulmonary hypertension, all participants had the opportunity to be educated about the importance of recreation and an active lifestyle, all surrounded by nature and fresh air.

Sports and running enthusiasts, recreationists, and all lovers of active lifestyles could participate alone, in pairs, or with families in the main cross-country race at eight kilometers, as well as in the citizens' race at two kilometers, but also in many children's races in the natural oasis, in the center of Zagreb.

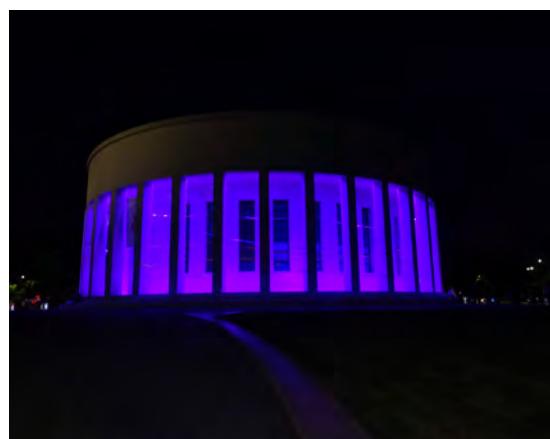
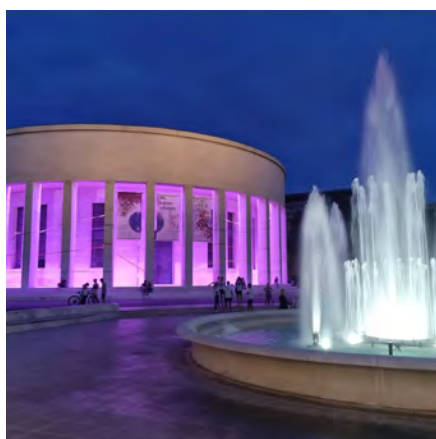
Bad weather did not discourage the people to spend Saturday morning in the fresh air and in many favorite sports activities. Children of all ages also ran their first races. Despite the bad weather, about 450 runners of all ages took part in the race.

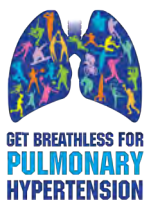
Among the runners was Mr. sc. Mira Pevec, MD, a doctor at the Jordanovac Clinic for Lung Diseases supports the work of the Blue Wings Association. Public awareness of pulmonary hypertension was also contributed by Prim. dr. sc. Ana Hećimović, MD, also from the Clinic for Lung Diseases Jordanovac, was available for all



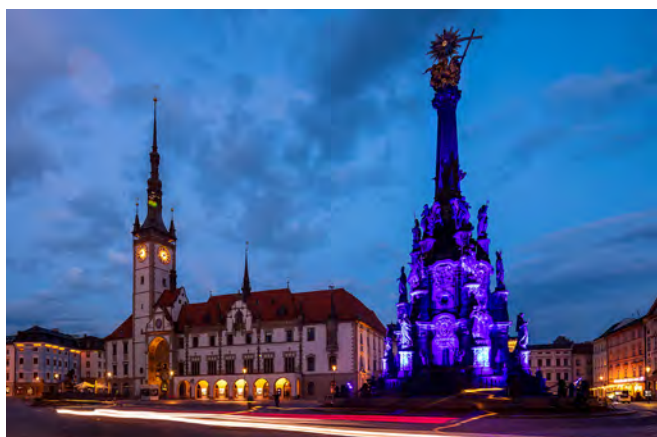
questions, advice, and information from journalists and interested citizens. As per usual we were supported by the “Croatian House of Breathing” Foundation, which was involved in the co-organization of MZ Zener. Our capital Zagreb joined the celebration of the jubilee tenth year of the WPHD by illuminating Meštrović’s pavilion in our colors, and in this way, they sent a message of support from the heart of Zagreb.

Katica Mavračić and Zdenka Bradač





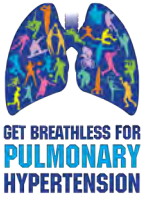
WPHD 2022 - CZECH REPUBLIC



This year the celebration of the World Day of Pulmonary Hypertension has turned back into a face-to-face campaign. On May 5, we supported the patients with a symbolic hike up 299 steps to the Petřín lookout tower in Prague. However, we were supported also by the Ministry of Health, the Dancing House Gallery in Prague, the Olomouc City Hall and the Janáček Theater, Omega Palace and the Goose on the string Theater in Brno on 5 May. On this day, monuments in Prague, Brno and Olomouc were illuminated in blue, which promoted awareness of pulmonary hypertension. Interviews also took place on radio and TV stations on this day, and over 50 articles on pulmonary hypertension were written in newspapers and magazines throughout the Czech Republic.

Milena Kaftanová

Sdružení pacientů s Plicní Hypertenzí www.plicni-hypertenze.cz



WPHD 2022 - FINLAND

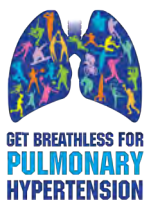
We celebrate WPHD on hybrid exercise lesson in Finland. Physiotherapy student had planned a body care class to PH patients. It was allowed to attend on the premises or online. We supported PH patients took with their close ones. In the event were 2 participates on the spot and 5 online. The lesson included muscle fitness exercises and a relaxation exercise. The feedback received from the session was

positive for example it encouraged herself to move more. Participates who were on the premises got drinking bottles with WPHD logo.

Also we have a social media campaign which we support people try to breath and move with nose clip and tie a cloth. We don't know how much tested it because anybody didn't share photo/video about it.

Tanja Sointu





WPHD 2022 - HUNGARY



This year at the WPHD we have not celebrated solely the 10th anniversary of the WPHD, but it was also the celebration of our 10th National Patient Meeting that we had to postpone for several years.

It was bittersweet to look back at the WPHD event pictures of the last 10 years, as many fellow patients are unfortunately not with us anymore, but at the same time the memories put a smile on our face, we remembered how much we enjoyed those moments.

Even though the COVID restrictions were released thus there was no obstacle to meet in person, the statistics were not entirely comforting, thus it was understandable that not everybody was willing to travel. Those who were there were greeted with great pleasure. But we were thinking about those who stayed at home with love.

We were able to listen to many useful presentations from our PH specialists. Among others about the future of the treatments, how to live with the pump, we





received good advice about exercising and a summary of the World PH Days and the APHEC.

This time, too, we couldn't miss out on making our participants to stand up and do some gymnastics with the leadership of our physiotherapist.

The presentations were recorded and were uploaded very quickly to YouTube, so everybody can watch them. Thus those fellow patients who were unable to attend would not miss out on useful information either.

To make this jubilee WPHD even more special we have joined those countries, where on the 5th May iconic buildings are lit up in blue. The cultural palace of Budapest, MŰPA has agreed as our cooperating partner that their palace will shine in blue. The team of our association was distributing flyers in front of the building to raise awareness of the pulmonary hypertension and our association.



Our sport ambassadors with bicycle were also active in the South-Hungarian region. They drew attention with their colorful T-shirts to themselves and this rare disease.



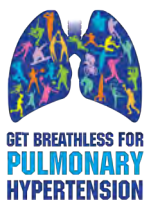
The fruits of our labor are beginning to ripen. The patients arriving to the PH Centers are in less advanced status compared to the past. Also, we get a lot of inquiries on the hotline, where potential patients report their symptoms and with our assistance after the appropriate test results those are received at the PH Centers where the suspicion is strong.

*Eszter Csabuda
Tüdőér Egylet*

www.tudoer.hu

<https://www.facebook.com/pages/Tüdőér-Egylet/151123348280359>





WPHD 2022 - ISRAEL



This year PH Israel was fortunate in partnering with sports celebrity Miki Hayat - Europe's Capoeira champion, 3rd place in the world and the largest capoeira school in the country for 3 public World PH Day events. We chose to focus on reaching a wide but targeted audience and ensure that as many people as possible were engaged, asking questions and finding out more about PH. Whilst working with the theme of sport and "Getting breathless for PH" we combined capoeira which we felt was a great match. The fundamental principles taught in capoeira include a corporal dialogue, the body's intelligence, the ability to react, balance, as well as the notions of space, time, rhythm, music and an understanding of the philosophy of the sport. Patients living with a rare disease such as PH can also be viewed in terms of the balance and dialogue in their lives. The balance of the mind, body and soul - striving to balance a fulfilling life with as little as possible limitation and a responsible approach to one's self care.

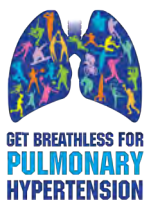
PH Israel co sponsored and promoted 3 events which were held around the country in 3 main cities. The first event was on the top of the Azrieli building - one of the tallest buildings in Tel Aviv, with over 300 visitors who attended. The second event took place in Jerusalem at a large sports stadium in the city and the third in Bnei Brak at the city center for martial arts. Overall we estimate around 1000 focused audience. At each performance, PH Israel CEO, Aryeh Copperman was

given the platform to speak and educate the audience about Pulmonary Hypertension. Highlighting to all present the symptoms, the effects on patients carers and details of how to ensure early diagnosis.

Following these introductions, the audience was afforded a wonderful performance of Capoeira students from around the country, sharing their art form. The boys all wore branded t-shirts with the PH Logo and blue gloves to further highlight the symptoms for people to remember. At each event our booth was manned and enabled all present to come take educational material, ask questions and simply show support! The participants then assisted in handing out flyers and each family went home with some more information to share with their loved ones.

"Celebrity" and Public figures who were present and assisted in creating more attention for PH where Miki Hayat - Europe's Capoeira champion, 3rd place in the world, the Brazilian Ambassador to Israel, Gerson Menandro Garcia de Freitas and Member of Parliament, Simon Davidson (Culture and Sport ministry).

Maayan Steele
Pulmonary Hypertension Association Israel
www.phisrael.org.il
<http://on.fb.me/1bPDL5v>



WPHD 2022 - ITALY AIPI



"LIFE IN A BREATH" CAMPAIGN

On May 5 on the occasion of World Pulmonary Hypertension Day, AIPI ODV took part in a press conference held in Milan at 11:00 am in the beautiful setting of Palazzo Bovara.

Joining us at this event were: *Emanuele Monti* (President of the III Health Commission at the Regional Council of Lombardy), *Carolina Kostner* (Olympic ice skating champion) in connection from Canada, *Prof. Nazzareno Galié* (Full Professor of Cardiology - Director Complex Unit of Cardiology, IRCCS-Policlinico di Sant'Orsola, Bologna), *Dott. sa Laura Scelsi* (Division of Cardiology, IRCCS Policlinico San Matteo Foundation, Pavia), *Dott. sa Nicoletta Del Papa* (Scleroderma Clinic, Dept. of Rheumatology, ASST Gaetano Pini - CTO, Milan), *Renata Zancanella* (Lombardy Referent Associazione Malati Ipertensione polmonare - AMIP), *Giovanna Campioni* (National Head of the Italian Association of Congenital Heart Disease Children and Adults - AICCA), *Ilaria Galetti* (Vice President Gruppo Italiano per la Lotta alla Sclerodermia - GILS) and *Loretta Mameli* (Patient Advocacy Lead Janssen Italia).

When talking about Pulmonary Hypertension (PH), it is always good to remember that we are talking about a rare and little-known disease that affects the heart

and lungs, which is difficult to recognize and therefore to diagnose.

With the aim of increasing knowledge, not only scientific, about Pulmonary Hypertension the pharmaceutical company Janssen Italia (of the Johnson & Johnson group), in collaboration with Associazione Ipertensione Polmonare Italiana (AIPI), Associazione Malati Ipertensione Polmonare (AMIP), Associazione Italiana dei Cardiopatici Congeniti bambini e Adulti (AICCA) and Gruppo Italiano per la lotta alla sclerodermia (GILS) brought an important awareness campaign entitled "Life in a Breath" to Lombardy on World Pulmonary Hypertension Day. With all the participants of the event, we delved into the situation, looking at how the care and management of patients with pulmonary hypertension takes place from the point of view of clinicians, patients and the Region.

Prof. Nazzareno Galié said: "The management of the patient with IAP begins with the correct diagnosis and extends to the most complex therapeutic resources. This process requires trained healthcare personnel and specific centers with all the necessary resources. The health care system should play a central role in fostering the development of these facilities, which are the only ones that guarantee correct and timely



diagnosis and appropriate therapeutic strategies. The concentration of many patients in a few expert centers is the only solution to improve the management and clinical research of rare diseases such as pulmonary arterial hypertension."

