

PULMONARY HYPERTENSION Mariposa Journal

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#PHMatters

Editors memo

SUMMER EDITION 2021



Dear Friends,

I am happy to share with you the Summer 2021 edition of Mariposa.

As you might know this edition is solely dedicated to World PH Day events all over the world and provides a nice overview of what has been achieved on a local, European and global level.

This year was challenging again due to the COVID pandemic and made the proper planning difficult, but we learnt from the previous year and were prepared for a plan “B” if needed.

There was a great variety of events organized by member associations: in some countries it was possible to run in-person events, however in other countries the activities were limited to the online world. We were also witness to a nice combination of both types of initiatives.

As of this year PHA Europe has taken over the global coordination of World PH Day events, which is a big honor, but on the other hand a great responsibility and a lot of work.

As part of this work, we have re-launched the WorldPHDay.org website which is a hub with ready-to-use materials in English and Spanish. The site contains an interactive calendar about events (with login details) organized all over the world, and information about pulmonary hypertension, the participating partners and also our sponsors, who made World PH Day celebrations possible this year.

You can learn more about the visuals we prepared and made available to the PH community in this edition. We managed to create enormous interest towards our messages and the online reach of 9,4 million (!) and almost 9 million (!) on Facebook and Instagram, respectively, was far better than our expectation. These results are even more impressive if we take into account how the social networks are overloaded with contents nowadays. On top of raising awareness of pulmonary hypertension we were busy with advocacy activities. You can get insight in the following part of Mariposa into an important initiative of an online petition we launched some days before World PH Day: we called upon the decision and policy makers to take immediate steps and address unmet needs of patients living with pulmonary hypertension. The call covers, among others, action on access, transplantation and holistic care.

But the online petition was not the only advocacy activity we planned and organized this year. You can learn more about the very high-profile online event co-organized with the European Respiratory Society in the next section. With the participation of members of the European Parliament, a representative from the European Commission and key opinion leaders from the medical field of PH an online webinar was held by the MEP Lung Health Group on Accelerating EU research for rare diseases – the case of pulmonary hypertension. We were happy and very optimistic that we have had the chance to include the patient perspective in this event by providing a patient journey. The webinar was recorded and made available on our social media channels. We plan to follow up on this event and make further progress on the research for the benefit of patients.

Some years ago, we started to include patient empowerment elements into World PH Day events. This year we were extremely successful and organized and co-organized five webinars in various languages on different topics. We put emphasis during these webinars on quality of life measures and everyday life's problems, but also touched upon the effects of COVID and congenital heart disease on PH patients. All the webinars were recorded and made available on our youtube channel. We hope that they will be important and valuable resources for the PH community.

The staff members of PHA Europe have also shown their dedication to World PH Day and marked this very day in different ways:

some of them got breathless for PH in trail running and triathlon races, others turned into our color of blue or wore our branded T-shirt and had fun.

The World PH Day events always have the same message: we are a big family! To facilitate interactions between



the patient associations from all over the world, we re-opened our virtual centre previously used for the Annual Pulmonary Hypertension European Conference and made fine-tunes, provided new materials and resources and held a meeting at our famous virtual pool!

Let me conclude this editorial with a big applause to the patient associations, patients, family members, carers, friends and last, but not least to our medical partners, physicians, surgeons and researchers, who joined us to celebrate WPHD events this year. Without their dedication we would not be where we are now. Special thanks go to our industry partners, who make our work possible and support our projects.

I am eager to learn about next years' WPHD plans and projects and looking forward to the fruitful collaboration!

Gergely Meszaros
WPHD Project manager • PHA Europe

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MEP event

MEP Lung Health Group: Accelerating EU research for rare diseases

In collaboration with the European Respiratory Society (ERS) a very important MEP Lung Health Group online event was organized on the 21st of April.

The MEP Lung Health Group is an informal platform for policymakers, health professionals and patients to identify the potential EU policy measures aimed at improving lung health. The group tackles EU level respiratory-related topics in various webinars. This time the possible ways of accelerating research for rare diseases in the EU was in the focus, more specifically the results of previous years and the challenges ahead of research on the field of pulmonary hypertension.

The event was supported by EURORDIS and endorsed by the European Lung Foundation (ELF), European Reference Network for Respiratory Diseases (ERN-Lung) and the Breathe Vision for 2030.

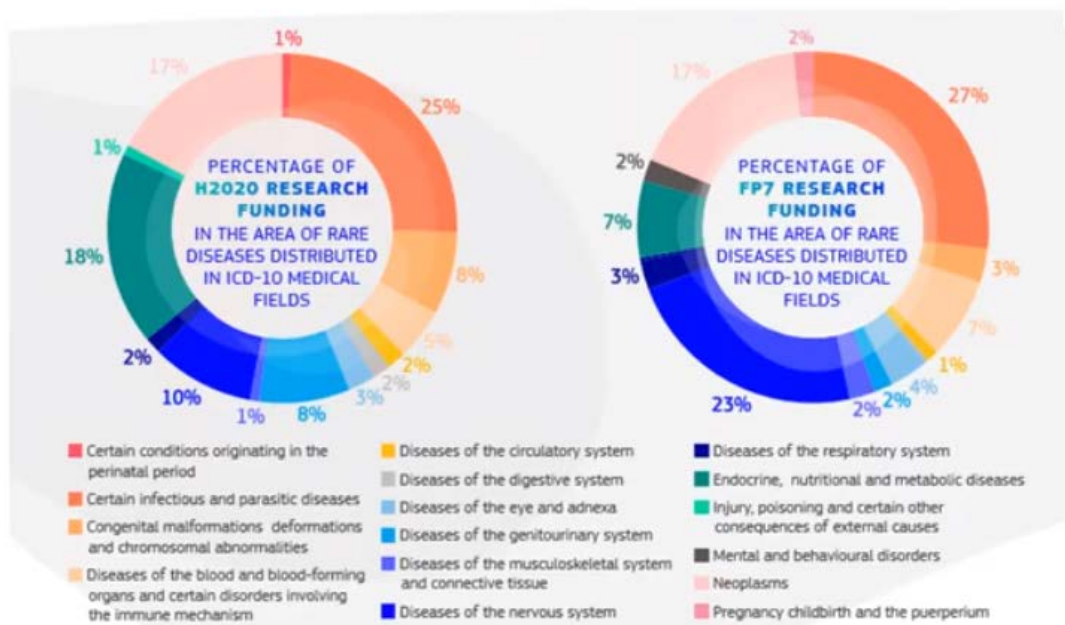
The hosts of the event were Members of the European Parliament (MEP): Maria da Graça Carvalho from Portugal and Istvan Ujhelyi from Hungary. We managed to invite key opinion leaders as speakers and the moderator was Prof. Carlos Robelo Cordiero,

vice president of ERS. Prof. Cordiero kicked-off the meeting with some housekeeping rules and underlined the importance EU research in rare and complex diseases like pulmonary hypertension. He also stressed the impact of the revision of the rare disease EU regulation on research.

In her introductory speech MEP Carvalho outlined the crucial role of EU to invest in the sustainable and consistent basic research and the importance of international collaboration and cooperation on the field of rare diseases. Horizon 2020 was also referred, which supported a couple of research projects.

Christina Kyriakopoulou from the European Commission (DG Research and Innovation) gave an overview of EU research and innovation on the rare diseases with the title of investing to shape our future. In her speech she highlighted the framework of future support of research in EU. To put into perspective these plans, she shared some slides which clearly showed the number of project and funds invested in the last decades to rare disease research and investments. The constantly growing trend is very promising.

EU support for collaborative R&I on rare diseases*

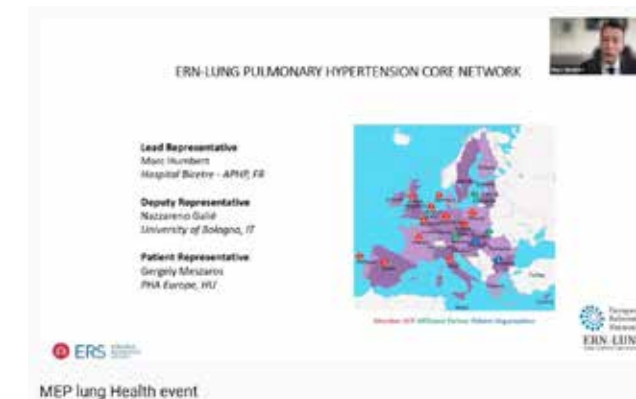


* please, note that these results correspond to a sub-set of the EU project portfolio –work in progress



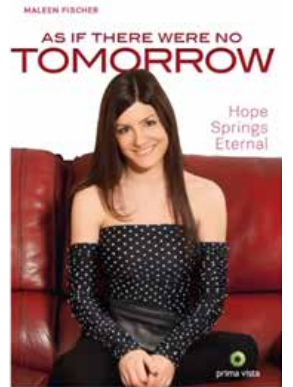
Ms. Kyriakopoulou briefly introduced the EJP-RD program and Horizon Europe, including the various clusters. In the coming years more focus will be made on European partnerships (like Innovative Health Initiative) to build on synergies and ultimately improve the lives of people living with a rare disease.

Prof. Marc Humbert, PH expert, president elect of ERS emphasized in his speech how successfully the results of basic research have been bridged to medical research on the field of PH. As a result of this, in the last 25 years 14 drugs have been approved with orphan drug status. Prof. Humbert introduced the concept of European Reference Networks, their objectives, the structure of core networks and functional committees.



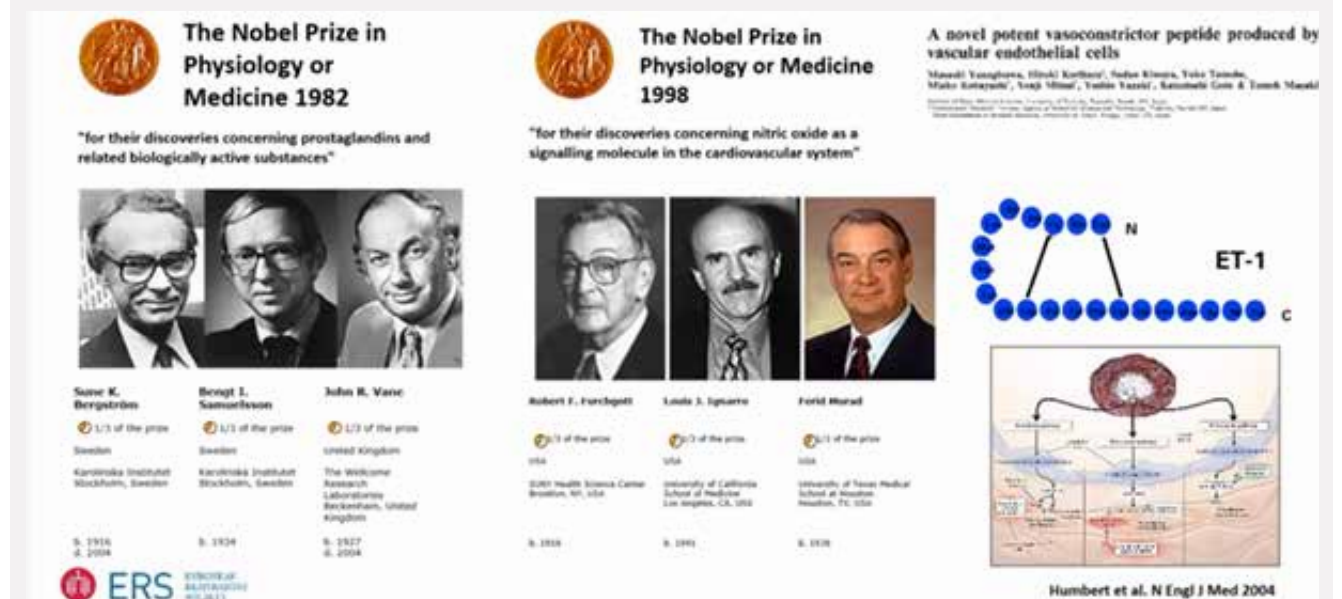
Prof. Humbert informed the audience about the milestones of research covering the various pathways and also outlined the major opportunities like various task forces and clinical research collaborations.