"The problem with IAP is that we are talking about a disease that is little known not only by the public, but also by physicians. The fact that it does not present specific symptoms, often leads to underestimating the alarm bells that present themselves in the form of exhaustion, breathlessness and fainting with significant delays in diagnosis." These are the words of Dr. Laura Scelsi, who explained that: "Without proper treatment, pulmonary arterial hypertension can culminate in heart failure and, as an extreme consequence, in the premature death of the patient. Better prognosis and early diagnosis go hand in hand. For this very reason, it is important to inform and raise awareness particularly in at-risk populations."

Also of the same opinion is Dr. Nicoletta Del Papa, who says: „The great challenge of pulmonary arterial hypertension lies precisely in the construction of more organized and standardized care pathways at the interdisciplinary level, with the involvement of professionals who intervene in the various stages of the pathway, which is clearly achievable only through early diagnosis. It is precisely the professionals who need to be involved in the exchange of experiences and realities: only in this way will we be able to find more and more innovative solutions to serve physicians, patients and caregivers."

Carolina Kostner spoke live from Canada (it was 5 o'clock at her place) to express how "honored she was

to continue to be part of this initiative," recounting that she "started this journey in 2020 to help bring everyone's attention to little-known diseases such as pulmonary arterial hypertension. To renew this commitment for me is to emphasize the ongoing need to address issues and needs that are not talked about enough."

"Pulmonary arterial hypertension is a rare disease that is still poorly understood," I said during my speech, emphasizing that: "Many patients come to a center with the specific expertise only when the disease is already in an advanced stage. The goals of AIPI and this awareness campaign aim to promote early diagnosis with timely and appropriate patient intervention. Since the campaign started, we as an association have witnessed an increase in inquiries and this gives us hope. We are also convinced that our experience as an association, can contribute to the opening of a new regulatory scenario that allows the relevant agencies to understand the real needs of pulmonary arterial hypertension patients."

"Pulmonary arterial hypertension is, yes, a rare and little-known disease, but unfortunately, it often does not occur on its own. In fact, it can present as a serious complication of systemic sclerosis." Explained Ilaria Galetti, GILS vice president. "To combat this complication, which, let's remember, affects 7 percent of all cases of systemic sclerosis, it is essential to obtain an early diagnosis and to refer to a center experienced in the management of pulmonary hypertension where professionals collaborate with a multidisciplinary approach in the management of each case in order to establish a personalized therapeutic approach early on."

"Pulmonary arterial hypertension should not be

considered a disease in itself. In fact, this rare disease can also be a problem for all those who suffer from congenital heart disease." Adds Giovanna Campioni, AICCA National Head who tells us that : "Currently, the diagnosis of congenital heart disease is made before childbirth, thus paving the way for different options to prevent the onset of pulmonary arterial hypertension, before it is too late. It is important to be aware of the correlation between these diseases so that more appropriate and targeted decisions can be made. Information among the general public, combined with research and the development of individualized diagnostic plans, is therefore the most effective tool at our disposal."

At this point, training of medical personnel becomes essential, so as to create a network of virtuous centers and arrive at the definition of a homogeneous and common diagnostic pathway throughout the country. "It is important to create collaborations and campaigns like this to promote research and information, as well as to network among the various centers. And being able to work openly and concretely with partners in industry, such as Janssen, is crucial for us. In this sense, we hope that this event is only a first step and that it will give input to the Lombardy Region to come up with the issuance of a regional PDTA that is more adherent to the needs of the patient. It would be desirable if the PDTAs of the different regions had assimilable characteristics, and even better would be to promote the birth of a national PDTA to have homogeneity of treatment throughout Italy." Says Renata

Zancanella, AMIP Lombardy Referent.

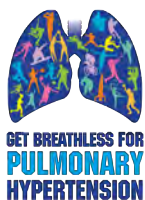
"Janssen Italia is in the forefront to search for innovative therapeutic solutions that can meet the treatment needs of people with a rare disease, such as pulmonary arterial hypertension, and to raise awareness of this disease and the importance of recognizing it early." So Loretta Mameli, Patient Advocacy Lead Janssen Italia who adds: "Our goal is to improve the quality and life expectancy of patients, making the disease increasingly manageable."

This Campaign project, which started in December 2020, concluded its first phase on World Pulmonary Hypertension Day on May 5, 2021. This year the journey restarted in Lazio on World Rare Disease Day on Feb. 28 and touched Sicily, Veneto, Piedmont to have its final stage in Lombardy. The Campaign was enhanced through a multichannel planning involving print, web and of course social media components together.

The event closed with the institutional greetings of Emanuele Monti, who made himself available for dialogue to create specific pathways and a series of interventions that look to the future, trying to understand how to concentrate everyone's forces to improve the pathways of diagnosis and access to treatment for people with Pulmonary Hypertension, unifying as much as possible, on a national level, a pathway that seems to be uneven in the various regions of Italy.

Leonardo Radicchi





WPHD 2022 - ITALY AMIP



Hi everyone! How are you?

After years of closure, of seeing each other on the web, now we are finally coming out of this nightmare, even if we can only think of our Ukrainian brothers.

We wanted to celebrate World Pulmonary Hypertension Day this year by organizing a solidarity concert. A jazz and pop concert at which artist of international caliber played. The event took place in Rome, at the Ghione theater, near San Peter, on 4 May (unfortunately the only useful this date for the theater).

We have embraced music as a vehicle to raise awareness of pulmonary hypertension. We are sure that this way we can reach many people.

At the concert we asked for the participation of some Ukrainian patients who are now in Italy, Olga and Dr. Irina, who live near Milan, came.

The hall, even though it was on a Wednesday, was almost full (it seats 300, but there were 200 people present). Think about it, a school in Rome asked to be

allowed to participate, taking Ukrainian citizens they welcome in this sad moment with them. We are sure we gave everyone two hours of light-heartedness and this is a goal that repays us for the great efforts we made to organize the event. Furthermore, we have embraced a great bond with the Ukrainian patients who are now in Italy, reported to us by PHURDA; these patients are followed by the various centers located on the Italian territory.

The solidarity concert was filmed by more than 20 newspapers, it had a large following on social media (Facebook, Twitter, Instagram)...in short, we can say without a doubt that we have reached more than 12,000 people.

But our commitment to raise awareness of the disease also has "sport" as a driving factor. This is because we took part in the Tagliacozzo (Aquila) marathon (1 May), which was attended by Romano Dessì, senator of the Rome marathon. What emotion!

In April we renewed our corporate offices because they





had expired. Now the president is *Vittorio Vivenzio* (Rome), vice president *Tina Lodato* (Naples), but there are five advisers: *Laura Gagliardini* (Rome), *Maria Pia Proia* (founder of AMIP – Rome), *Renata Zancanella* (Milan), *Luisa Grispu* (Sardinia) and *Antonella Albanese* (Sicily). As you can see, we embrace all of Italy and we are sure that the network road throughout the territory is the right one to allow us to give our best to the patients (early diagnosis, care near the home).

In the recent months we have been present at numerous web meetings with the institutions. One of the main requests we made was to send medicines to Ukraine for patients who cannot come to Italy or other country. We can say that we have been listened to and have had contact with all government organizations dealing with this aspect.

Furthermore, the institutions have listened to us regarding the request that the Ukrainian patients who

have arrived in Italy be treated in the best possible way and like all Italian patients.

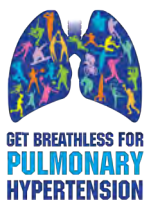
This World Day of Pulmonary Hypertension tasted different from others. Covid, the war, the fear of seeing each other in person have influenced our initiatives that still continue unabated...in short, we start again “de visus” and the results are starting to show (new organization meeting doctor/patients in some centers, invitations to conferences including other pathologies similar, invitation to decision-making tables).

All this has been possible and is possible because the AMIP team involves all the members and each in his own small way and in his ability brings added value, because TOGETHER IT'S POSSIBLE!

And now „coffee break” ...

Vittorio





WPHD 2022 - NORTH MACEDONIA

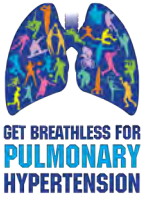


In May, we held more events for the celebration of 5th of May, World Pulmonary Hypertension Day and for raising the awareness and therapy for the PH patients. We had Concert in Dojran from the young music band "3ta Doza". Also we had more than 100 mountain climbers from all over Macedonia who climbed mountains with the motto: "Climb it and breathe for PH" in an organisation from Zelen Raj Veles. There were also runners who ran in several marathons for PH. Support for the children with PH we also had from our young national team tennis player Aleksandar Grujic.

Ratko Kjaev - APH Macedonia „Moment plus”

<http://www.phmomentplus.com.mk/>





WPHD 2022 - NORWAY

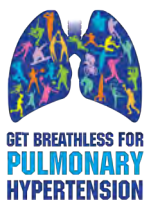
A great team of us, Sølvi Molnes, Marit Nydal Nicholson and Ann-Kathrin Bruheim represented PHA Norway in the World PH Day event this year. We had the arrangement with a stand at the Heart and Lung Hospital at Gardermoen on the 4th of May. This due to other prior engagements in our group on the 5th. We had a stand in the reception area of the

hospital where both staff and patients would pass is during the day.

There was a lot of interest and we gave out our printed information leaflets to many people. We had long talks with both patients and staff.

Ann-Kathrin Bruheim





WPHD 2022 - PORTUGAL



The first World PH Day (WPHD) event was a Conference Meeting, held in Hospital Garcia de Orta, a PH Reference Center located in Lisbon. The sessions were all led by specialists from this PH center and moderated by Teresa Carvalho, project manager and responsible for patient support at the Portuguese Association for PH.

The first session was about the balloon pulmonary angioplasty and implantation of a subcutaneous pump for administration of Treprostinil in patients with PH. The speaker was *Dr Filipa Ferreira*, cardiologist and coordinator of the PH Unit. *Dr Filipa* also addressed investigational treatments that are currently under clinical trials, a session that was predicted to be led by another PH specialist who could not attend the event.

The following session was taken over by *Dr Sofia Bento*, a specialist in Cardiac Rehabilitation in patients with PH.

Nutrition was the last session before the Coffee Break. The

speaker was *Dr Débora Repolho*, cardiopneumologist at the PH Unit of that PH Center.

At the end of these sessions, a lot of questions were made by all participants. The audience was composed not only of patients, but also of their relatives and friends.

After the coffee break, it was time for a round table discussion that was a meaningful highlight of the Conference. Attendees loved this session because everyone had the chance to participate in the conversation, share their stories, thoughts and fears.

The second part of WPHD took place in Leiria – elected European City of Sport in 2022 – on the May 28. Despite the hot weather, patients, family and friends "put on their shirt" and got breathless for PH in an event that was attended by almost 200 people. The day started with a climb to the famous



Castle. For some people was a moment of conquering, for others it became a moment of sharing stories and emotions.

After this cultural moment, the participants gathered at Leiria Stadium and joined more than 150 athletes from one of the biggest athletics clubs in Portugal, for a 100-meter sprint race. This event, sponsored by two famous former athletes – *Mónica Rosa* and *Susana Feitor* – was the highlight of a day filled with color, smiles and hope.

Speaking of which... the event also had the presence of the new mascot of the Portuguese Pulmonary Hypertension Association (APHP), the "Hopey" zebra, who delighted kids and adults with its good mood without ever fading or letting down by fatigue.

The energies were soon restored in a delicious picnic at a park nearby, with lots of chatting and traditional



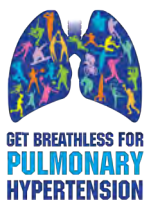
games for the younger ones.

At night, at the Theater, one of the most famous Portuguese actresses – *Marina Mota* – and her cast, wore our colors.

Captive flights in hot air balloons were planned, however the weather conditions did not allow this activity to be carried out. Despite this unexpected situation, the event was a success and fulfilled its mission: raise awareness for PH, awake mentalities and promote the (re)union of patients after two years of isolation.