We had the opportunity to provide the patient perspective. Maleen Fischer from Austria had the chance to share with the audience her patient journey. When she was diagnosed in 1998 there was no proper treatment available in Europe, so she was the first European child who received intravenous treatment from the US. Maleen also informed the audience about the efforts of patients how they try to raise funds for research and raise awareness of the PH and introduced her book, “As if there were no tomorrow”.



The webinar continued with two PH specific programs. Prof. Marion Delcroix talked about “Positive research outcomes in pulmonary hypertension leading to better care” in one of the PH subgroups, CTEPH. Following the brief introduction of the medical background of CTEPH, and the timeline of CTEPH treatment development, we learnt about funding applications submitted E-Rare Joint Transnational call and EJP-RD and the lack of funding in those diseases (eg. PH) which are not purely genetic ones. CTEPH is an excellent example that within 10 years how the treatment options evolved: modern therapeutic approach includes PEA (pulmonary endarterectomy), BPA (balloon pulmonary angioplasty)

TARGETING THE PROSTACYCLIN, ENDOTHELIN AND NO PATHWAYS



MEP lung Health event

and EMA approved medications. All this development have been summarized in an ERS Statement on CTEPH (<https://www.phaeurope.org/news/ers-statement-on-cteph-is-published/>) which has proposal on future research.

Dr. Gabor Kovacs was the next with his presentation on PEX-NET which is an abbreviation of an ERS Clinical Research Collaboration (CRC) established in 2017 focusing on hemodynamics during exercise and including 39 participating centres from 15 countries. The CRC was launched following an ERS statement issued in 2017 about haemodynamics during exercise as a lot of open questions have been identified such as prognostic relevance, added value to resting haemodynamics, differential diagnostic values and re-introduction of “exercise-PH” (currently on hold). ERS prolonged the support of this CRC between 2020-2023: the patient assessment and delivering the results – in the format addressing patient needs – need to be delivered. This session was followed by a Q&A session: some of

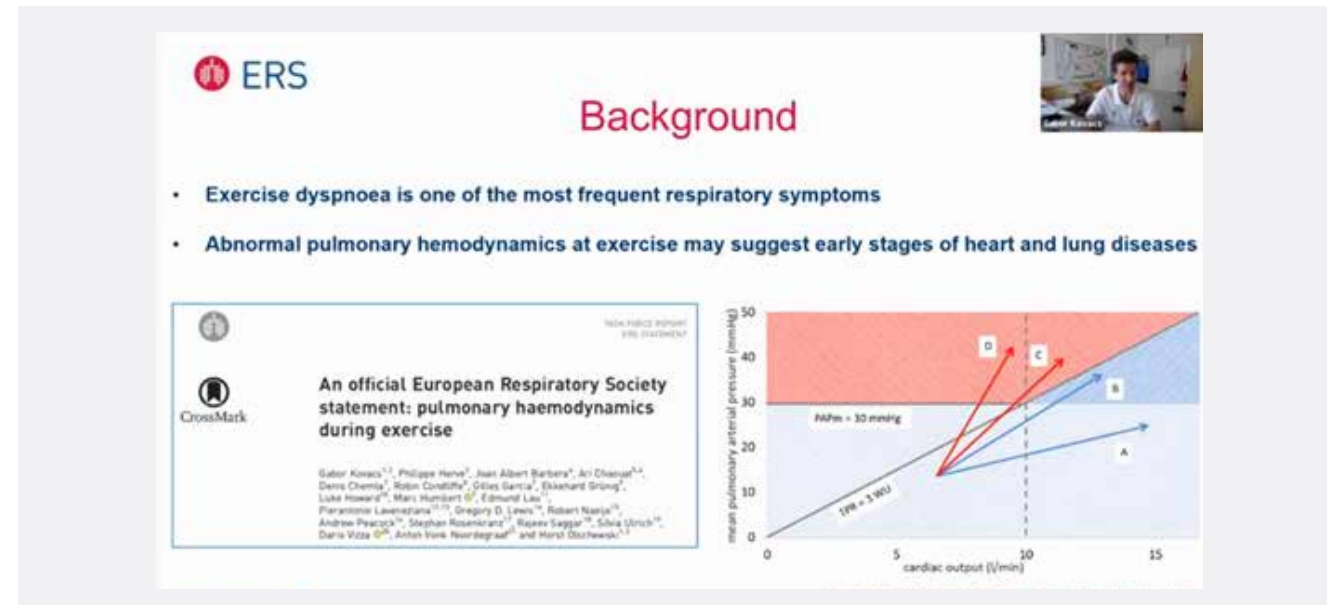
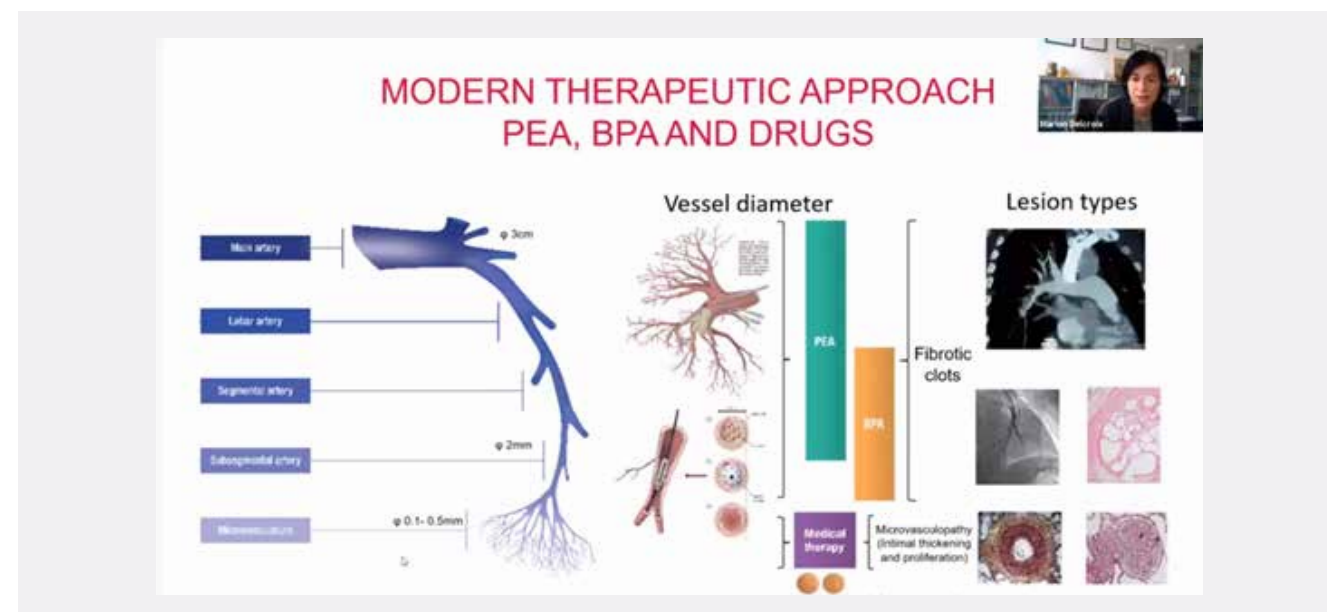
the questions covered the difficulties of applying for research funds.

MEP Istvan Ujhelyi from Hungary closed the event. He nicely summarized the event and stressed the importance of continuing the discussion about common projects in the field of health, especially on the field on pulmonary hypertension and other rare disease. MEP Ujhelyi also emphasized the mount of funds the EU plans to invest in the healthcare in the coming years.

The event has been recorded and available from: <https://lnnk.in/algF>

We were happy with the result of the event and hope we can further build on this opportunity during our advocacy work.

Gergely Meszaros



WEBPAGE

WorldPHDay.org

The worldphday.org webpage always functioned as a resource hub, however when PHA Europe has taken over the global coordination of the World PH Day events, we thought a page refresh would be beneficial.

Our page development did not only mean the re-designing of the webpage, but also the content has been revised. The medical content has been reviewed by our physician partners to ensure that only reliable and up-to-date information is available.

We built the new site as a truly bilingual one: all the information, subpages, downloadable materials are available in English and Spanish language and you can simply switch between the languages by using the country flags on the top right-hand side.

We kept what worked in the past:

- the global calendar: every member can submit their event with posters, descriptions, webpages and following the approval of the administrator the event is published and easily accessible for the visitors
- the structure of the page remained, only some finetunes were made
- the page continues to work as a download center: all the materials are easily downloadable in various format – for further details please visit the article on visuals and self-recorded video in this edition of Mariposa

A lot of new content and features have been introduced:

- we made the landing page fresh looking which attracts the visitors. All the features are in line with

the newest trends and the most important contents are easily available from the landing page in a fancy way. Some statistics and video made the landing page even more colorful

- we collected ample of PH patient photos from all over the world and made this gallery section of the page truly global. A nice carousel is running which makes the browsing amongst the pictures easy
- we also collected quotes from our fellow patients: what do they think about World PH Day, what is the first thing or idea which comes to their mind once they hear about World PH Day
- the medical part of the page was updated with nice and easy-to-understand visuals
- we have updated the list of the participating associations, grouped them in a carousel and transformed their logos clickable: wherever it was possible we linked their webpage or Facebook page to their logos
- we made a special subpage solely dedicated to webinars and an integrated registration platform of Eventbrite with a lot of functionality (eg. reminder before the event and future event of PHA Europe)
- we included the clickable logos of the sponsors on the page

Hope you have already had the chance to visit our new page. If you have not done so, please have a look at it!

Gergely Meszaros

WORLD PH DAY CENTRE

Unfortunately, the COVID-19 pandemic stopped us from meeting in person, but hopefully the World PH Centre will help us stay in touch.

The WPHD Centre is a virtual platform where leaders of the PH patient associations from all over the world can meet online, share their experiences or simply chat.

The Centre provides various possibilities: you can find a special section with booths from national member associations. Many of them share interesting videos and documents.

In the presentation room, a number of presentations are already available and you can see all of them whenever it fits your schedule.

The sessions are available in English and the themes are varying from scientific sessions about transplantation and future outlook of PH treatment to rehabilitation issues and day-to-day guidance. This year the COVID-related lectures could not be missed from the agenda: we can learn how the PH patient management has changed due to the pandemic from the perspective of a nurse and get insight of the perspective of PAH in light of COVID-19.