Teresa Carvalho
project manager and responsible for patient support
at PH Portugal





WPHD 2022 - SERBIA

Back in February while we were still preparing for our upcoming events, Day of Rare diseases and WPHD, with the help of generous sponsors PH Serbia participated in the press conference about PH together with Serbia's most eminent experts in the field of Pulmonary hypertension, Danijela Pesic, gave her testimony from the point of view of a patient and she explained what difficulties are still present for each patient living with this disease, even despite the available therapeutically options. In Serbia, there are 12 medications in total, and with them, we can reduce mortality by some 43 percent. We were discussing the challenges that PH patients had to face during the COVID19 pandemics and how patient associations can be of great help in those challenging situations. Our president stressed the importance of lung transplantation and the broader more encompassing approach to treating this very progressive disease.

PH Serbia had a great honor and privilege to celebrate WPHD 2022 and to mark this very special 10th anniversary of WPHD at the new University Clinical Centre of Serbia. It was a great coincidence that we were there at the opening of a new department for pulmonary hypertension with state-of-the-art equipment and to celebrate the 10th anniversary of WPHD at the same time. There is no greater present for all the PH patients here in Serbia than to have a facility with modern equipment and a place where they can keep their condition under control. Moments like that can only reignite the hope of a final cure for PH. Our association together with our doctors had one more reason to be happy during this year's WPHD. The whole event was streamed on our National television (RTS) in a primetime and Danijela Pešić, President of PH Serbia tried her best to explain the importance of this new facility and to raise awareness





of PH among the general audience, her host even used the straw and the nose clip to demonstrate what kind of difficulties PH patients face every day.

Great support came from our honorary ambassadors too, celebrated European actor Goran Bogdan recorded a video of support not only for PH Serbia's patients but for all the PH patients in the Balkan region, our initiative to involve persons like Goran Bogdan will certainly have a strong impact as we plan to prepare several movies with him with the single aim of raising of awareness of PH and other rare respiratory conditions. Our second honorary ambassador Jovica Spajić is preparing for one of the most important races this year in the USA, it will take place in August.

Together with official part of marking this year's 10th WPHD, our Inspired by HOPE racers and the most prominent representative of PH Serbia, proved once again that they have big hearts and that they are always willing to get breathless for those that live every day gasping for air. At the Belgrade marathon, the most famous manifestation of that type in our country, they were proudly wearing our shirts well aware of our lung symbol. We prepared a small surprise for them at the 35th kilometre of the marathon. PH Serbia's booth with drinks and food was visited by some 70 racers from across the globe, they were all asking about pulmonary hypertension. We gave our best to provide them with some illustrative answers – PH is everything that you are experiencing right now, but PH patients are running their marathons and are experiencing tiredness without a break, for the rest of their lives.

We are sure that we have left a strong impact on all participants.

Just shortly after the marking of WPHD 2022 – we continued our new campaign under the title „Zajedno za PH“ – „Together for PH“ and prepared our booth and materials during the three day convention of pulmonologist in Serbia, the event hosted several hundred doctors and experts from the country and abroad. The magnitude of the event left us in shock, but we managed to bring enough materials, leaflets, shirts to present everyone with PH and with patient's perspective.

Then came June the 3rd and Patient association PH Serbia had a tremendous honor to be one of the honorary guests of a very significant event – Marking the first Century of Serbian pulmonology. The ceremony of celebration of 100 years of clinics took place in a hall room

of a National Theatre. The organization of the whole event was supported by the Ministry of Health and the state of Serbia. We had that honor to sit among the giants of today's medicine in Serbia. Together with marking this very significant date, pulmonologists of Serbia voted for individuals and institutions who made a contribution to the advancement of modern pulmonology in our country and the region. Among the awarded academics, associates, colleagues, and institutions, we heard our name, and received a special thanks on behalf of our association PH Serbia for a contribution to the advancements in Serbian pulmonology. This recognition was unexpected and we are a bit taken back, proud and silent. We are certainly very grateful to everyone who recognized our work and especially to all the pomological society in Serbia, as we are breathing because of them and their expertise. Thank you on the behalf of all PH fighters! Thank you for placing your confidence in us.

PH Serbia was at the session dedicated to rare respiratory diseases organized as part of The one Century of Serbian pulmonology conference, doctors from Serbia and the region had an ideal chance to talk about the news in the field of treating PH and to share the knowledge that they have gained. A lot was told about better diagnostics and the importance of early screenings when there is doubt of PH. We could hear a lot about PH and PAH in children patients and how treating options are getting even better with this group of patients. One session was dedicated to lung transplantation. With many challenges in that particular sphere, we will have to work harder than

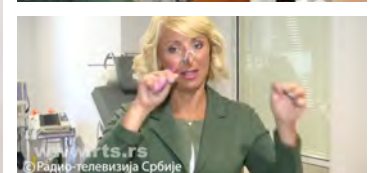
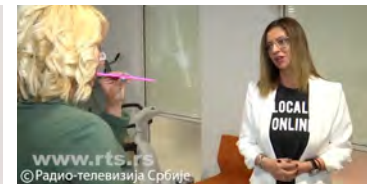
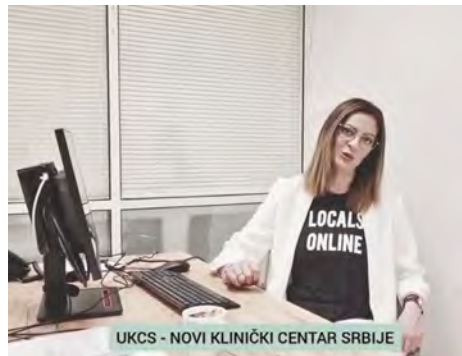


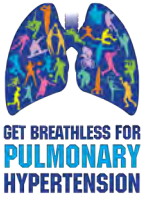
ever to make that possible in Serbia. Lectures about PH and lung transplantation were given by our most eminent experts like: Prof. Arsen Ristić, Prof. dr Arsen Ristić, Prof. (UKSC), dr Ilija Andrijević (IPBV "Sremska Kamenica" Prof. dr Predrag Minić, Institut za majku i dete "Dr Vukan Čupić") Prof. dr Branislava Milenković (UKSC).

There are a lot of races and battles ahead of us, in that we are certain. What we have realized from all these years of experience is that raising awareness of PH provides strong results only if we continue with it each time with more energy and dedication. We will

continue in the same style with even more energy. Our new ideas are in the process of realization and we are more than ready to see them through. New shirts for our most loyal INSPIRED BY HOPE team are ready, and they will proudly wear them everywhere they go, representing all the patients and getting breathless for all of us. It's the first step that matters, and we are all (doctors, patient association and the state) joined in a mutual effort to make a big leap to the future where PH will remain in a distant past.

Danijela Pešić and Uroš Antonijević





WPHD 2022 - SLOVAKIA

After two years of covid, we started our project of climbing to the tops of the Slovak mountains again with the motto "I will climb for you". We have organized the sixth edition of this event. On the eve of the climbing, an information seminar on topic of PH was held, where we commemorated the 10th Anniversary of World PH Day, the latest PH treatment in Slovakia, but also successes in the lives of PH patients. The main lecturer was MD. Milan Luknár, cardiologist of National Institute for cardiovascular diseases and the largest PH center in Slovakia.

The event was attended by 65 people, of which 45 climbed Chmeľová mountain, the second highest peak in the White Carpathians. It took place on May 7 from the Hotel Vršatec. The goal was clear - to simulate

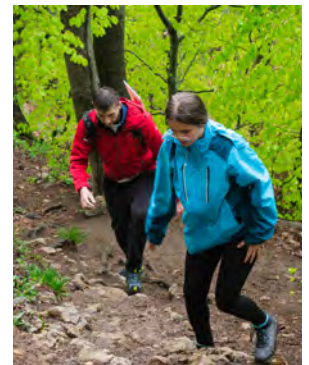
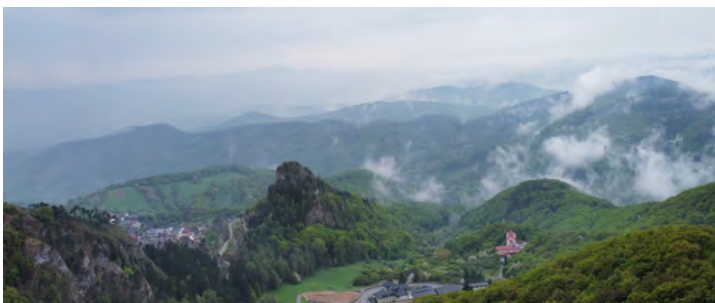
breathing of PH patient during normal daily activities. Hike attendees took 25 photos of patients to the top of the mountain. Climbing happened to be difficult due to rain, especially when descent. But no one complained. On the contrary, people returned from the climb in a good mood. The invitation was also accepted by the Slovak television staff from Banská Bystrica, which regularly supports us and has an irreplaceable place for us in spreading awareness of PH.

The story was broadcast in the TV show a rerun:

www.rtvs.sk/televizia/archiv/14048/328286#1171

We have documented the event in number of photographs and video film:

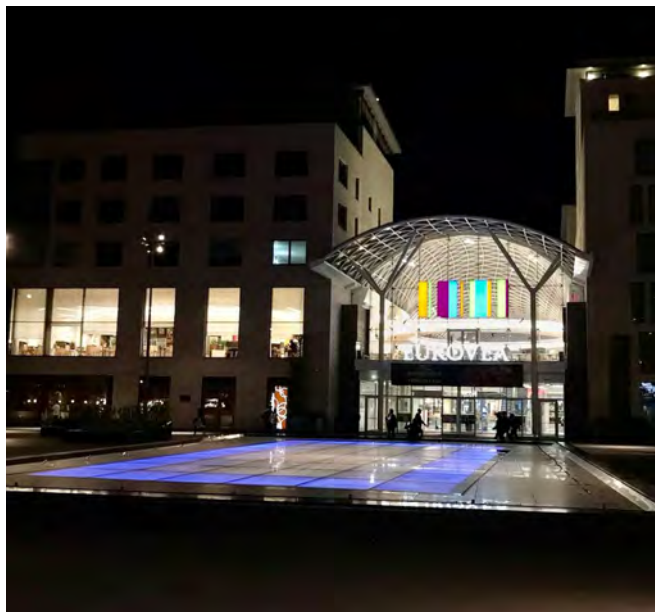
<https://www.youtube.com/watch?v=Kw0bUJ9TTmA>

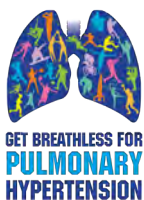


We have been running a social media campaign since mid-April. We have set up an electronic mailing service for health and lifestyle journalists (print, TV, radio), implemented it as a newsletter in the Mailchimp application. It contains all the information about World PH Day and upcoming activities, as well as about the disease itself.

Another accompanying activity was the lighting of important buildings in the capital city of Bratislava. Despite multiple requests, only two of them accepted. The illumination of the Presidential Palace and Shopping Center Eurovea with a fountain on M.R. Štefánik Square. On the 14th-15th of May, 16 members of our running team promoted our cause during the Vltava Run 2022 relay race in the length of more than 360 km from Šumava to Prague. The run took place for Slovak patients in the Czech Republic, because the spread of awareness of PH has no geographic limits.

Iveta Makovníková
Združenie pacientov s pľúcnou hypertenziou, o.z.
<http://phaslovakia.org/>





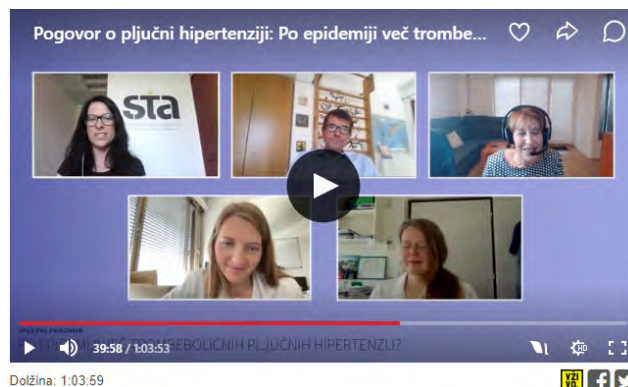
WPHD 2022 - SLOVENIA

We are pleased that the situation around the world regarding the epidemic has improved and we have been able to transfer our activities also live. So, May in Slovenia was active month. We had 4 projects - for PH patients and also for public awareness. For all of this we had a support also from Medis and MSD.