... and if you would like to chill a bit and have some talk with fellow leaders your place is at the virtual pool, where you can enjoy Vittorio's «coffee break» moments. Here you can chat with other participants that are logged on. You can even do video calls with them including meetings with several participants. And you will also be able to send chat messages to other registered participants whether they are online or not.

If you are a leader of a PH association and would like to add your association to this platform, please email your association details to info@phaeurope.org or get in contact with us.

Enjoy World PH Day Centre open 24/7!



ONLINE PETITION

*Online petition about unmet needs
of patients living with pulmonary hypertension*

Despite many years of advocacy work access to PH treatments is still problematic in many countries. During our discussion with PH associations around the world it became obvious that a unified call is needed.

The pandemic made it difficult to organize an in-person event, thus we circulated both in English and Spanish our proposal within the international PH community. As a result of two rounds of discussions we finalized our position in a concise way and launched an online petition on 12th of April by calling policy and decision makers to make a change.

We have chosen the platform of Change.org which is the world's largest platform for social change, with over 329 million users globally.

We grouped our message in the following main topics:

- Establishment of expert centres
- Availability and accessibility of medications and treatments
- Promotion of transplantation and existence of organ donation program
- Holistic care of patients

You can learn more about these points by visiting the website of the online petition at: <http://chnng.it/YJ6Dj6tH>.

The petition has more than 600 supporters, 5600 views and 175 shares on the change.org platform and multiple of these numbers on various social media networks: we received almost 900.000 impressions on Facebook.

We hope that this online petition will help us in getting attention to these unmet patient needs and immediate actions will be taken to address these difficulties and make the life of patients living with pulmonary hypertension better!

Please advance our common cause and become our supporter at <http://chnng.it/YJ6Dj6tH>!

Gergely Meszaros



PULMONARY HYPERTENSION

(also known as PH) is a progressive rare lung disease, without any known cure. Several treatments are available targeting the improvement of the symptoms, however if the condition of the patient is still deteriorating, ultimately a heart and lung transplantation may be an option.

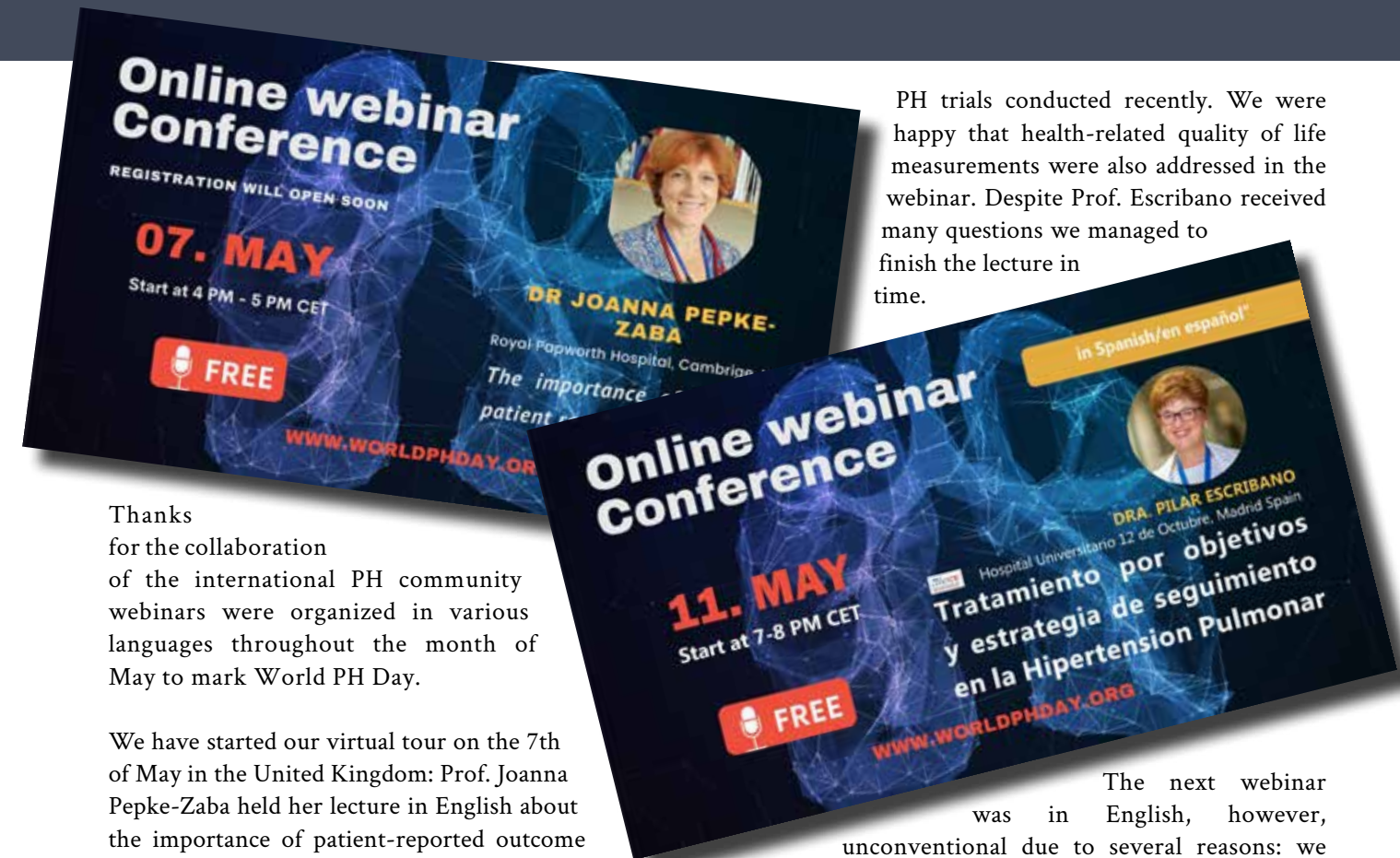
Unfortunately, holistic care and appropriate treatments are not available in all countries and immediate actions are needed:

- establish expert centres and improve access to the already existing ones
- ensure that medications and treatments (including surgical interventions) are available for the patients and their accessibility is not limited by national policies and lack of reimbursement
- ensure that appropriate policies are in place to promote organ donation and an effective transplantation program exists
- ensure that PH patients are treated as a "whole" by tackling the psychological, nutritional, and rehabilitative aspects of the disease; ensure that patients living with PH are granted disabled status to facilitate their integration to the community and self-reliance.

We, the PH community, call upon immediate action to address these unmet needs of patients with pulmonary hypertension.

WEBINARS

Virtual tour around the world



Thanks for the collaboration of the international PH community webinars were organized in various languages throughout the month of May to mark World PH Day.

We have started our virtual tour on the 7th of May in the United Kingdom: Prof. Joanna Pepke-Zaba held her lecture in English about the importance of patient-reported outcome (PRO) measures. We could learn the wide variety of PH specific questionnaires and how they can be used: they are essential to better understand the condition of the patients, they are practical tools for quality assessment of the health care service provider, and last, but not least they are useful endpoints in trials. As a result of COVID lockdowns – which resulted in the lack of patient visits – such PRO information coming directly from the patients about the patients have become more and more important feedbacks for the treating physicians. Prof. Pepke-Zaba underlined the practicality of PROs in the pediatric population. The webinar was closed with a lively Q&A session.

On the next Tuesday, on the 11th of May we continued our session of webinars – this time in Spanish language – in Madrid, Spain. Prof. Pilar Escibano informed the audience of the psychology of the lungs, the various types of pulmonary hypertension, including CTEPH. We could learn how PH is diagnosed with right-heart catheterization and echocardiogram from easy-to-understand visuals, got insight into the treatment algorithms and strategies in light of risk stratification and various available pathways. Some slides were presented about trials in general and the most important

PH trials conducted recently. We were happy that health-related quality of life measurements were also addressed in the webinar. Despite Prof. Escibano received many questions we managed to finish the lecture in time.

The next webinar was in English, however, unconventional due to several reasons: we could welcome two speakers from different continents – Prof. Sahay Sandeep from the US and Prof. Prashant Bobhate from India. The webinar did not start with lectures, but was completely dedicated to questions. The title of “How to stop worrying and start living with PH” was very attractive and we received questions prior to the event. Naturally, there was a possibility to directly address the physician with questions during the event. A great variety of inquiries made this session very interesting. Some of the questions related to how to cope with symptoms, like breathlessness, fatigue, tiredness and leg pains especially during night. Somebody was interested in fluid retaining issues and weight loss difficulties. A question came up about symptoms worsening: what are the clear signs and when immediate hospitalization is required. The possible correspondence between deteriorating mental and emotional health and symptoms worsening was also discussed as well as the effect of high altitude on symptoms.

On the very same day, on the 20th of May we moved virtually to another continent, to South-America and held a very successful webinar in Portuguese with the title of “PAH: current challenges and futures perspectives post-COVID 19 era”. The speaker was Prof. Marcelo

WEBINARS

Virtual tour around the world



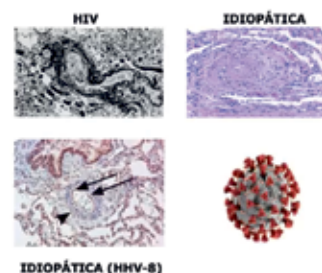
Conexão HP - COVID-19: ela é real ?

HIV: 32 milhões de óbitos desde 1981 até os dias atuais (UNAIDS)

Década de 90: presença de LESÕES PLEXIFORMES em pacientes HIV+ ;
Incidência de HAP (grupo 1) em 0.5% dos pacientes [1] 2

2003: Aqs de HIV-8 por IHQ em lesões plexiformes de pacientes com
a forma IDIOPÁTICA [1] 3

**A pandemia vigente pode mudar
a epidemiologia global da HP ??**



#WorldPHDay2021 #PHMatters

Bandeira. The lecture aim was to find a response whether there is any connection between COVID-19 and pulmonary hypertension and whether the pandemic will change the classification of PH. During the webinar the role of telemedicine was discussed in details. The lecture was followed by Q&A session.

The series of webinars was concluded with a theme from the pediatric field. In her lecture, held in Portuguese on the 26th of May, Dr. Flavia Navarro talked about pulmonary hypertension associated with congenital heart diseases. The presentation started with a very spectacular 3D video which outlined how the circulatory system works and how the heart pumps the blood in every part of the body. We could learn about the updated classification, risk assessment as well as the treatment algorithm and strategy of these patients. Despite the detailed presentation Dr. Navarro was addressed with many questions.

We are happy and satisfied with the result of these webinars as many people joined the live sessions from various parts of the world and visited the recordings available on our social media channels:

<https://lnnk.in/bIdc>

Many of these webinars are result of an international cooperation. I would like to thank again the help and efforts of Abraf - Brasil, ANHP - Spain, APHP - Portugal and Pulmonary Hypertension India, because their assistance was fundamental to this success.

Gergely Meszaros



VISUALS

Visuals and self-recorded videos

Visuals

Earlier this year we were very optimistic and hoped that our members would organize a whale of in-person events, however, we would have liked to be also on the safe side and prepared visuals to run a successful online campaign. We were aware, though, that eye-catching visuals, powerful messages, well-grounded dissemination and promotion plan are essential elements in the very busy online world.

The theme, which we built the whole campaign around, is very timely: mental health issues and difficulties. The various measures and quarantines introduced due to the COVID pandemic put a big burden on everybody's shoulder. These difficulties were more serious to PH patients who are (and were) at high risk. We were aware of many cases where patients did not leave – even temporarily – their houses and did not meet their loved ones for months. On the other hand, COVID helped us the spread and acceptance of these messages, because the general public also faced lockdowns and could better understand these difficulties.

Originally our visuals were available in English and Spanish <https://worldphday.org/toolkit/>, <https://worldphday.org/es/herramientas/>, but local versions were also elaborated. We made them in poster and story version to fit the requirements of the different social media channels. Despite we provided templates for the text of the posts, naturally, there was a possibility of translating and making the posts tailor-made to better fit the local conditions.



Self-recorded videos for social media sharing

Possible idea for the video text

Hi, I am XY from <country> living with pulmonary hypertension (also known as PH), a progressive rare lung disease, without any known cure. Patients with PH may feel breathless and it may take up to 3 years to get the appropriate treatment.

<your patient story/journey in very few sentences>

Since 2012 we have been organizing World PH Day on May 5th, a series of awareness events. We hope these events help earlier diagnosis and medication to raise quality of life and life expectancy.

COVID-19 put a stop to this year's events.<< <Me> and my fellow patients who are at high risk could not leave our home for months for several reasons. >>

Although we keep in touch virtually with our loved ones, our situation is mentally challenging.

Please help us spread awareness about pulmonary hypertension and stay connected with us.

PH matters. Stay safe!

Post recording tasks: English subtitle | logo (s) | blue ribbon with „Coping with PH“ | direct upload to social media channels



How to film your video:

- On mother tongue
- Make horizontal video, if using a phone
- Use microphone or headset - no noise nearby
- Use as high video quality as possible
- Do not zoom on your face/body too much, use only the 2/3 of the screen, preferably the lower part
- Avoid dotted and striped clothes
- Light background preferably in nature (garden) or in your house
- Max. 1 min. to comply with social media platforms

Need more tips?

<https://lnnk.in/ate8>



Overall, 9 different posters were published on specific days from the 30th of April until the 14th of May, generating huge attention and traffic on social media channels. We reached an impressive result of total reach with more than 9,4 million (!) and almost 9 million (!) on Facebook and Instagram respectively.

Self-recorded videos

We are also proud of the other initiative of self-made videos: our main idea was to have the same message in local languages and from these materials we planned to make a collage video with English subtitle.

PHA Europe provided the template text both in English and Spanish which started with an introduction and a possibility of sharing some words about the own patient journey which makes the video more personal. Following that a reference was made to World PH Day,

the importance of such raising awareness events and the difficulties COVID brought in. The script is concluded with a call of spreading our message: PH matters! Hints and tips how to make a proper video was also shared, which also aimed to have standardized videos.

We received a lot of videos from Bosnia and Hercegovina to Portugal, from Ukraine to Bulgaria, from Spain to Austria, from Israel to Lithuania and from Canada to Serbia. Thanks to these materials we could not implement our original plan, but could make even a longer version of the video, which has been finalized in the first weeks of June. Despite the video is available for only few weeks at <https://lnnk.in/e5bi>, it has more than 146.000 views! Please watch and share our materials if you have not done so!

Gergely Meszaros





WPHD 2021 - AUSTRIA

OUTSTANDING ACHIEVEMENT - A LONG-TERM RESEARCH PROJECT BECOMES AN APP, THE BLUE LIPS CAMPAIGN CONTINUES, VIENNA'S MAJOR ATTRACTION ILLUMINATED IN BLUE.

As in the previous year, due to Covid-19, no major events could be held this year, which is why we are particularly proud of the launch of our 6 min.test app! As part of the joint project between the University of Innsbruck and the Lungenkinder Forschungsverein (Lung Kids Research Association) of PH Austria, the first app was created that enables medical staff to use a mobile application to determine the Z-scores* of the 6-minute walking distance during growth in children and to measure young people (4-19 years) in a standardised way. The app is based on published, validated publications (<https://lnnk.in/fCbk>).

**The Z-Score indicates the distance of a measured value from the mean value (in this case the walking distance) in standard deviations.*

Thanks to the 6 min.test app including Z-Score calculator, measurements can now be assigned time-efficiently to reference values that show whether a change in the course of the disease has occurred, especially in young people. The app allows a more precise classification of mobility and better monitoring of the effects of an intervention or treatment. More information: <https://lnnk.in/gbaY>

The 6 min.test app is available in German, English and Spanish and can be downloaded free of charge from the Apple Store (<https://lnnk.in/ixaL>) and the Google Playstore (<https://lnnk.in/iCaX>). There is also a desktop version available: <https://6-min-test.org/en/>. Please get in touch for detailed information!

For the test we use a special designed distance measuring

wheel, it has two wheels, expandable telescopic rod and a dinosaur to attract the children. The wheel can be ordered at phaustria.org free of charge by any pediatric department worldwide.



Besides this great achievement, we revived the blue lips campaign via social media. Many of our members and sponsors took again part to bring this important topic into the public eye and to support those affected by the incurable disease. The campaign shows that in addition to states of exhaustion, shortness of breath and other symptoms, blue lips are a visible sign of pulmonary hypertension.

Because of the great success in the last few years, we asked the owners of the Giant Ferris Wheel in Vienna's Prater again whether they would illuminate the Ferris Wheel in blue on May 5th to set a sign for pulmonary hypertension, as this has almost become a tradition. They did and we are more than happy about the good cooperation!

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



WPHD 2021 - BELARUS



HI PHAMILY!

May is over and we're happy to share some of the activities that we had during our WPHD in Belarus.

Although Belarus is still going through the hard times due to the regime and repressions against civilians, we were able to organize some online and offline events to support PH patients and raise a little bit more of PH awareness.

Comparing to our previous WPHD which was more about online campaigns, this time we were able to organize some offline events as well.

This year we managed to contact Belarusian Republican Youth Union which helped us involve young people and children from schools and boarding schools in the participation.

Our social networks are now full of bright and colorful arts and crafts which were made by kids from all around Belarus. This included children and youngsters of all ages and health conditions. We also had a few preschoolers involved and this makes the atmosphere of the celebration warmer and even more special.

Not without blue lips campaign which was more about "blue hearts on the cheeks". We had a few preschoolers involved and this made the atmosphere of the celebration warmer and even more special.





Another event which we're truly proud of is Volleyball competition.

Minsk Association of Amateur Sports held volleyball tournaments in support of people with pulmonary hypertension: "We hope that our participation will be a small step towards achieving a big goal - finding the optimal treatment method and conducting additional research on all types of PH."

The May games of the volleyball tournament named "25:23" took place on 15.05, 22.05 and 29.05. The games were aimed at showing the patients with PH that they're not alone. They're visible and they're supported. All the participants were dressed in t-shirts with lungs picture to make the event more symbolic.

We do appreciate the participation of the Association of Amateur Sports and we do believe that such kind of events makes it possible to feel through a live example that we are a real team that share joyful events, and, if necessary, will come to the rescue in the most difficult life situations.

To sum it up, we're excited about what we managed to make this year and hope our future is filled with a number of colorful and happy events.

*Alina Katsubinskaya
PH Belarus*



WPHD 2021 - BOSNIA AND HERZEGOVINA

UNITED IN THE FIGHT FOR A BETTER POSITION OF PH PATIENTS

World Pulmonary Hypertension Day in Bosnia and Herzegovina is marked by many activities, so it is very difficult to write everything in one short text and at the same time convey pride, success, positive reactions and all the nice things we experienced during the implementation of our project WPHD 2021. In Bosnia and Herzegovina, we traditionally mark this day with a series of activities that give the opportunity to all generations from 7 to 77 years, children and people from all continents, to be actively involved and raise awareness with us about this rare and serious disease. We must point out that every year we are more active, louder and that we are really supported by many people not only in our country, but all over the world.

ONLINE ACTIVITIES

We had the sweetest support this year from our youngest from the First Elementary School in Zavidovici. They sent us 52 beautiful drawings and one special video on the topic of pulmonary hypertension. Our relationship has become unbreakable. They grow into people who will one day be responsible people with a special empathy for the patients and all those who needs help. We are happy for them, and they are happy to help us at least in some way. This year we received confirmation that our work is followed by people all over the world. On our FB page we launched the activity „View from the window for PH” and in a very short time we received over 100 photos from Croatia, Serbia, Slovenia, Macedonia, Finland , USA, Austria, Russia, Great Britain, Sweden, Denmark, Germany, Qatar, the Netherlands, Turkey, Ukraine and Bosnia and Herzegovina, with a view from the window and a visible inscription WPHD 2021, as well as the name of the city from which they send us their photos. In this way, supporting the Association of

Citizens with Pulmonary Hypertension „Dah” - in Bosnia and Herzegovina, especially in the month in which we celebrate WPHD 2021, in addition to being accompanied and supported by a large number of people, they each year actively participate in the celebration of WPHD. We are happy to have such a large number of followers who want to express their support publicly in any way!

STREET ACTIVITIES

We also realized several street activities. Group of runners from Sarajevo „Trcanje i TO” supported those who suffer from pulmonary hypertension by running through the streets of Sarajevo with signs of the European PH community, drawing the attention and point out the need for better position of PH patients in our country. These young, healthy people left us breathless with their enthusiasm, cheerfulness and willingness to help us. On the streets of our capital city, we conducted a survey: „What do we know about pulmonary hypertension?”. The poll in Sarajevo gives the best answer to that question. Despite the fact that we work hard and diligently to raise awareness about this disease, of the total number of respondents, 25% knew or heard something about PH, among other things, thanks to the work of our Association. We must increase that percentage and it will continue to be our continuous task.

We cannot but mention the video banners that we have been placing in the two cities of Bosnia and Herzegovina, Zavidovići and Maglaj, for the second year in a row, throughout the month of May. Banners are located in both cities at major intersections and are very noticeable to all passers-by during the month of May.

SPECIAL ACTIVITIES

Finally, we left three more sporting events that marked this year's celebration of WPHD 2021 in Bosnia and Herzegovina. Support for patients with pulmonary



President of Assembly of Association of citizens suffering from Pulmonary Hypertension „Dah“ in Bosnia and Herzegovina



The celebration of the World Pulmonary Hypertension Day in Sofia was held under the patronage of Sofia Mayor Yordanka Fandakova. “Sofia is one of the cities that took part in the celebration of the World Pulmonary Hypertension Day. Your enthusiasm is contagious and helps a lot to inform people about this rare disease, which means that together we can help people who suffer from this disease”, said Sofia Mayor in a video message on the occasion of the event.

The world vice-champion in wrestling Kiril Milov also congratulated the participants: “With this disease every step is a hardship. For every patient, every breath is a gift, and this disease is discovered late and it is important to talk about it”.



The sports event Get Breathless for PH took place in the form of high-intensity interval training, which in addition to increasing the heart rate, helps increase the levels of some key human hormones, which in turn creates conditions for burning fat and developing muscle mass. During part of such a workout, the heart rate rises to 85–90%, and the metabolism remains active for hours after the end of the workout. From 5th to 15th May every person who attends the sport complex joined the initiative by donating his/her 5 km running and mark that at the dedicated place in the fitness hall. For each run kilometer, the BSPPH donated resources for buying two portable oxygen concentrators, which will be provided to PH patients.