ONLINE WORKSHOP FOR OUR MEMBERS "HOW TO COPE WITH STRESS AND ILLNESS"

We have maintained the habit of hanging out with members at the Zoom meeting in a lecture on how emotions affect health.

On May 10, 2022, at 6 pm, we connected and learned how to get rid of stress, anxiety, how to turn negative emotions into positive ones and how can we make big changes with small changes in our daily lives. This workshop motivated participants to think what we can really do on our own to feel better, to motivate our self to think more positive and to except issue on which we do not have a power to change.



STA • SLOVENIAN NEWS AGENCY HELP US BEING HEARD

With a help of MSD we organised an online round table with the largest Slovenian news agency. Both leading doctors for pulmonary hypertension participated in the conversation: *dr. Salobir* and *dr. Mlakar* and two patients Iztok and Mojca, with thromboembolic pulmonary hypertension, as we wanted to highlight importance





of early diagnose and exposed the main symptoms. This topic was covid related, because expertise expects in the future a higher number of thromboembolic pulmonary hypertension patients, due to covid infections. Hopefully in the future CTEPH patients will be cured in Slovenia. Not in Vienna anymore, which is great news for Slovenian patients.

LIVE EVENT "GET BREATHLESS FOT PH"

On Saturday, May 21, 2022, we traditionally organized an event "Get breathless for pulmonary hypertension" in the natural resort Mostec. At the event, we introduced all visitors to non-specific symptoms, which may also indicate pulmonary hypertension. For several years now, one Saturday in May has been dedicated to this rare disease and the event is always fun, sporty, educational and full of emotions. Runners who ran in support of the patients wore T-shirts with recognizable lungs and were left breathless in support of us. In addition, many visitors with the customized 6-minute test actually felt what it is like to breathe with a patient's lungs and were visibly surprised.

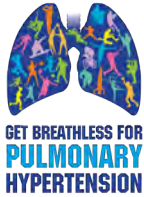
This year we were also joined by a representative of the organization Slovenia Transplant, who was able to answer questions to all event visitors about organ donation and opted for or against organ donation.

HOSTS IN NATIONAL TV TALK SHOW

Monday 30.5. at 9 am, as part of the World Pulmonary Hypertension Day, we were guests on the show Morning on Planet TV. Asist. dr. Polona Mlakar, a specialist in internal medicine, spoke about what pulmonary hypertension is, what its typical symptoms are and what family doctors should pay attention to. Our members Nina and Iztok also shared their experience with this disease. They expressed satisfaction with the therapy, they have been using it for several years. Only this enables them a better quality of life.

Tadeja Ravnik
Društvo Za Pljučno Hipertenzijo Slovenije
www.pljucna-hipertenzija.si





WPHD 2022 - SPAIN ANHP

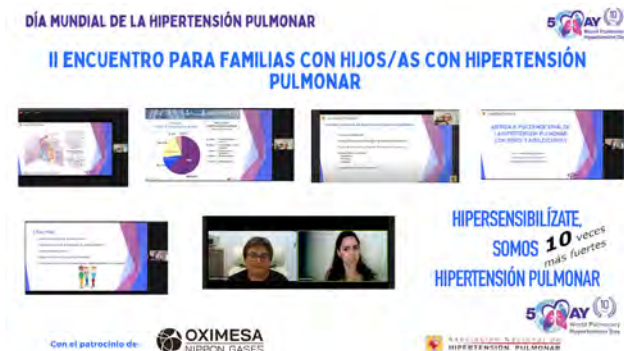
ACTIVITIES WE HAVE ORGANIZED FOR WORLD PULMONARY HYPERTENSION DAY

The activities that the National Association of Pulmonary Hypertension have organized within the Campaign for World Pulmonary Hypertension Day under the slogan "*Hypersensitize yourself, we are Pulmonary Hypertension. 10 times stronger*", have had the objective of raising awareness about pulmonary hypertension not only among people who suffer from it or their families, but also society in general.

- Cycle of Conferences "*Evolution of Pulmonary Hypertension in a decade*". Being in virtual format, we divided it into two sessions:
- May 9 "Research and advances in pulmonary hypertension". For the first session we have the collaboration of Dr. Pilar Escribano Subías, Cardiologist, specialist in Pulmonary Hypertension. Head of the Pulmonary Hypertension Multidisciplinary Unit of the Hospital 12 de Octubre (Madrid) and CIBERCV and Dr. Joan Albert Barberà, Head of the Research Group of the Hospital Clínic-IDIBAPS of Barcelona, Principal Investigator of the Pulmonary Hypertension Line of the Center for Biomedical Research Network of Respiratory Diseases (CIBERES). We also had Paqui Escobar, a pulmonary hypertension patient with experience in a clinical trial, who highlighted the control, care and safety of the patient by the trial doctors. To access the conference click on the following link: <https://www.youtube.com/watch?v=eScotHIIgM>
- May 25 "*Pulmonary Hypertension seen in a decade*." In this second session of the Cycle of Conferences we have the collaboration of Dr. María Lázaro, cardiologist specializing in pulmonary hypertension at the University Hospital of Toledo, and Anna Herranz, nurse and clinical case manager at the Pulmonary Hypertension Unit at Hospital del Mar. in Barcelona. As a patient of Pulmonary Hypertension, Karina Lozano intervened, who wanted to share her day to day with the disease. In this session we were able to see how the world of Pulmonary Hypertension has advanced when it comes to achieving an early diagnosis of the disease, for example, and how more and more nursing staff are present in pulmonary hypertension units as providers of care for people with pulmonary hypertension but also, for their families. <https://www.youtube.com/watch?v=yFnVOF3-bvc&t=13s>



- On May 5, different emblematic monuments of some towns and cities in Spain were illuminated in blue in support of World Pulmonary Hypertension Day.
 - Gandia City Council joined the World Day with our banner on the facade of the city hall and its subsequent lighting. In addition to the illumination of the façade, they illuminated: The house of the Marchioness.
 - One more year we have the collaboration of the Club Athletic de Bilbao that lit up the San Mamés Stadium.
 - Ávila, illuminated the Four Posts monument.
 - The Madrid City Council illuminated the Cibeles fountain.
 - The City of Arts and Sciences in Valencia lit up the City in blue.
 - Seville, illuminated the fountain in the Plaza de España and the fountain in the Plaza de Juan de Austria.
 - The Town Hall of the town of Lorquí (Murcia), illuminated its façade.
 - Mijas (Málaga) illuminated the façade of the Tenencia de la Cala
- On May 13, we organized the II Meeting of families with children with pulmonary hypertension. In it we were able to count on Dr. Antonio Moreno, a pulmonologist at the Vall d'Hebron Hospital in Barcelona, a State Reference Center for the care of children with pulmonary hypertension, to talk about the current situation in the approach to pulmonary hypertension in pediatric population. Jennifer Moreno-Jiménez, a psychologist from our



entity, also participated, who addressed a topic of concern for parents, how to treat the disease with children and especially in adolescence. As a representative of the patients, we had the pleasure of having Leticia Mozas, mother of a child with pulmonary hypertension diagnosed at birth, who spoke to us about what that moment was like and the importance of support groups for parents.

- On May 19, a workshop was held on Well-being and self-care: Working towards our values, given by Jennifer Moreno, the entity's psychologist. Where we talk about the importance of psychological flexibility, of accepting not only the good things that happen to us but also the bad ones, as our values help us establish goals and motivation.



- From May 27 to 29, we virtually organized the II Race "Deja tu huella por la Hipertensión Pulmonar (leave your footprint for the PH)" through the Rockthesport platform.

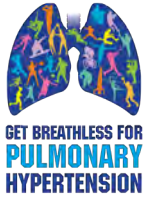
In addition, throughout the month we publish on our social networks about the disease and what it means to live with it.

ACTIVITIES IN WHICH WE HAVE JOINED FOR WORLD PH DAY

On May 5, we participated in the Webinar organized by PHA Europe, in commemoration of the 10th Anniversary of the first World Day. Irene Delgado spoke about the organization of the first World Day.

Eva García
Asociación Nacional de Hipertensión Pulmonar
www.hipertensionpulmonar.es
<http://www.facebook.com/hipertensionpulmonar>





WPHD 2022 - SPAIN FCHP

ILLUMINATION OF EMBLEMATIC BUILDINGS FOR PH

On 5 May, World Pulmonary Hypertension Day, the Pulmonary Hypertension Foundation, together with the local councils that joined the cause, carried out the illumination of the most representative buildings in several cities. The aim was to raise awareness of Pulmonary Hypertension by illuminating the most representative buildings in blue.

The colour blue is representative of Pulmonary Hypertension, due to the cyanosis, or bluish colour that those affected have due to lack of oxygenation.

Enrique Carazo, president of the Foundation against Pulmonary Hypertension, thanked all the city councils and communities that have supported this important day for us.

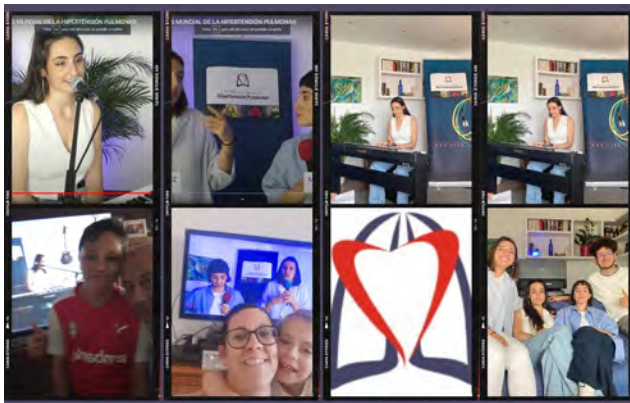


initiative that we are very happy about and that has been going on for months.

Finally, on such a special day, they have gone on sale, says Enrique Carazo, president of the Foundation against Pulmonary Hypertension. This line of personalised socks comes in two different models: sanitary and blue kisses/blue lips. They can be purchased through our website: www.fchp.es

The profits obtained from the sale of the socks will go to the RESEARCH of Pulmonary Hypertension. Specifically, to the two research projects of which the FCHP is an official collaborator: the EMPATHY PROJECT and the PASION HP GENETICS PROJECT, two national projects of which the Foundation has raised more than 420,000 euros.

This initiative has been created thanks to the agreement signed with the Blood Bros Socks socks brand, which has not hesitated to help us with this exciting project.



SOLIDARITY CONCERT FOR PULMONARY HYPERTENSION

On the occasion of World Pulmonary Hypertension Month, on 20 May at 16:30h the Foundation against Pulmonary Hypertension gave a micro concert online with a great artist and medical student involved in the cause, Elena Hidalgo and with an exceptional director Luis Roca /@rocaattheboss/, in order to give visibility to the disease and to raise funds with the solidarity ticket that you can buy by sending a BIZUM to 02276. The concert can be seen through our You Tube channel of the foundation against pulmonary hypertension.

SOCKS OF SOLIDARITY FOUNDATION AGAINST PULMONARY HYPERTENSION

On World Pulmonary Hypertension Day, we launched the foundation against pulmonary hypertension foundation solidarity socks. It is an



III MULTIDISCIPLINARY CONFERENCE ON PH

III Multidisciplinary Conference on Pulmonary Hypertension at the Dr. Negrín Hospital (Las Palmas de Gran Canaria). On 5 May, coinciding with World Pulmonary Hypertension Day, the 3rd Multidisciplinary Conference on Pulmonary Hypertension was held, in which the Pulmonary Hypertension Foundation participated by giving the voice of patients and organisations.

In the framework of this conference, several lectures and round tables will be held in which topics of interest related to pulmonary hypertension will be discussed.

We thank the organisers for their invitation and congratulate them on the success of the conference.



PARATRIATHLON WORLD CHAMPION

Paratriathlon World Champion takes Pulmonary Hypertension to the top of her career Andrea Miguélez, Paratriathlon World Champion in 2021 and recent European Paratriathlon Champion 2022, wanted to have the nice detail of running the European Championships in Poland, with the logo of the Foundation against Pulmonary Hypertension. It is a way to give visibility to the disease, and a good standard bearer for invisible diseases. We thank her for being our flag bearer for Pulmonary Hypertension.