Actor Ivaylo Zahariev also supported our Give Breath initiative with a video message in which he and his wonderful kids talk about pulmonary hypertension.

Despite the efforts of the patient organization, the National Health Insurance Fund continues to not fund oxygen devices for patients with pulmonary hypertension. Most of the patients in functional classes III and IV of the disease need expensive intravenous therapy, which is also not available in our country. For them, lung transplantation is life-saving—a problem that has been unsolvable in our country for years.

For more info, please visit: <https://bit.ly/343Kt9H>
Video: <https://tinyurl.hu/nKZ9/>

Natalia Maeva, Bulgarian Society of Patients with Pulmonary Hypertension - BSPPH
www.bspph.net
www.facebook.com/BSPPH.Bulgaria?ref=h



WPHD 2021 - BULGARIA PHA

In the difficult times of isolation and uncertainty for all the society, but even more for people with chronic disease PHA Bulgaria is constantly trying to encourage patients suffering from the PH.

Besides the everyday phone call support, support with medical specialist and healthcare, PHA Bulgaria prepared a nice gift as a part of the World PH Day campaign.

T-shirt, teacup, and oximeter receiver every PH patient who write a message to request it in our social media page.

As for now close social contacts are yet no preferred, we stimulated every PH patient to take a picture with the T-shirt with logos and we post in social media.

PH Bulgaria World PH Day continue with the annual “Vitosha 100” run and cycling race in Sofia when PH society is traditionally presented.

Our social and awareness videos were re promoted and have reached new auditory.

Still to realize is a volleyball event we plan to realize in the summer. Word PH Day was well presented in media including TV and important radio stations.

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





WPHD 2021 - CROATIA

Dear friends and PH family,

We trust that to all of you this time of year is special, precisely because we are celebrating our day on the 5th of May. The excitement, growing for weeks, we spend time planning projects that we hope will best convey our message to people on the occasion of WHPD.

After last 2020, let's call it a covid year, when we had more or less just an online campaign, with 2021, despite minor difficulties we can still be much more satisfied.

On the 5th of May, the city of Zagreb responded to our invitation and illuminated the Zagreb fountains in our colors, that is, our two logos alternated on the fountains, "get breathless for ph" and "world ph day" in Croatian. Active fountains are in themselves an attraction, located near the center of Zagreb, and again along two very busy roads where people can see fountains from their vehicles and read messages.

The acting mayor of Zagreb supported our day in that way, unfortunately, the press conference that was supposed to be held was canceled due to precautionary measures.

Also on the same day, a virtual race "Running with a Heart for the Lungs" was held across the country involving

around 180 runners. Their task was to run a symbolic 5.5 km and share the announcement of the race and the image on social networks. We rewarded the most creative images with our T-shirts that delighted the runners so they will surely run in them many times again. A small group of runners ran their 5.5 km right at the fountain.

The project we are especially proud of this year refers to the rowing on the river Kupa from the source to the confluence, called "By the river Kupa in a breath". It is a project we collaborated on with gentle giants of a big heart, our heroes from the "Adriatic breathless adventure", Bjelovar Argonauts.

Brave rowers, about 15 of them, rowed the Kupa river in less than 4 days, with a total length of 296 km. The Kupa is the longest Croatian river with its source and confluence in Croatia. With its course, it crosses beautiful landscapes and through a total of 4 regions, ie counties: Primorsko-Goranska, Karlovačka Zagrebačka and Sisačko-Moslavačka.

The Argonauts had incidental stops, socializing with children, and educations about pulmonary hypertension but also about the importance of playing sports for our health. Also, the children who wanted to had the opportunity to try rowing with the Argonauts who were vigilant to make sure nothing happened to someone.



We had not seen so much joy in a long time, and the joy on the children's faces showed how much they themselves had suffered all these months under strict measures of keeping their distance and wearing masks.

The project with the Argonauts is special to us in every way, and we try to continue our cooperation with them, through several projects, and together we applied for a tender for EU funds. For now, we have passed the first round, if we go through, this wonderful story and now the friendship between our two associations will continue.

Finally, let's just share with you the news, in 5 months we managed to raise funds and donate 2 ultrasound inhalers for use in our PH center, for urgent needs, or for patients

who need an inhaler, for example on weekends when it can not be bought. So that they can use it until they manage to obtain one for themselves.

We hope that in time there will be more to come.

Our wish for us all is to be well, to be careful, and for all of us to gather again in the fall as before, we send you greetings from Croatia.

Katica Mavračić and Zdenka Bradač

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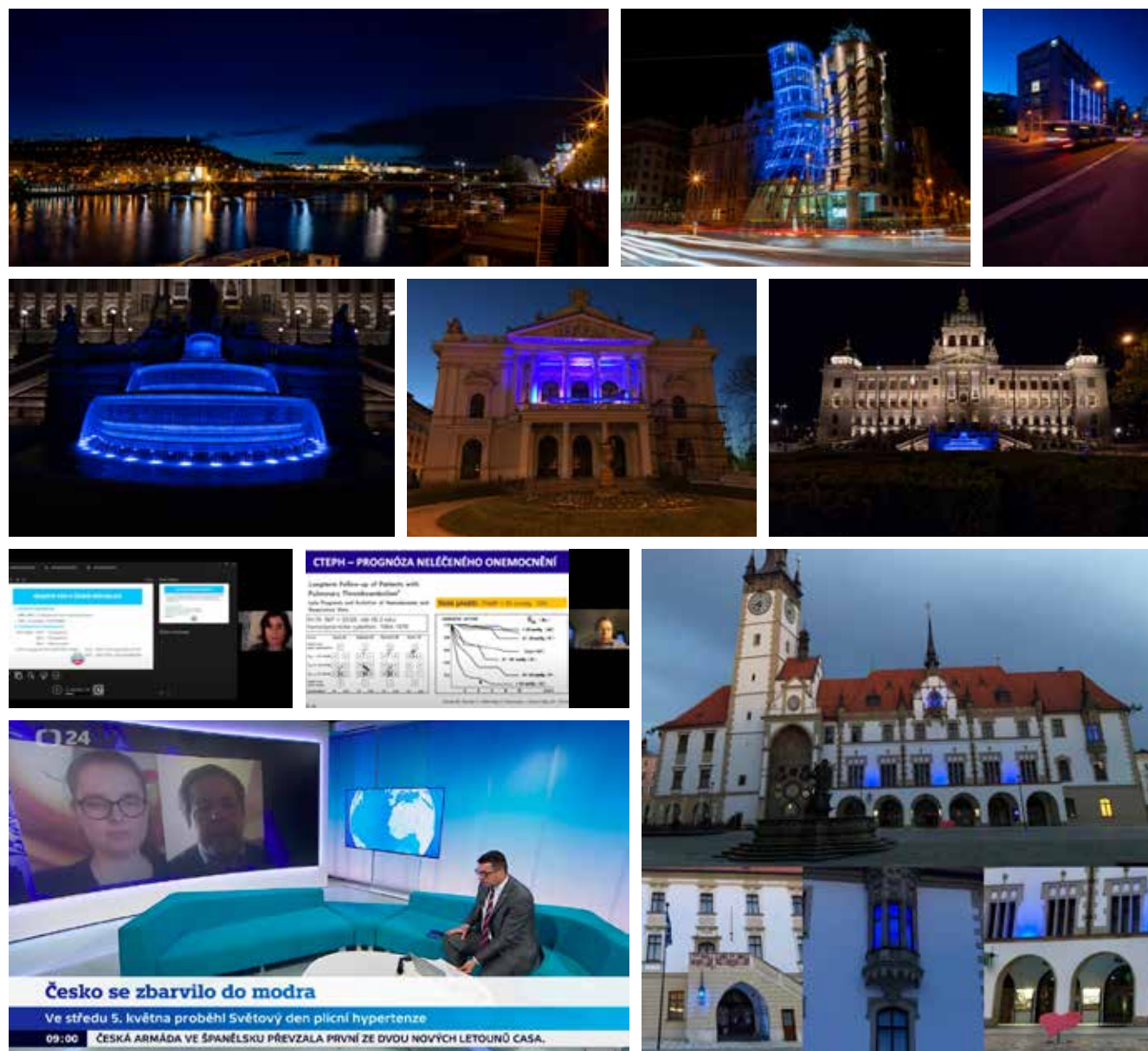




On this day, monuments in Prague, Brno and Olomouc were illuminated in blue, which promoted awareness of pulmonary hypertension. Interviews also took place on

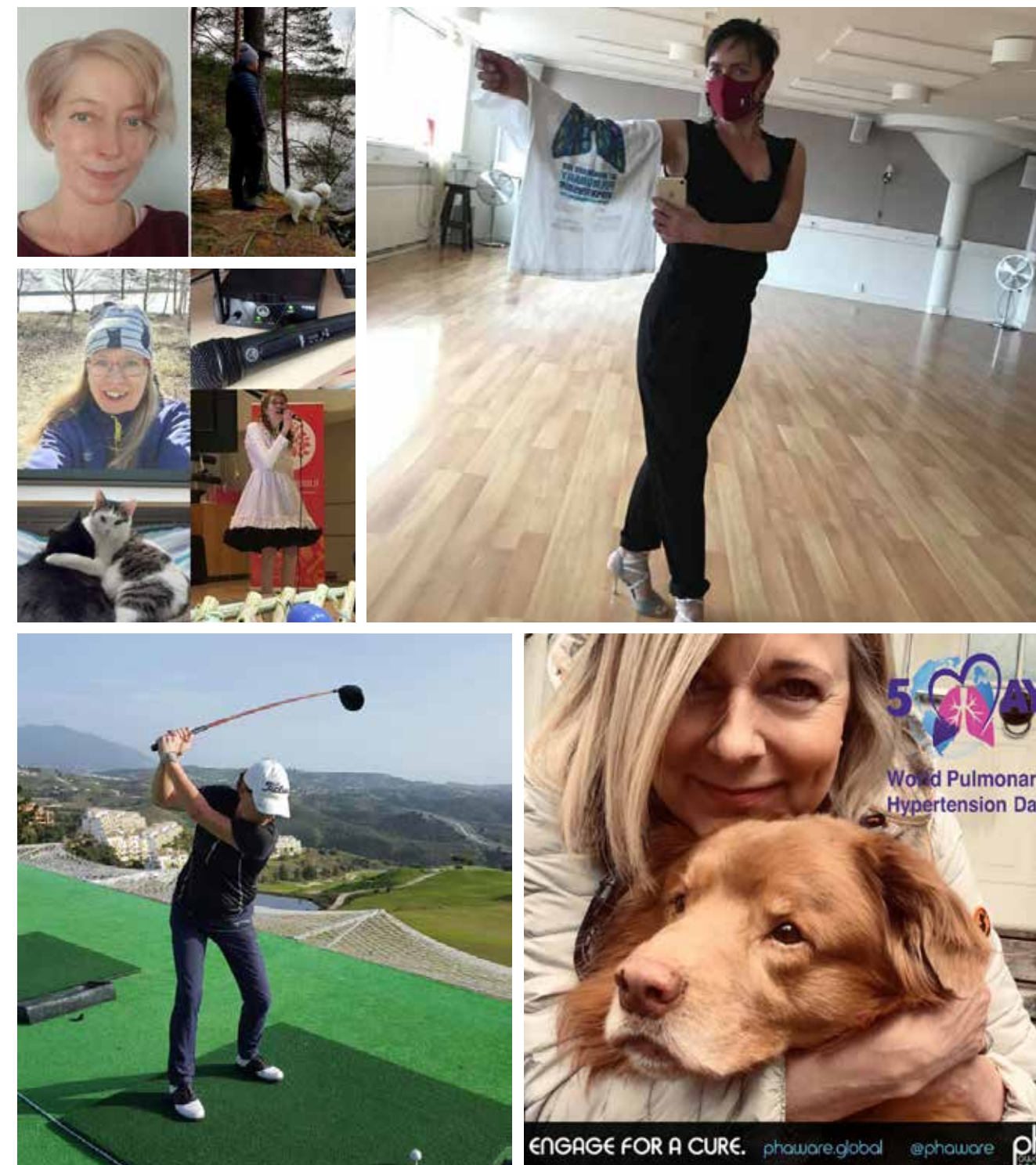
A press conference was held at the General University Hospital in Prague on the anniversary of the 400th operated patients with CTEPH (PEA).

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



walking were most popular. In addition, pets and close ones brought happiness. Good nutrition and adequate sleep are important part of well-being. There were six publications and they received almost 100 likes.

Tania Sointu





WPHD 2021 - HUNGARY

Raising awareness remains the main mission of Tüdőér Egylet, to achieve that the time until the disease is identified is as short as possible, thus there is a bigger chance to stop the progression with the appropriate treatment. As a result, patients can live an almost normal life for a longer period. In COVID 19 times, of course, this is difficult, as the symptoms of the COVID patients and even post COVID appear to be similar to those experienced by people living with PH.

The awareness raising materials prepared by PH Europe were great help. They were translated to Hungarian and published, and many were touched by the pictures and quotes. Last year we achieved a record income from PIT 1% offerings, so we also emphasized the way to do this on Facebook.

We also had an opportunity to share information about PH and our association on one of the most popular morning TV shows. We were also on a radio show, not to mention the several online media articles and videos. In our communication we were trying to make it clear,

what qualifies as a well-founded suspicion, and where potential patients should turn to for a diagnosis (to avoid that people are flooding HC facilities). We also shared different patient journeys, and talked about transplantation as well.

In our country many PH patients are reluctant to let their environment know what they are living with, so as not to be regarded as someone you cannot really rely on. However, some of our fellow patients were brave to share their stories to raise awareness of WPHD and the disease. We have also received videos where our supporters were „Getting breathless for PH” by singing and dancing. Thank you very much!

April 2021. The Hungarian COVID statistics are depressing. The vaccination of the people with chronic illnesses was in progress, most of them have only received the first dose. Because the strict closing and curfew most of the people were stuck between four walls again. The planned opening and thus the possibility of outdoor events is postponed weekly. We could feel that our



patients miss very much personal meetings. Thus after the first easing we have organized our PH picnic in Városliget, one of the biggest parks of Budapest.

Kristof Karlocai, our Head Physician PH specialist has shared his advice in a video message. We have enjoyed the fresh air and the company of each other. During a tour in the park, we have approached people and gave them flyers that informed them about the disease with the help of the infographic, and also about our activity and the ways to help us. We have encouraged those interested to offer 1% of their PIT to us. Our colourful T-shirts has drawn attention to us.

This year our cycling ambassadors will get breathless for us in June.

In the village of Diósjenő, where our headquarter is, the football team of the local primary school has volunteered to play in the T-shirts of our association. We can hardly wait for the first matches, so that we can cheer for them.

Eszter Csabuda, Tüdőér Egylet

www.tudoer.hu

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



WPHD 2021 - ISRAEL

GET BREATHLESS FOR PH 2021

Never before did an entire World understand the concept of being Breathless!

Corona, Covid 19 created a new reality for the world over the past year! In over 100 years the world has not known such a far-reaching pandemic – I can only imagine the journey that our fellow PH friends around the world experienced but can share with you a taste of Israel during Corona and specifically from the eyes of a PH Fellow.

As the news of Corona and its effects on our country and the world at large spread I witnessed the fear, anxiety and concern in the back and forth chatter of our over 100 strong WhatsApp group. As our members chatted with one another they discussed isolation, the fear of how to get to doctors' appointments (thankfully our association was able to secure funding for a taxi service that would subsidise rides to doctors appointments and medical centre check-ups), who to consult with on whether it was safe to leave their homes and on how to remain positive and maintain stable mental health.

None of us could have imagined that this pandemic, the restrictions and the limitations could have continued for



as long as they did. As a fellow working with my “PH friends” for over 4 years I was suddenly overwhelmed with the realisation that never before had I understood what I had heard hundreds of times before: The fear of stepping outside, the lack of freedom to breathe and the uncertainty of how you’ll feel at any given moment. I watched healthy young family and friends get ill with Corona and all I could think was if this was one of my PH Friends it would be too much. I thought about the pressure on my friends’ lungs, the stress they felt walking up the stairs and all of a sudden this theoretical rare disease I had cared about so much became that much more real! I am blessed with good health, my family are healthy and every time I meet someone new on this journey they ask if it’s me or my husband who are not well. I discovered that it might as well have been – We are all so susceptible to unexpected change in our health and we can never know. It could be me, it could be the person next to me on the bus, at the grocery store, helping behind the counter.

Standing in line for groceries, 2 meters apart from the customer in front of me, wearing a medical grade mask, gloves and armed with hand sanitiser I spent an extra moment thinking about my PH friends – this is a day to day fear they might live with – especially if they don’t have early diagnosis and sufficient accessible medical care! And yet, with all the anxiety and concern that Corona created my PH family was sharing funny stories, recommending recipes, focusing on exercise they could do at home and advising one another on how to make sure they saw their grandkids using the modern wonders of technology while still staying safe! How strong and resilient they are! I am humbled by their bravery and by the challenge they face every day and I am honoured to be a part of this journey creating awareness for PH. If I can share awareness for PH with one more person I am grateful!

This year’s restrictions meant the need for an online campaign – and thankfully we have modern technology! We wouldn’t have to focus our awareness campaign on the people who joined our event – we could reach out to new audiences who we had never spoken to. We could speak to total strangers and ask them – have you heard of PH. We decided to focus on 3 areas and I’ll mention each briefly: Women of our country – the mothers, daughters, sisters and wives of Israel! We reached out via social media influencers, fashion bloggers,

marketing and business development gurus who focus on female entrepreneurs and we made sure to make some WPHD MAY 5 noise. Over 100k followers where reached and the conversations were started! In a radio interview with Radio 9, association CEO Aryeh Copperman discussed the realities of living with a rare disease during Corona. Aryeh spoke about woman’s rights to complain about their shortness of breath without being sent to psychologists for their “Stress and anxiety” management – a situation which often leads to misdiagnosis and years of wondering from one doctor to another! He focused the listeners attention to demanding an echo test and ensuring early diagnosis.

Next we spoke to a totally new audience: Netflix Series released the new season of their popular and much awaited series “Shtisel”. This series based on Ultra orthodox Jews has been watched and enjoyed by millions of viewers around the world. We were able to focus on 3 Facebook groups, totalling over 150k followers, sharing posts with interaction comments and discussion about PH. Ruchami, one of the main characters, is diagnosed with PH. The discussion evolves around her pregnancy, her orthodox dilemma and the question of abortion. This intense and very controversial conversation was cast as part of the series as a direct result of one of our special and dear members Oshrat.

Oshrat was ill with PH, had a successful lung transplant and after years and years of yearning for a child decided to use a surrogate. During her process of surrogacy Oshrat met someone on the production team and in her efforts to raise awareness she shared her journey.



Unfortunately, before her beautiful daughters second birthday Oshrat passed away at the beginning of the Corona pandemic. She is sorely missed but for every person who is made aware of this rare disease we are certain Oshrat is guiding this awareness campaign. Her husband Yossi and their daughter continue to be Awareness ambassadors for PH. And finally, while our association makes a point of not getting involved in Middle eastern politics we felt that our patients, members of all parts of society rose to the challenge and showed us all who the real ISRAELI is.

We are very proud of our associations ability to extend beyond the barriers of the Arab/Jewish conflict which exists in our country and around the world at the moment. Using PH as a common focus our members (from all walks of life) where able to focus on extending a hand to one another – we translated our “GIVE PH A HAND” graphic to English, Hebrew and Arabic and had a great response from family and friends of patients and carers around the country who felt united in their attempt to create awareness and put all other issues aside!

Corona has affected us all in different ways around the world and we can all look at it from a global perspective and analyse its affects – both short and long term. For me, as an individual Corona taught me the value and fragility of our health and gifted me with a greater sensitivity for my PH family. Get Breathless for PH! PH Matters!

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



WPHD 2021 - ITALY AIPI

5 MAY World Pulmonary Hypertension Day

On the occasion of this day, we carried out an activity as part of the FACTOR J project, an initiative dedicated to high school students, of which we are proud protagonists in partnership with Fondazione Mondo Digitale and Janssen Italia. We addressed important aspects related to the symptoms and diagnosis of pulmonary hypertension, always referring to the three key words of the FATTORE J project: empathy, respect and inclusion.

The meeting began with a speech by Mirta Michilli (Director of the Fondazione Mondo Digitale) who stressed how challenging it had been to carry out this project in the context of the pandemic: to have brought dialogue back into schools and raised awareness among young students by talking about a rare disease such as pulmonary hypertension and, more generally, about the disease as a component of everyday life. Mirta Michilli stressed the numbers of this project, which are truly exciting: 100,000 young people involved from all over Italy; 600 students connected during the live event on 5 May.

Carolina Kostner, testimonial of our campaign "Life in a Breath" spoke of her commitment to our side, of the message to raise awareness of pulmonary hypertension, of the importance of taking care of ourselves, of listening to our bodies... in a word, of prevention! He reiterated the importance of disclosure, because only by knowing certain pathologies can we recognise their symptoms.

Loredana Bergamini (Medical Director of Janssen Italy) explained how important it is to give voice to patients' stories, as happened in FACTOR J. Through these stories it is possible to learn about a rare pathology such as Pulmonary Hypertension, to work on prevention and early diagnosis, and to keep investing in research for therapeutic opportunities. Dr. Bergamini also spoke of a future in which, in addition to synergies with the clinicians who follow this disease, we will try to create new connections with the institutions so that patients can feel protected and have their demands recognised.

During my speech, I tried to make people understand how complex it is to live with this pathology, through a brief account of my personal experience. Then I wanted to reiterate three key concepts that I consider fundamental: dissemination of information on the

disease and therefore knowledge of it; early diagnosis; and the importance of communicating with a treatment centre of excellence that has in-depth knowledge of the disease, the treatment pathways, and knows how to define the right therapy for each individual patient. I concluded, as usual, with a message of optimism, which has characterised all my webinars, addressed in particular to the young students who followed us. It is possible to live with a disease, it is our duty not to give up in the face of difficulties, and it is also a source of great personal growth to show empathy towards those who are close to us and who are experiencing difficulties.