SOLIDARITY SHOWER FOR PH

From time to time Paco Tutor, from Cantillana (Seville), gives us something to talk about. This time he has been seen in the streets of Seville on the occasion of the Europa League final between the fans of Eintracht and Rangers, with a portable shower with which he "wets himself" for all patients with pulmonary hypertension, especially for his 6 year old granddaughter Alexandra.

Sometimes they call him crazy, but for more than four years he has been taking advantage of the hot months



to be seen in crowded areas of Seville and other cities, or at large events such as the World Cup qualifying match at the Cartuja Stadium. "Mexican television did a live report on me", he tells Sevilla Solidaria. He has photos of artists, journalists and footballers getting wet with his shower. Grandpa Paco is an example of the fight for Pulmonary Hypertension, and we would like to thank him for his unceasing help in spreading awareness of the disease.





PH GOES TO SCHOOL

In the world month of Pulmonary Hypertension, we bring the disease to school. Because it is important for children to be aware of Pulmonary Hypertension. Thanks to the teachers and the management team of CEIP Rafael Altamira de Alicante to which little Laia belongs, to the families who have collaborated in it, and to the little ones who know a little more about their classmate with Hipertensión pulmonar.

ELECTRIC SCOOTER FOR PEOPLE

Electric scooter for people affected by Pulmonary Hypertension and other diseases with reduced mobility. At the Infanta Cristina University Hospital (Parla), the Foundation against Pulmonary Hypertension is collaborating in a project for people with reduced mobility. The idea is that anyone affected by Pulmonary Hypertension, or people with reduced mobility, can go to the hospital without needing help. With the electric scooter, they will be able to move around any area of the hospital independently. This is a pioneering project that will be taken to other hospitals in Spain.

INFORMATION TABLE AT THE HOSPITAL UNIVERSITARIO CLÍNIC DE BARCELONA

On such an important day as World Pulmonary Hypertension Day, we were located with an information table at the Hospital Universitario Clinic de Barcelona. The main task was to raise awareness of the importance of early diagnosis of Pulmonary Hypertension. It was a great success.

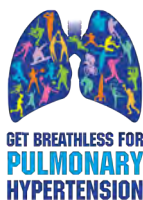


INFORMATION TABLE AT THE SALÓN DEL CÓMIC WITH STAR WARS CHARACTERS

During World Pulmonary Hypertension Month, we shared a weekend at the Barcelona Comic Fair, together with the Star Wars characters. If you stopped by the stand, you could get information about Pulmonary Hypertension, have your photo taken with the characters, and collaborate in the collection of funds for the cure of the disease. Thanks to each of the characters for having this important space.

Día Mundial





WPHD 2022 - SPAIN HPE

10TH ANNIVERSARY OF 5 MAY

Once again, at HPE-ORG we have carried out our own campaign, carrying out different activities throughout the month of May, celebrating such an important event as the 10th anniversary of World Pulmonary Hypertension Day (WPHDay). Joining together with PHA Europe and the entire PH community in the global #togetherstronger #PHMatters campaign that has taken place.

We have organised work commissions by regions, so that patients, families and friends could propose different activities that they could promote within their territorial area, thus involving their closest environment both at a personal and institutional level.

Together with the support of the association organising the activities, the result has been a success, both in terms of the organisation and participation of the activities and their dissemination.

Thanks to the union of all patients, families, institutions, volunteers and collaborators, it has been possible to have a wider and more participative impact, thanks also to the involvement of institutions such as: *Sant Feliu de Llobregat City Council with the support of the health councillor Loren Rider, Tarragona City Council, Guardo City Council, Churriana de la Vega City Council with the support of the Equality Councillor Luís Rodríguez, Lalín City Council, Les Tovallols Civic Centre, Victory Centre, Domus VI Residence, Los Xiquets de Tarragona, Viladecans Badminton Club, Estradense Football Club and Lalín Handball Club*

The activities that took place were a workshop on psychological and social health in a transversal way for greater impact of the disease "Health in your hands" in which Alicia Navarro, clinical psychologist expert in Mindfulness and coach of our entity invited us to reflect on various aspects of the concept of "health" in an interactive and participative workshop, proposing different topics concerning co-responsibility and self-care of our psycho-emotional health (what health means to us, post Covid-19 health, we are infocated and we are agents of change in our health); participation in the creation of a human castle called Castell; Pilates class, badminton training, football and handball match, and tai chi class. Two people from the organisation affected

by Pulmonary Hypertension were also interviewed; Lorea Ullibarriarana in the radio program *Mediodía de Cope Galicia* and Esther Cotano in the paper *Diari de Tarragona*.

On the 5th of May, the association also has organised the HAPNEEDS conference in the Autonomous Region of Castilla León at the SACYL in Valladolid, the aim of this working table was to identify and prioritise the needs and areas of improvement in the care received by patients with PH in the Autonomous Region.

HPE-ORG has joined the European initiative to light up public buildings, illuminating in blue the Sant Feliu de Llobregat City Hall Cathedral, the Miner's Fountain in Guardo (Palencia), the Origa Square and the Domus VI residence in Lalín (Pontevedra), the Valencia Conference Centre in Valencia, the Churriana de la Vega Cultural Centre in Churriana de la Vega (Granada) and the facade of the Tarragona City Hall, the Torre dels Vents and the Kesse Youth Building in Tarragona.



We have also joined Ferrer España with the PHantasticals awareness campaign, an initiative that seeks to raise public awareness of rare and chronic pathologies. With this World Pulmonary Hypertension Day campaign, we have achieved great growth in all our social networks. Our Facebook followers have increased by 1%, our Twitter followers by 3.26% and our Instagram followers by 5.34%. On LinkedIn followers have increase 11.11%.

In addition to the repercussion we have had on our own, we have managed to get other entities to echo our publications, sharing our content on Social Networks to support us and help us to give visibility to Pulmonary Hypertension.

To conclude, we are very satisfied with the results obtained and with the involvement of the people who have participated in the different cities, as once again this year we have managed, at the end of May, to make

more people aware of Pulmonary Hypertension, to raise awareness of the importance and seriousness of this pathology, as well as to make our organisation and the services we offer more visible.

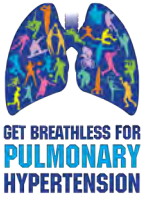
María Rodríguez, Hipertensión Pulmonar España

www.hipertension-pulmonar.com

www.facebook.com/pg/HPSpain.org







WPHD 2022 - SWEDEN

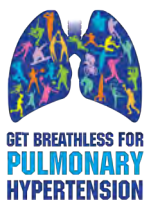
For the sixth consecutive year PAH Sweden was the center point of the round table discussions between healthcare providers, the pharmaceutical industry and politicians. The annual meeting has become an important arena to discuss and debate what measures are required to develop the PH care in Sweden. The meeting was held May 6 as a contribution to WPHD. Link to the event (in Swedish):

<https://pah-forum.se/om-ph-dagen/>

In June, PAH Sweden organized a camp for PH patients for the fourth time. The camp took place on Gotland as in the previous times, but this time the target group was those over 50 years old. In total we were 30 participants and we had 4 wonderful days together! The picture shows our visit to the spectacular rock formations in the island Fårö, north of Gotland.

Patrik Hassel



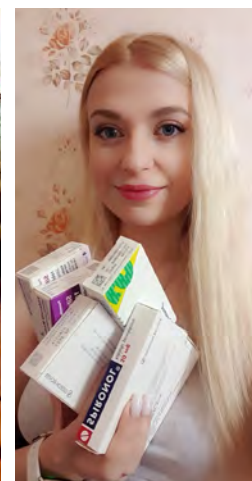
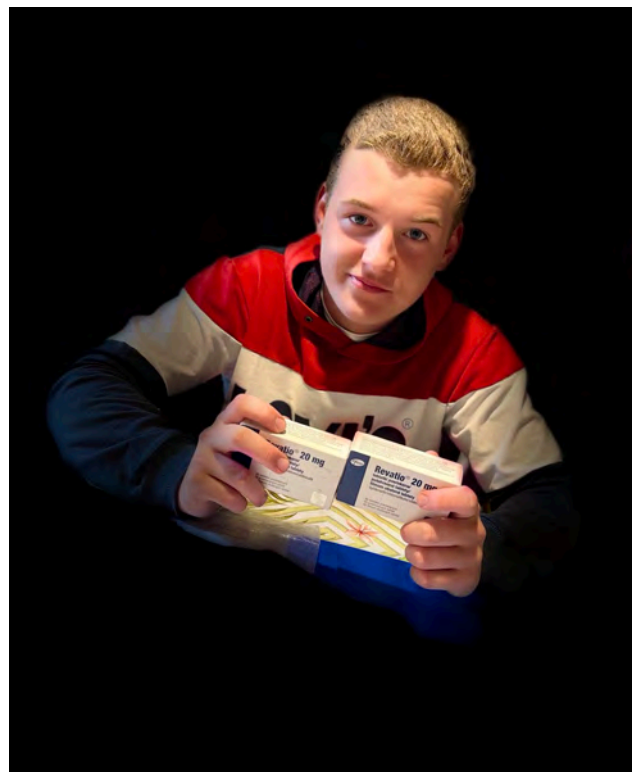


WPHD 2022 - UKRAINE PHA

The full-scale war in Ukraine in 2022 changed the whole ordinary life of Ukrainian patients with pulmonary hypertension. Many patients left their homes, up to 20% were forced to go abroad in search of shelter and treatment.

For those who stayed in Ukraine, it is important to continue the treatment they have started, to prevent the disease from progressing. Therefore, all the efforts of the Association of Patients with Pulmonary Hypertension in Ukraine this year were aimed at helping patients in this critical situation and providing them with medicines. By World Pulmonary Hypertension Day, more than 260 patients received medication and were able to continue treatment. Many European organizations helped us in this. It was Pulmonary Hypertension Day in action! Thanks everyone for the helping hand!

Oksana Aleksandrova
Ukraine Association of Patients with PH
www.pha.org.ua
info@pha.org.ua





WPHD 2022 - UKRAINE PHURDA

February 24, 2022

Became a starting point that changed the life of every inhabitant of Ukraine. The war came to Ukraine. Bombing, rocket fire, and Russian atrocities against the people of Ukraine occur daily. Thousands of destroyed houses and lives. This is something that it is impossible to remain silent about. And we can't help but write about it. Our peace and tranquility are fought for every day by the military, sacrificing the most precious thing - life. We thank them for their sacrifice!

Helping PH patients fleeing the war abroad and helping PH patients staying in Ukraine is what the PHURDA team, CF Sister Dalila, is working on every day.

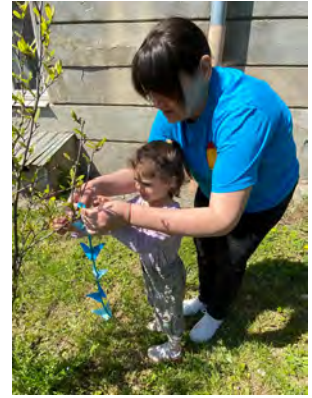


This year's World Pulmonary Hypertension Day was designed to bring together PH patients who found themselves abroad and those who remained in Ukraine to share useful information about opportunities for them.

On May 5 PHURDA CF "Sister Dalila" held an online meeting for patients with pulmonary hypertension (PH) on Zoom with the topic: *"Problems and opportunities for patients with pulmonary hypertension during the war in Ukraine"*.

The meeting was attended by 56 PH patients, including those who found themselves abroad and those who remained in Ukraine.





President of the Association of Pulmonary Hypertension of Italy - AMIP Vittorio Vivencio joined the meeting and made a welcoming speech for patients of PH in Ukraine, expressing words of support. Oksana Kulish Skaara spoke about the activities of PHURDA, CF "Sister Dalila", about helping patients during the war.

Cardiologist of the State Institution "NSC" "Strazhesko M.D. Institute of Cardiology" Iryna Zhyvylo shared her experience of being in Italy, told about the constant communication with PH patients in Ukraine and abroad. Informed about statistics on European countries: which European countries, how many patients were admitted. She also talked about the pros and cons of countries and what to be prepared for. They also talked about the possibility of renting accommodation to patients with rare diseases from the joint project Airbnb and Eurordis and the questionnaire of Eurordis patients.

Mykola Konyk, a cardiac surgeon at the Lviv Regional Clinical Hospital, spoke about the possibility of including PH patients in the register of the Lviv region and receiving medication under the state program. This is important because many patients have fled the war to western Ukraine to the Lviv region and need medication.