The first interventions of the young people arrived, involving Prof. Galiè with some questions: "does pulmonary hypertension strike at what age?", "what are the symptoms?", "how can it be prevented?" and "what impact does the pathology have on an adolescent patient?". Prof. Galiè presented a diagram of our circulatory system, explained how it works and explained at what stage pulmonary hypertension occurs, so that the pathology was immediately clear. He then started to answer the children's questions by talking about the symptoms, common to many diseases, such as breathlessness and fatigue, which occur in adolescents as well as adults. He explained that adolescents often experience these symptoms earlier than adults because they exercise frequently, but pointed out that in the more advanced forms of the disease, symptoms occur even during the simplest actions of daily life, such as climbing the stairs or going for a walk. Prof. Galiè, talking about the types of examinations that are carried out after the first symptoms appear, said that certainly the first investigation, non-invasive and very fast, is the echocardiogram. A student asked the professor: "Is it possible to recover from pulmonary hypertension?" and Prof. Galiè analysed the concept of recovery in detail. He gave the example of a pneumonia where the patient gets sick, takes antibiotics, gets well and returns to the state before the symptoms of the disease by suspending the therapy.

The problem, however, is that most diseases are chronic, which means that it is not possible to heal, but it is possible to cure, eliminating the symptoms so that the patient can return to a more or less normal life, but without stopping the medication. It's clear that if you take away the drugs you go backwards. The Professor was keen for the students to understand the process

involved in researching a pathology through clinical trials: the greater the number of patients included in a trial, the better the quality of the results obtained. This process becomes complex when it comes to patients with pulmonary hypertension, because the disease is rare and doctors need to work on a global scale to get the right number of patients into a clinical trial. The good news is that in pulmonary hypertension, over the last 20 years, there has been great cooperation at international level which has allowed the completion of almost 50 clinical trials, with 12 approved drugs; this fact is a success and in some ways a real exception as there are still rare diseases that do not yet have approved drugs. The last girl to take the floor asked the Professor "when and why is a disease defined as rare?". Prof. Galiè quoted the definition of the European Union, which has set the number of cases at 500 (or less) per 1,000,000 inhabitants, and pulmonary hypertension has an incidence of about 60 cases per 1,000,000 inhabitants, the paediatric form (up to 18 years) has lower numbers and stands at 2 cases per 1,000,000 inhabitants. Each rare disease is infrequent and therefore doctors have little opportunity to gain experience, which

is why there are specialist centres dealing with it and why investment in research is necessary, as is the structuring of centres that can work in networks to have the numbers of patients and the statistical capacity to carry out clinical studies.

The meeting ended with a speech by Carolina Kostner, who wanted to greet the students and encourage them to always fight for the desires they have in their lives, but also to inform themselves and to listen and take care of their bodies.

Finally, I wanted to close the meeting by thanking the FACTOR J project, which put us in contact with these young people, to whom we gave a lot and from whom we received a lot: questions, requests, food for thought and emotions. In these months of pandemic, when we are shut in our homes, this activity has been a real breath of fresh air for everyone.

Leonardo Radicchi
www.aiptalia.it





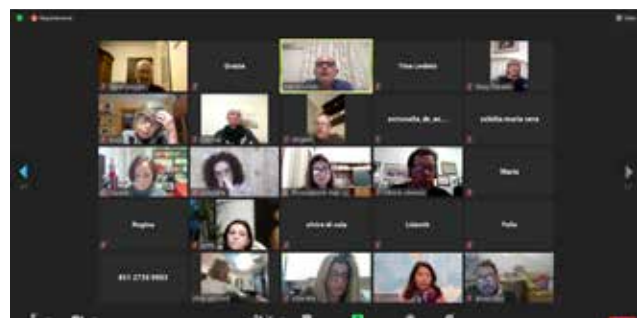
WPHD 2021 - ITALY AMIP

Hello!

Since January AMIP, like everyone else, has had to invent many activities that support pulmonary hypertension patients in Italy, that make them feel like one family, that make them an active part of the diagnosis and therapy process.

We have had a lot of contacts with all national and regional institutions so that PH patients have the necessary care in this terrible period marked by the restrictions of COVID-19. Well in many cases we have succeeded, in others we had to act personally to meet the needs of the sick ... fortunately our members are very close to each other and when someone was in difficulty (even psychological) there was always someone who came to help.

We have organized two meetings, in the web, with our specialists in Palermo and Pavia. The web helps, indeed it amplifies because even people under treatment in other centers in Italy have been able to ask their questions to professionals in Palermo and Pavia.



We organized a scientific conference for the World PH Day on May 5, followed, in the evening, by a jazz concert for us. Great coverage in all newspapers, online and printed, national and local. Our entire scientific committee participated in the event and received numerous questions which they answered in the following days.

We participated in two institutional tables, together with 54 other associations, to make the government understand the difficulties of rare patients. Now a permanent table for rare patients has been set up at the Ministry of Health and it is there that we make our voice heard.

We had to fight with numerous regions because they did not supply the prescribed drugs, but, contrary to any scientific evidence, they wanted to give unsuitable generic drugs.

A member of ours gave us a great gift. On the occasion of her son's first communion, she made solidarity

favours for AMIP.

Our awareness-raising work continues through the jazz concerts that will now take place all over Italy (we started with Milan).

In short, as you can well understand, it was an intense six months and, with the health emergency easing, now even more intense periods await us. But the determination, the desire to fight against bureaucracy and against evil give us an ever greater push to continue with our work.

A little gem: on our journey we have found other people who have joined us to help us. What more do we want? Defeating the PH.

TOGETHER IT'S POSSIBLE!

Laura, AMIP Italy

<https://www.assoamip.net/en/>





WPHD 2021 - LATVIA

PHA Latvia organized a campaign with the title of "I feel better, if..." It was an online campaign which nicely supplemented the visuals and posts from PHA Europe's, which were shared on various social media channels. Thanks to these initiatives within one month we reached 15.584 reached people on Facebook, 8507 impressions on Twitter.

The news about World PH Day events was published via network of Latvian Alliance of Rare Diseases, Latvian Patients' Organization Network, Rare Diseases Coordination Centre, P.Stradins Clinical University Hospital, the Eastern Clinical University of Riga.

We send press release on April 22 about photo contest, and World PH Day online events to the national news agency LETA.

We have the following events:

1. Photography contest "I feel better if..." from 21.04. until 05.05.2021. We received 14 photos for contest with various stories of "I feel better, if...". We published the photos on PHA Latvia Facebook and Twitter profile. 3 independent experts voted for best photo and main prize. It went to person from non-PH patients' community. The Board of PHA Latvia decided to give also recognition award for PH patient's photo for the creative slogan and

positive attitude.

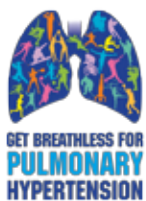
2. Scientific session on 22.04. Presentation of research "Resilience and cognitive distortions in PH patients" results for health care specialists, medical students, researchers in psychology. Lecturer: Gunita Skaldere-Darmudasa, psychology specialist. Scientific session took place online in Riga Stradins University Scientific conference "Health and personal development: interdisciplinary approach". We had 215 participants.
3. Practical workshop "Where do my emotions stay?" about psychosomatic symptoms, emotions and illness. Venue: Zoom online on May 6th. We had 14 participants: PH patients and participants from general public.

On April 23 there was a radio interview on National Radio station "Latvijas Radio 1" with PHA Latvia President Ieva Plume about diagnostics of PH, and non-covered needs of PH patients in Latvia. Radio evening news auditorium by media monitoring data: 25619 people.

Ieva Plume

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WPHD 2021 - LITHUANIA

Each year gives us new experiences and opens up new possibilities. Despite the difficult situation around the world, including Lithuania, due to the COVID-19 pandemic, life continues, and we can enjoy it.

Although the pandemic has suspended all contact events, we are happy to have a great opportunity to spread the message about this rare disease, pulmonary hypertension (PH), from the comfort of our home.

Like the last year, this year we also organized the “Blue Lips” contest to celebrate the World PH Day. Participants were asked to share the pictures with blue lips symbolism under the contest announcement post on the ŽSPHA page. We asked the participants to edit their profile pictures adding blue lips using the snapchat mobile app, blue lipstick or any other means.

We suggested drawing lips on a sheet of paper, palm, shirt, or use other ways to depict them – the most important thing was that blue lips are seen on a picture. We had 16 participants who shared their smiling faces with blue lips. Even more people showed their support by hitting likes under the pictures. The four lucky ones were awarded with gift kits consisting of Brazil nuts, dried mulberry berries, handmade brooches – blue lips or heart-shaped, and a cup with blue lip symbol GET BREATHLESS FOR PH. It would be a great reward to see this competition becoming a beautiful tradition with more and more supporters joining every year.



We were very happy to have been shown support by runners who participated in running on May 5 for those who cannot run – those with PH. We received support messages from Lithuanians who ran in different cities and countries: *Utena, Vilnius, Kaunas, London, Rushden (UK), Širvinta, Aberdeenshire(Scotland), Kudirkos Naumiestis, Ennis (Ireland), Storrington (England), Dublin, Mojacar (Spain)*. We are extremely grateful to these people who have expressed their support for us and sent pictures from their running.



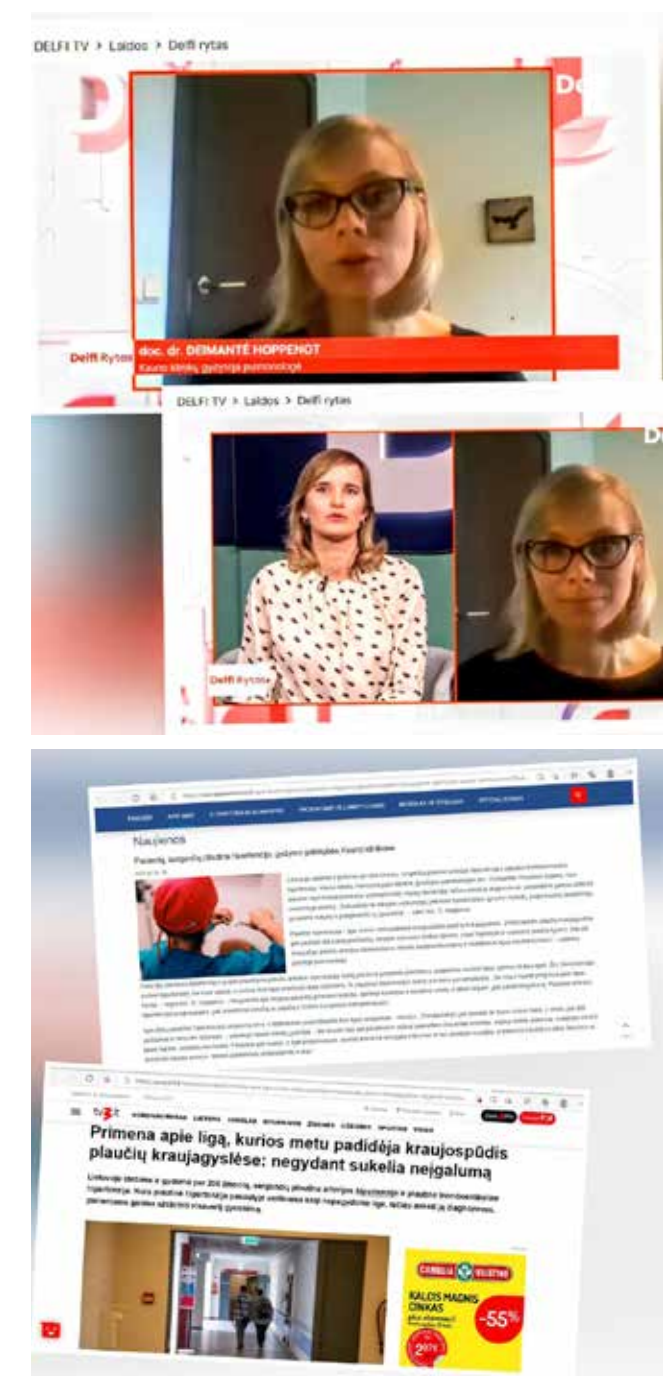
On May 5, four bridges of Vilnius city (the capital of Lithuania) (King Mindaugas Bridge, the Green Bridge, the White Bridge and Žvėrynas Bridge) were lightened up in blue to mark World PH Day. In this way we sent a message of support to those suffering from this complex disease and sought to draw public attention to this disease, pulmonary hypertension (PH). By drawing the public's attention to this, we hope that this will contribute to earlier diagnosis of the disease, which can significantly improve the quality of life of the affected persons and increase their life expectancy. We made a mini-photo shoot with WPHD symbols in the background of blue bridges.