Roman Andres, Head of the Department of Social Protection of the Population of the Lviv Region, spoke about the importance of registering the status of an internally displaced person within Ukraine and on other social issues.

Lawyer of PHURDA, CF "Sister Dalila" Andrii Hulei spoke about the legal issues of border crossing for people with disabilities and accompanying persons, renewal of disability documents, passing the disability commission, the state of drug supply in Ukraine for the state budget.

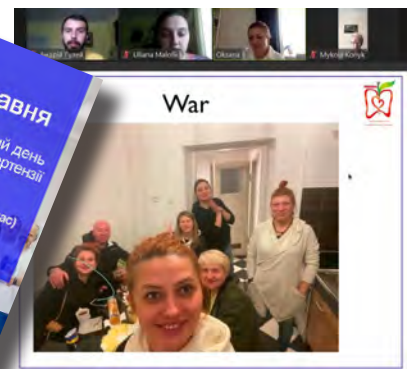
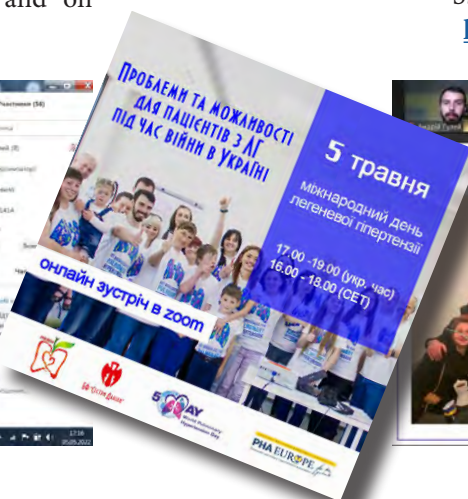
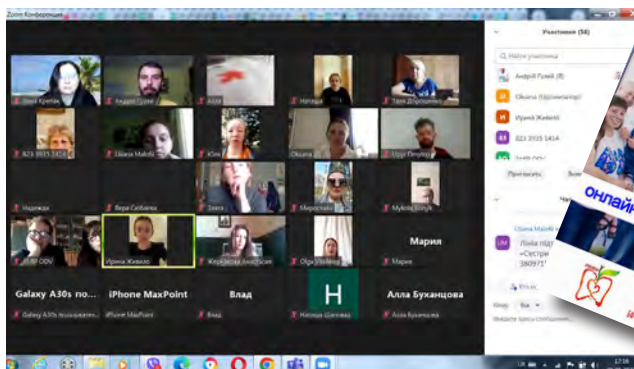
PH patients - Vasylchuk Svitlana, Oksana Yunak, Olena Sydorenko and everyone who wished to, talked about their own experience in Italy, Poland, Germany and Norway.

During the meeting, patients received useful contacts for legal and medical online consultations; information for internally displaced persons within Ukraine; on the rules of crossing the state border by citizens of Ukraine; about the possibilities of the Airbnb and Eurordis project to pay for housing for up to 30 days abroad. On May 5, Lviv educational institutions held a flash mob [#blue butterfly](#) on social networks to raise public awareness of the rare disease PH. Schools and kindergartens published words of support for PH patients on social networks, raising the voice of PH patients.

We truly thank PHA Europe for its friendly support of Ukraine during the war. This is very valuable and important for us!

Glory to Ukraine! Glory to our heroes!

Oksana Kulish
Sister Dalila-PHURDA-Ukraine
<http://poryatunok.info/uk/>



Media clippings AUSTRIA

Privat-Show von Ambros

Live. Am Dienstag startet **Wolfgang Ambros** in Linz seine Jubiläumstour (Karten zum Bestpreis auf ticket24.at). Als Warm-up spielte er am Wochenende in Würflach mehr als ein Geburtstagsständchen für Lungenhochdruck-Charity-Boss **Gerry Fischer**: zwei Stunden Privatkonzert



Mausi, Ambros, Fischer, Fendrich und Maleen.

mit allen Hits. Darüber jubelten auch **Mausi Lugner, Maleen Fischer, Harley Papst Ferdinand Fischer und Andrea Fendrich**. Zu **Rainhard** hat Ambros ja keinen Kontakt mehr.

Ambros ehrte große Kämpferin mit 2-Stunden-Privatkonzert

Als sie drei Jahre alt war, bekam sie die niederschmetternde Diagnose idiopathische pulmonalerarterielle Hypertonie. Lungenhochdruck. 700 Menschen in Österreich leiden daran. Die Ärzte gaben **Maleen Fischer** nur ein paar Jahre, aber sie und die Papa **Gerry Fischer** aus Wien-Medling gaben nie auf. Eine Reise, die sie bis nach New York führte, begann – und sie haben ein gutes Ende.

Heute ist **Maleen** 27 Jahre alt, führt ein erfülltes Leben, ist als Digitalmanagerin aktiv, hat ein Buch geschrieben: „Als ich die Diagnose bekam“. Ihr Papa engagiert sich in der „Initiative Lungenhochdruck“ und lud in Würflach (Steiermark) zur Fest mit 250 Gästen, **Wolfgang Ambros** (79) gab ein zweistündiges (!) Privatkonzert und alle sangen mit.



Gerry Fischer (Mitte), Tochter Maleen (R) und Maus Lugner, Ferdinand Fischer, Wolfgang Ambros, Andrea Fendrich

BOSNIA & HERZEGOVINA

Završen 21. međunarodni Krivaja rafting

22.05.2022. u 19:35



U Zavidovićima se danas završava 21. međunarodni Krivaja rafting. Idealno vrijeme ovog vikenda omogućilo je rafterima iz cijelog regiona nezapamćeni ugođaj. Sve je funkcionisalo besprijekorno, osim što je nivo rijeke Krivaje nizak, pa je ruta skraćena za oko šest kilometara do sad tradicionalne dužine.

Start je bio u Čuništu, a Dišćici. Nezaboravno i neobično se ovaj lijepoj bosanskohercegovačkoj prirodi.



Pored raftera svoju podršku oboljelima od ove bolesti ovom prilikom su dali i rekreativni planinari iz Zavidovića, tako da je ovogodišnji Krivaja rafting protekao osim u sportskom-rekreativnom raspoloženju, djelomično i u edukativnom duhu.



Start je bio u Čuništu, a Dišćici. Nezaboravno i neobično se ovaj lijepoj bosanskohercegovačkoj prirodi.



U Zavidovićima obilježen Svjetski dan plućne hipertenzije



HRONIKA: Zavidovići Vera Hodić PROSLAVLJENICA UDRUŽENJA OBOLJELIH OD PH "DAH" U BiH



Adnan Vilić OBOLJELI OD PLUĆNE HIPERTENZIJU



U Zavidovićima obilježen Svjetski dan plućne hipertenzije

DEŠAVANJA



Učeni Prve osnovne škole iz Zavidovića već tradicionalno obilježavaju Svjetski dan plućne hipertenzije zajedno sa članovima Udruga građana oboljelih od plućne hipertenzije "Dah" u Bosni i Hercegovini.



ZDICI.INFO

Zdici.info | Zavidovićanin Ismet Škulj na novoj PH turneji

Bosanskohercegovački biciklist rekreativac Ismet Škulj krenuo je jučer iz Zavidovića na put dug ...

https://www.zdici.info/zavidovicanin-ismet-skulj-na-novoj...

Организиран състезание с „драконови лодки“ в Панчаревското езеро в подкрепа на пациенти с пулмонална хипертензия



10.05.2022 11:14
Местно образно-физическо спортно училище
Мил, при съдействието

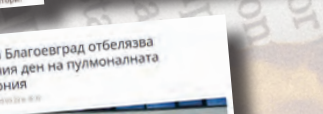
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10.05.2022 11:14
Местно образно-физическо спортно училище
Мил, при съдействието

Пациенти с пулмонална хипертензия ще премерят сили в състезание по гребане

Състезанието „Дари дъх за пулмонална хипертензия“ ще отбележи световния ден на заболяването 29 май



29 май 2022 г.
08:00 ч. | 10:00 ч.

Състезание с драконови лодки на Панчарево в подкрепа на пациенти с пулмонална хипертензия



Визуализация на състезание с драконови лодки на Панчарево в подкрепа на пациенти с пулмонална хипертензия

ИНТЕРЕСЪТ КЪМ ПУЛМОНАЛНАТА ХИПЕРТЕНЗИЯ СТИХА



Визуализация на интересът към пулмоналната хипертензия

Доц. Васил Велчев: Илюзия е, че ще имаме център за белодробни трансплантации

НЗОК запазва надеждата, макар на нивото от най-силните медицински кадри в състезанието у нас, продължаващо на пациентите обаче не се посвещава от страна на МЗ, подкрепата хипертензия



Община Благоевград отбелязва Световния ден на пулмоналната хипертензия



Община Благоевград се вписва в отбелязването на Световния ден на пулмоналната хипертензия, който се отбелязва на 5 май. В тази връзка общината организира състезание по гребане в местния басейн „Белица“.

Конкурент

Днес - световен ден на пулмонална хипертензия, сгради светват в синьо



Синя светлина в знак на съпричастност с болните от пулмонална хипертензия

Инициативата се провежда за 10-ти път у нас, тази година е под надслов „Дари дъх“



НДК ще свети в синьо в знак на съпричастност към „болестта на сините устни“

Публикувано на 05.05.2022 в 10:07

10-то юбилейно издание 5 май СВЕТОВЕН ДЕН НА ПУЛМОНАЛНАТА ХИПЕРТЕНЗИЯ



На 5 май отбелязваме световния ден на „болестта на сините устни“

Съобщено на 04.05.2022 в 15:04



Световният ден на пулмоналната хипертензия се отбелязва на 5 май. В тази връзка общината организира състезание по гребане в местния басейн „Белица“.



Световният ден на пулмоналната хипертензия се отбелязва на 5 май. В тази връзка общината организира състезание по гребане в местния басейн „Белица“.

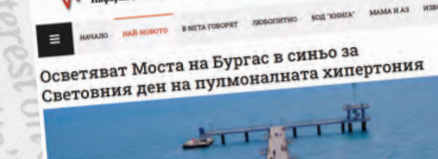


Световният ден на пулмоналната хипертензия се отбелязва на 5 май. В тази връзка общината организира състезание по гребане в местния басейн „Белица“.

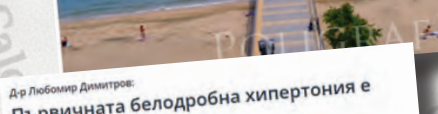


Световният ден на пулмоналната хипертензия се отбелязва на 5 май. В тази връзка общината организира състезание по гребане в местния басейн „Белица“.

Осветяват Моста на Бургас в синьо за Световния ден на пулмоналната хипертензия



Осветяват Моста на Бургас в синьо за Световния ден на пулмоналната хипертензия



Осветяват Моста на Бургас в синьо за Световния ден на пулмоналната хипертензия



Осветяват Моста на Бургас в синьо за Световния ден на пулмоналната хипертензия



Осветяват Моста на Бургас в синьо за Световния ден на пулмоналната хипертензия

За 10-ти път отбелязваме Световния ден на белодробната хипертензия с кампания „Дари Дъх“

Депубликувано на 05.05.2022



За 10-ти път отбелязваме Световния ден на белодробната хипертензия с кампания „Дари Дъх“



За 10-ти път отбелязваме Световния ден на белодробната хипертензия с кампания „Дари Дъх“



За 10-ти път отбелязваме Световния ден на белодробната хипертензия с кампания „Дари Дъх“

Осветяват Моста в Бургас в синьо за Световния ден на пулмоналната хипертензия

Осветяват Моста в Бургас в синьо за Световния ден на пулмоналната хипертензия



Осветяват Моста в Бургас в синьо за Световния ден на пулмоналната хипертензия



Осветяват Моста в Бургас в синьо за Световния ден на пулмоналната хипертензия



Осветяват Моста в Бургас в синьо за Световния ден на пулмоналната хипертензия

Синьо

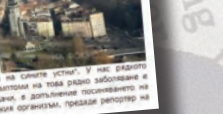
Синьо



Синьо



Синьо



Синьо



Синьо



Синьо

CROATIA



CZECH REPUBLIC



HUNGARY



Magyar Szervátültetettek Szövetsége is with Dóra Er and Tüdőér Egylet
May 8 at 7:05 PM · 43

Május 5. a Pulmonális Hypertonia (PH) Világnapja, melynek alkalmából tüdőtranszplantált társunk, Dóra küldött nekünk - részvevőként - beszámolót.

Világszerte több mint 25 millió ember érintett ebben a betegségben, hazánkban is több száza becsülhető a betegek száma.

A PH betegek egyesületeként a Tüdőér Egylet a PHA Europe szervezettel karöltve a PH Világnapján határokon átnyúló kampányt indított a közösségi médián keresztül, hogy felhívja a nyilvánosság figyelmét erre. ... See more



Tisztekecske Egészségfejlesztési Iroda
May 9 at 11:04 AM · 12

Május 5-e a Pulmonális Hypertonia (PH) Világnapja

Világszerte több mint 25 millió ember érintett ebben a betegségben. Hazánkban is több száza becsülhető a betegek száma.

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REHABORTALHU
Ma van a pulmonális hipertonia világnapja
A pulmonális hipertóniában (PH) szenvedő betegek egyesületeként a Tüdőér Egylet...

Ma van a pulmonális hypertonia világnapja



A pulmonális hipertóniában (PH) szenvedő betegek egyesületeként a Tüdőér Egylet a PHA Europe szervezettel karöltve a PH Világnapján határokon átnyúló kampányt indított a közösségi médián keresztül, hogy felhívja a nyilvánosság figyelmét erre a ritka betegségre. ... See more

Pulmonális hipertónia

A pulmonális hipertónia (PH) egy ritka, de súlyos szív- és tüdőbetegség, amely a tüdő erekben a normálisnál magasabb vérnyomást okoz. A betegség leggyakrabban a tüdő artériák szűküléséből ered, ami a tüdő és a szív közötti vérkeringést akadályozza. A betegség tünetei közé tartozik a légszomj, a fáradtság, a szívdobogás és a lábszékélyek duzzanata. A betegség kezelése általában gyógyszeres, de súlyosabb esetekben tüdőátültetésre lehet szükség.



TUDOMÁNY
Tüdőembólia után- felépülés és prevenció

A mélyvénás trombózis (MVT) utáni tüdőembólia (TE) a tüdő artériáiban a vértől elválasztott véralvadékok miatt alakul ki. A TE súlyos tüdőbetegség, amely a tüdő artériáinak elzáródásához vezet, ami a tüdő és a szív közötti vérkeringést akadályozza. A TE kezelése általában gyógyszeres, de súlyosabb esetekben tüdőátültetésre lehet szükség.



WEBORVOS.HU
Ma van a pulmonális hypertonia világnapja
<p>Világszerte több mint 25 millió ember érintett ebben a betegségben, hazánkban is több száza becsülhető a betegek száma.

ISRAEL



PORTUGALIA

Resultados mediáticos

Imprensa

Dia Mundial da Hipertensão Pulmonar



Diário de Coimbra
Tiragem média: 8 000 exemplares

Hipertensão Pulmonar: campanha a qualidade de vida de doentes e c



Jornal da Beira
Tiragem média: 2 300 exemplares

Notícias Impressas: 2

Presenças televisivas: 7
Tempo em TV: 93m30s

Notícias Online: 13



Resultados mediáticos

Televisão



Casa Feliz (SIC)
Catarina Morais, doente de HP
Audiência média: 311 700 pessoas



Consultório (Porto Canal)
Dr. Rui Baptista, médico cardiologista
Audiência média: 2 700 pessoas

SERBIA

ПОЛИТИКА

Uz terapiju smrtnost od plućne hipertenzije u Srbiji manja za 43 odsto



Sve pacijente koji boluju od plućne hipertenzije (PH) u Srbiji sada se leče prema aktivnim smernicama, a zahvaljujući sedam dostupnih terapija život ih ljudi u Srbiji je olakšan, ali je Beogradu, koji je u skladu sa svetovnim danima rešiti bolesti koji se obolavka 28. februara.

Plućna hipertenzija se leči, ali je treba otkriti na vreme



Plućna hipertenzija se leči, ali je treba otkriti na vreme. U Srbiji se leči oko 350 pacijenata. Većina se uči prate ih lekari kardiološki centra Srbije. Za neke pacijente, kada boluju, otkriveno se na redovnim pregledima. Ali, važno je otkriti na vreme.

ESPRESSO



PLA BOLEST KOJA DOSLOVNO UBIJA MLADE: Posetite lekara ŠTO PRE dok ne bude KASNO

Plućna hipertenzija je veoma nezgodna bolest od koje oboli 50 ljudi na milion stanovnika. Ukoliko se ne leči na vreme, bolesnici u proseku žive tri i po godine.

SLOVENIA

Kot bi dihali s ščipalko na nosu in slamicama v ustih

Družinski zdravniki naj imajo pri ugotavljanju diagnoze v mislih tudi redko bolezen, ki jo ima do dvesto Slovencev in ki jo večkrat zamenjajo z astmo.



Obstojni indikator za pljučno hipertenzijo je v pljučnem tlaku. Medtem ljudje s pljučnimi in srčnimi boleznimi običajno priplivajo hipertenzijo. Poročilo: Andrej Džurina za pljučno hipertenzijo.

Nezveličtelne ochorenie



Plućna hipertenzija je bolezen, pri kateri se v pljučih razvije prevelik tlak. To povzroča težave pri dihanju in lahko vodi do srčnega popuščanja. Bolezen je redka, a hujša, zato je pomembno, da zdravniki na njo mislijo tudi pri bolnikih, ki imajo druge bolezni.

Plućna hipertenzija je



Vysoký tlak v plúcach ničí aj srdce

Plućna arteriálna hipertenzia môže vzniknúť z akýchkoľvek príčin, najčastejšie je jej príčinou inho ochorenie: porucha srdca či ochorenie pľúc.

SLOVAKIA



Plućna hipertenzia je bolezen, pri kateri se v pljučih razvije prevelik tlak. To povzroča težave pri dihanju in lahko vodi do srčnega popuščanja. Bolezen je redka, a hujša, zato je pomembno, da zdravniki na njo mislijo tudi pri bolnikih, ki imajo druge bolezni.



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SPAIN FCHP

'10 veces más fuertes' en el Día Mundial de la Hipertensión Pulmonar



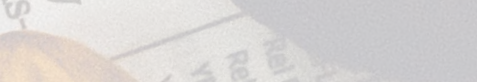
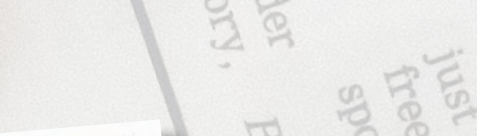
El Hospital Negrín rastrea nuevos genes implicados en la hipertensión pulmonar en jóvenes



La Real Casa de Correos y Cibeles se iluminan de azul por el Día Mundial de la Hipertensión Pulmonar



públicista



SPAIN HPE

Hipertensión Pulmonar España @HPE.ORG - 18 may. ¡Muchas gracias a @badvlladecans por haber ayudado a visibilizar de la #HipertensiónPulmonar participando en el #DíaMundialdeLaHipertensiónPulmonar!



Hipertensión Pulmonar España @HPE.ORG - 11 may. Muchas gracias #AliciaNavarro, #CentreCivicsLesTovallies y @ajsantfeliu por participar en el #DíaMundialdeLaHipertensiónPulmonar con el taller #LaSaludEnTusManos.

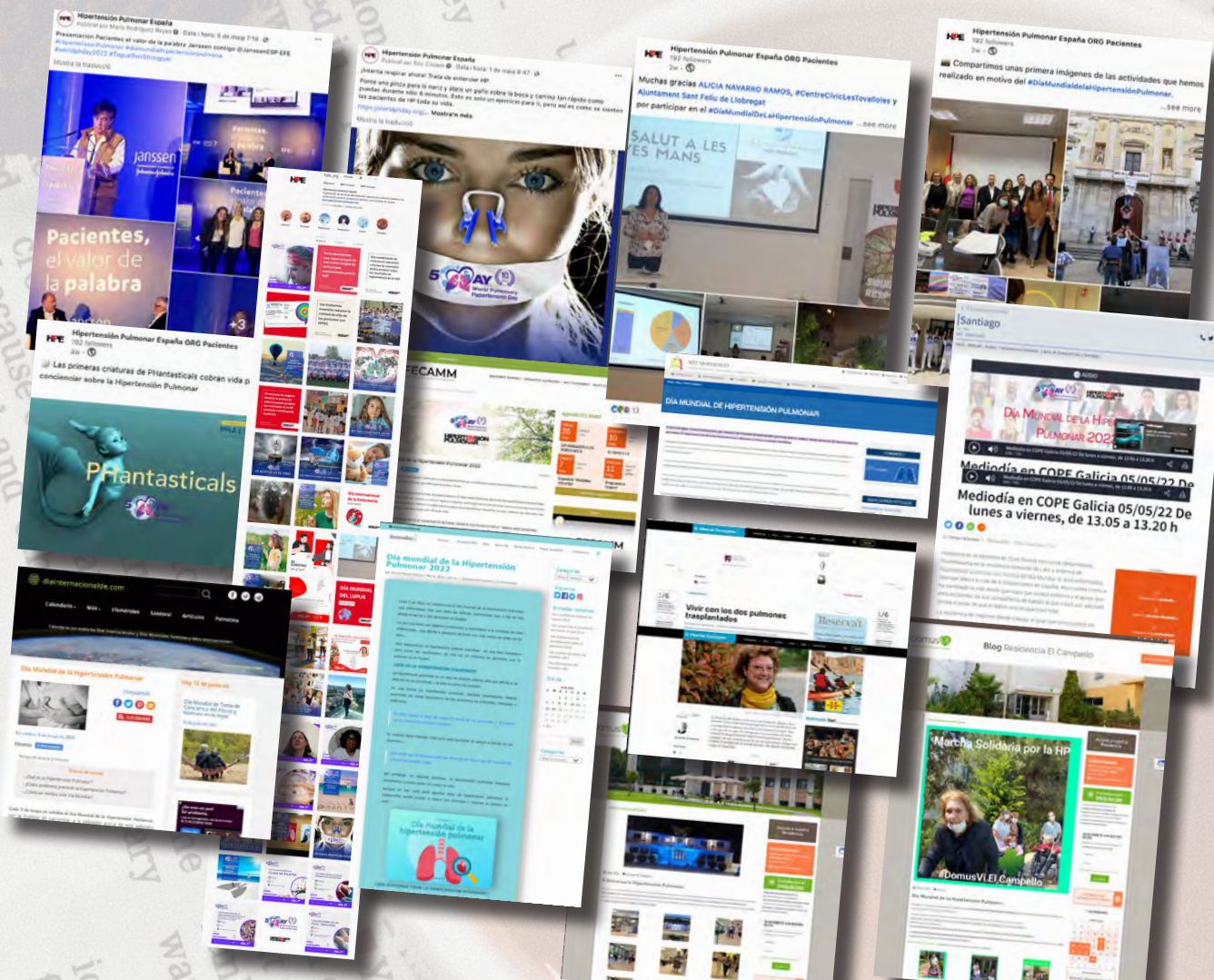


Hipertensión Pulmonar España @HPE.ORG - 5 may. Jornada de trabajo 'necesidades no cubiertas' Castilla León en la Consejería de Sanidad, trabajo colaborativo en mejoras asistenciales con la colaboración @JanssenESP

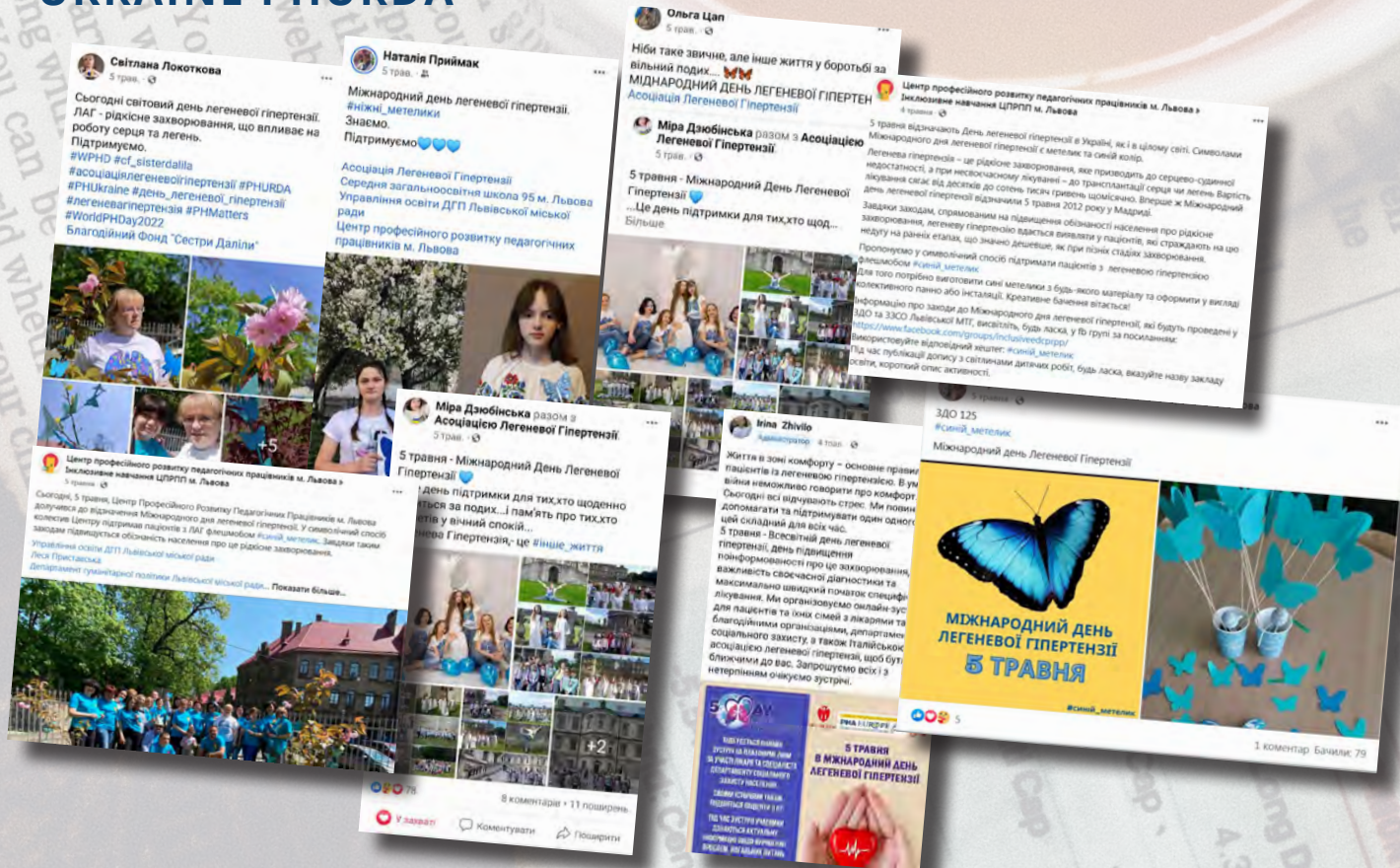


Hipertensión Pulmonar España @HPE.ORG - 5 may. Hoy compartimos el testimonio de Tony. En motivo del #WorldPulmonaryHypertensionDay2022 que se celebra este mes de mayo damos voz a #HipertensiónPulmonar. (Gracias por compartir estas palabras... Mostrá más)



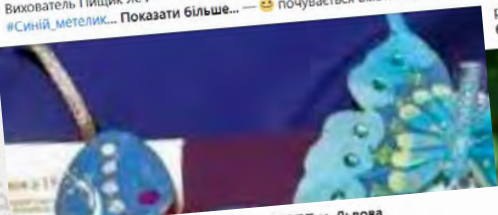


UKRAINE PHURDA



Zhanna Pyshchuk » Початкова школа "Дзвіночок"

5 травня у цілому світі відзначають День легеневої гіпертензії. Дошкільники старшої групи "Підняйки" долучаються до спільної підтримки орфанним захворюванням. Ми виготовили дерево життя, на якому довкола діти дізналися про роль органів дихання, про значення спортивних занять, важливо, щоб кожен розумів, чому треба берегти здоров'я. Вихователь Пилик Ж. І



Ольга Литвиненко » Інтегроване навчання ЦПРП м. Львова

05.05. 2022р вихованці ЗДО 6 та педагоги Надія Лучечко та Марія Кандяк взяли участь у флешмобі - Всесвітній День Легеневої Гіпертензії, символом якого є синій колір та 🦋. Це водночас і сумна, і надзвичайно важлива дата для окремих людей. Дату 5 травня обрано, в зв'язку з летальним випадком першої дитини в Іспанії. Від тоді в цей день по всьому світі проводять заходи щоб підвищити обізнаність, розуміння захворювання ЛГ та сприяти розвитку дбайливого ставлення до... Показати більше...



Валентина Стецюк » Інтегроване навчання ЦПРП м. Львова

У ЗДО №102 м. Львова закружляли сьогодні сині метелики, які нагадали усім, що 5 травня світова спільнота щороку відзначає Міжнародний день боротьби за права осіб з інвалідністю, а також Всесвітній День Легеневої Гіпертензії, символом якого є #синій_метелик — з Надією Фігурською та Оленою Наконечною.



Галина Мельник » Сайво 67 школа



Центр професійного розвитку педагогічних працівників м. Львова » Інтегроване навчання ЦПРП м. Львова

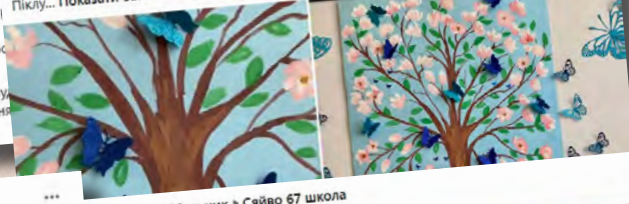
5 травня відзначають День легеневої гіпертензії в Україні, як і в цілому світі. Міжнародного дня легеневої гіпертензії є метелик та синій колір. Легенева гіпертензія – це рідкісне захворювання, яке призводить до серця недостатності, а при несвочасному лікуванні – до трансплантації серця чи лікування сягає від десятків до сотень тисяч гривень щомісячно. Вперше ж день легеневої гіпертензії відзначили 5 травня 2012 року у Мадриді. Завдяки заходам, спрямованим на підвищення обізнаності населення про захворювання, легенева гіпертензія вдається виявляти у пацієнтів, які страждають на ранніх етапах, що значно дешевше, як при пізніх стадіях захворювання. Пропонуємо у символічний спосіб підтримати пацієнтів з легеневою гіпертензією флешмобом #синій_метелик. Для того потрібно виготовити сині метелики з будь-якого матеріалу та офіційно колективного панно або інсталяції. Креативне бачення вітається! Інформацію про заходи до Міжнародного дня легеневої гіпертензії, які будуть проводити ЗДО та ЗЗСО Львівської МТГ, висвітліть, будь ласка, у fb групі за посиланням: <https://www.facebook.com/groups/inclusiveedcprrp/>

Галина Чучман » Інтегроване навчання ЦПРП м. Львова

ЗДО 29

#синій_метелик

Кажуть, дерева – легені нашої планети. 🌳 Адже це «фабрика» з вироблення кисню. Ми хочемо додати ще одну легеню – синю метелика. Це символ необхідності для всіх живих організмів. Загально відомо, що кисень необхідний для всіх живих організмів. У Міжнародний день легеневої гіпертензії ми хочемо долучитися до підтримки людей, які страждають цією недугою. Піклу... Показати більше...



Валентина Стецюк » Інтегроване навчання ЦПРП м. Львова

У ЗДО №102 м. Львова закружляли сьогодні сині метелики, які нагадали усім, що 5 травня світова спільнота щороку відзначає Міжнародний день боротьби за права осіб з інвалідністю, а також Всесвітній День Легеневої Гіпертензії, символом якого є #синій_метелик — з Надією Фігурською та Оленою Наконечною.



Галина Мельник » Сайво 67 школа



Ірина Цюнглевич

ЗДО №187 м. Львів

#синій_метелик

5 травня світова спільнота щороку відзначає Міжнародний день боротьби за права осіб з інвалідністю, а також Всесвітній День Легеневої Гіпертензії, символом якого є синій колір та 🦋.

Педагоги м. Львова підтримують спільноту пацієнтів із легеневою гіпертензією та долучилися до флешмобу #синій_метелик. Це день боротьби. День надії. День подиху та життя. Центр професійного розвитку педагогічних працівників м. Львова Інтегроване навчання ЦПРП м. Львова Леся Приставська

Галина Ковалишин

Сьогодні - Міжнародний день легеневої гіпертензії, символом якого є синій колір та 🦋. Педагоги м. Львова підтримують спільноту пацієнтів із легеневою гіпертензією та долучилися до флешмобу #синій_метелик. Це день боротьби. День надії. День подиху та життя. Центр професійного розвитку педагогічних працівників м. Львова Інтегроване навчання ЦПРП м. Львова Леся Приставська



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

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European pulmonary hypertension association

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THERAPEUTICS

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

PHhuman™



Hollie, 37
United Kingdom
Entrepreneur
Living with pulmonary
arterial hypertension



Vision ▪ Connection ▪ Innovation

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

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

Gossamer Bio is proud to support PAH awareness and education programmes for the community across Europe.

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

 @GossamerBio

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In order to fulfill our purpose, we offer transformative therapeutic solutions with a special focus on pulmonary vascular and interstitial lung diseases.

#FerrerForGood



In addition, OrphaCare is acting as a manufacturer of a software medical product risk class I according to MDR*.

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talk about
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medicine,
WE LIVE IT!***



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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

vipah  **prn**^{2B}

**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 non profit organisation. PHA EUROPE is an umbrella organization bringing together Pulmonary Hyper-tension 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 for pulmonary arterial hyper-tension, 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

AUSTRIA



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Wilhelmstraße 21 - 1120 Wien
www.phaustria.org
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ESTONIA



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+37253004221

BELARUS



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FINLAND



Suomen PAH-potilasyhdistys ry. PHA Finland
c/o Sonja Koski
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BOSNIA AND HERZEGOVINA



Udruženje građana oboljelih od plućne hipertenzije "DAH" - u Bosni i Hercegovini
Zlatnih ljiljana 33, 72220 Zavidovići, BiH
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HUNGARY



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www.tudoer.hu
csabuda.eszter@t-online.hu

BULGARIA



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info@phabulgaria.eu

ISRAEL



PHA Israel
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The Bulgarian Society of Patients with Pulmonary Hypertension - BSPPH
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ITALY



Associazione Ipertensione Polmonare Italiana Onlus
Via della Spiga, 10 - 06135 Ponte S. Giovanni-PG
presidente@aipiitalia.it

CROATIA



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infoplavakrila@gmail.com
www.plavakrila.hr



Associazione Malati di Ipertensione Polmonare Onlus
Via Ardea 1/B - 00183 Rome
www.assoamip.net
info@assoamip.net

CZECH REPUBLIC



Sdružení pacientů s plicní hypertenzí, z.s.
Bělehradská 13/7 - 140 00 Praha 4
www.plicni-hypertenze.cz
info@plicni-hypertenze.cz

LATVIA



PHA Latvia
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www.phlatvia.lv/en/
phbbiedriba@gmail.com

DENMARK



PAH Patientforeningen
c/o Sofie M. Christensen
Store Moelle vej 40, 1.tv
DK- 2300 Copenhagen S
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pahforening@gmail.com

LITHUANIA



Žmonių sergančių plautinė hipertenzija asociacija
Biržų g. 2, Papilys, LT-41221, Biržų raj., Lietuva
www.zspha.lt
info@zspha.lt
(rima.gruodis@gmail.com)

NORTH MACEDONIA



APH Moment Plus Macedonia

„Association for Pulmonary Hypertension
Moment Plus Macedonia”
Tance Kamberov 29,1480 Gevgelija
phmomentplus@gmail.com

SLOVAKIA



Združenie pacientov s pľúcnou hypertenziou,
o.z. Lučenská 31 - 990 01 Veľký Krtíš
www.phaslovakia.org
phaslovakia@gmail.com

MOLDOVA



Asociatia Obsteasca

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SLOVENIA



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www.facebook.com/PljucnaHipertenzija

NORWAY



PHA Norway

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