We also made a short video to raise awareness about PH and World PH Day. We shared this video on Facebook and YouTube.

We are very happy to have received support from doctors at the PH Centre, who have contributed to the spread of information about this disease and WPHD through public media. Doctor pulmonologist Assoc. Deimantė Hoppenot participated in the live TV broadcast and talked about pulmonary hypertension – what kind of disease it is and what challenges it raises for those affected by this disease.

To mark the WPHD, two articles were published: one of them on the LSMUL Kaunas Clinic website and another in the news portal TV3.lt. It is wonderful to receive help and support from doctors. It just shows that we're stronger together.



Those affected by PH and not only them have had the opportunity to participate in a remote seminar „Respiratory techniques: Health, energy, peace”.

Participants learned how the quality of life depends on controlled breathing; why we „lose” the right breathing, what you should do to start breathing calmly, deep and rhythmically; what is the importance of diaphragm in the respiratory process, and what exercises strengthen the diaphragm and how to perform breathing exercises safely.

The participants of the seminar were introduced the breathing exercises NADHI SHODHANA (balances the sympathetic and parasympathetic nervous system; helps to control stress, anxiety, fears; treats insomnia, lack of concentration, distraction; helps to calm down) and UJAY (warms up the body; gives the body deep relaxation and calms down the mind while increasing the flexibility of the body).

In addition, in cooperation with doctors, we prepared and printed PH patient passports, which will be given to the patients by their doctor in PH centre. The patient passport shall contain important information about your diagnosis, treatment, and key contacts.

Wherever possible, ŽSPHA strives to help patients and contribute to improving their quality of life. This time,

we have bought pulse oximeters for those members of the organization who still have not got such device but feel the need to have one. This device helps the patient to monitor their health condition at home.

Rima Gruodienė, Žmonių sergančių plautinė hipertenzija asociacija (ŽSPHA), Lithuania

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WPHD 2021 - MOLDOVA

Pulmonary arterial hypertension (PH) is a rare progressive disease that reduces blood flow and causes increased pressure in the arteries of the lungs due to the enlargement and multiplication of cells lining the inside of these arteries. As a result, the walls of the arteries can contract and thicken, causing resistance to the flow of blood flowing through them and thus increasing blood pressure.

In most countries of the world, PH is recognized and registered as a rare disease, facilitating proper detection and treatment. The Republic of Moldova is not part of these countries, moreover, it does not have a register of rare diseases, only a short version for children.

Due to the insistence, including through the courts, from 2018 there is a list of rare diseases, including pulmonary hypertension and the Regulation on how to establish and approve the needs of drugs and medical devices for the implementation of National Programs and treatment of rare diseases.

Affected individuals should consult pulmonologists and cardiologists, who should have the knowledge and skills necessary to diagnose PH. However, in most cases, this disease is misdiagnosed and belatedly diagnosed as heart failure, when PH is already progressing too much.

Information about PH is not brought to the attention of the population, nor in specialized medical institutions - cardiologists' and pulmonologists' offices in Family Physicians' Centers, the Institute of Cardiology of the Republic of Moldova, the Republican Hospital of the Republic of Moldova, etc., nor by family doctors. Family physicians, as well as cardiology ambulance teams, know nothing about PH and can only provide first aid specific to cardiovascular disease. (According to a member of the cardiology ambulance team: "We are not obliged to know everything.")

Moreover, even after demonstrating the results of all investigations, including right cardiac catheterization - no medical council in the Republic of Moldova assumes the responsibility for diagnosing Pulmonary Hypertension. In the best case you can receive a recommendation to go for diagnosis abroad.

Patients, who have managed to prove the diagnosis of PH (either in Romania, in Ukraine or in another country), are ignored by the health system of the Republic of Moldova, being provided only basic blood tests (at medical institutions) and compensation of some drugs for diseases of the cardiovascular and pulmonary system.

In order to obtain access to blood investigations at home, the extension, even provided by law, of the list of reimbursed medicines, the supply of oxygen in the oxygen

cylinder, etc. it is necessary to address countless times to all levels of medical administration, from family doctor to deputy director, or even to the Ministry of Health, Labor and Social Protection.

These urgent needs were possible only after addressing the official letters registered in 2016-2020 and initiating the trial on behalf of the Ministry of Health, Labor and Social Protection in 2017, which is currently pending in the court of appeal (Supreme Court of Appeal). Justice). Despite all efforts, several issues remain unresolved to date, such as:

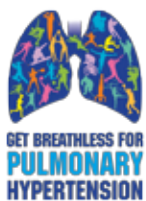
- lack of oxygen ambulances - the average time to find an oxygen ambulance is one hour;
- lack of equipping ambulances with means of transporting patients who cannot travel independently to the ambulance - ambulance teams most often refuse to transport the patient, urging the use of neighbors' forces, the Fire Service, etc.;
- lack of psychological care at home - only the visit to the psychologist's office is offered, even for patients with PH and severe disabilities, who do not have the opportunity to move much;
- lack of information to the population about PH, early diagnosis, treatments, etc. - this is partially covered by the volunteers' money, but in a minimum volume;
- lack of seminars / events for the exchange of experience in the field of PH organized for doctors - all our proposals for organization are not accepted - neither partial funding nor participation in these events abroad due to lack of budget.

However, patients with PH organize themselves into associations, participate in online events, distribute information obtained among relatives and people who support them, without losing hope.

The hope is that the Republic of Moldova will naturally create the conditions for a decent life for people with PH, for which at the moment, it is necessary to fight.

Roman Balmush
<https://phamoldova.org/>





WPHD 2021 - NORTH MACEDONIA

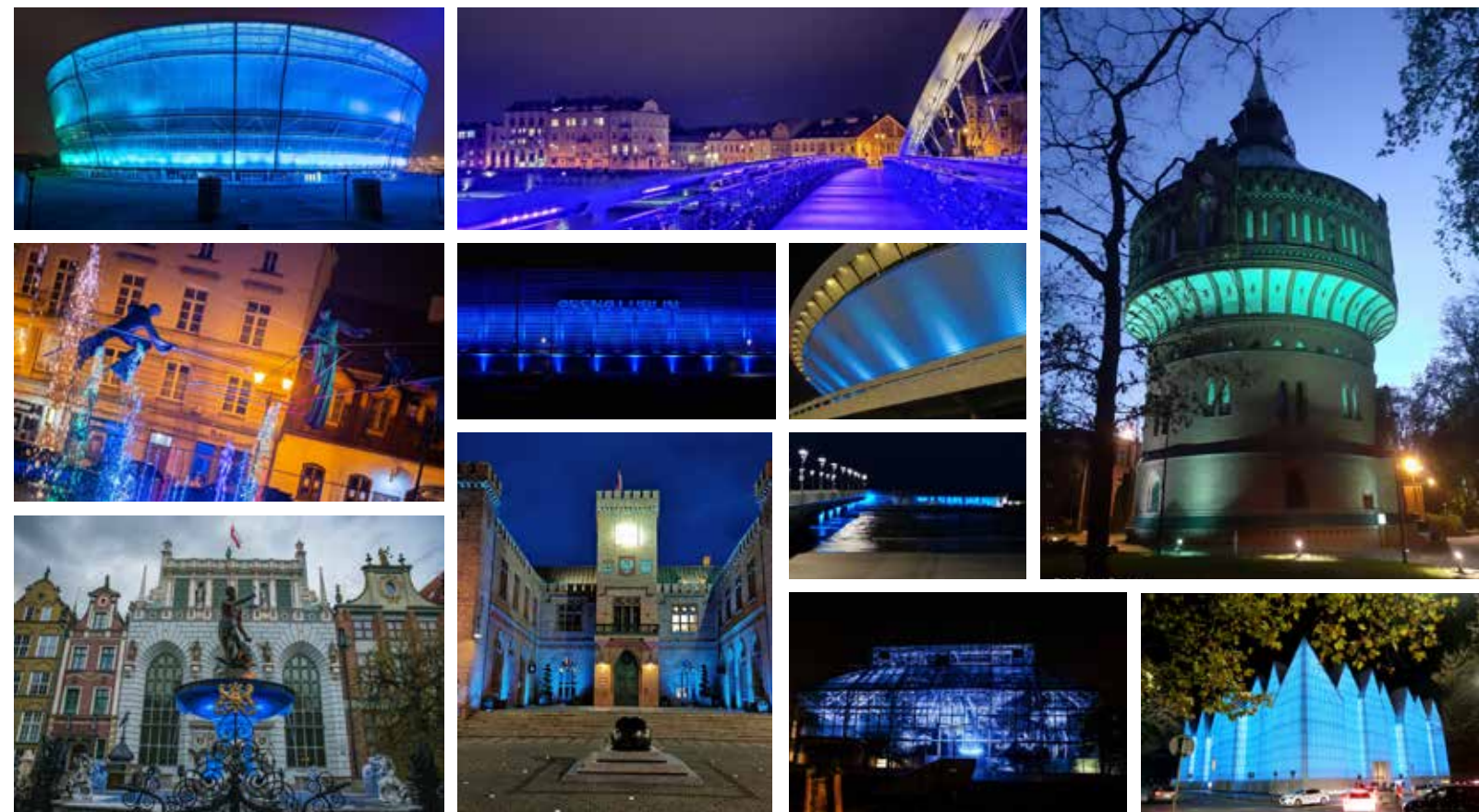
The Association for Pulmonary Hypertension Moment Plus Macedonia this year marked 5 May, World Pulmonary Hypertension Day with participations from our ambassador marathoners which got breathless for patients with pulmonary hypertension in Struga and Ohrid, also Women Handball team club from Gevgelija played for PH patients and Mountain club Kozuv climbed on Kozuv mountain while Zelen raj (Green

Paradise) from Veles climbed on top Kadica, mountain Oraov dol. They all got breathless for patients with PH and they will keep supporting and raising the awareness for pulmonary hypertension.

Ratko Kjaev - APH Macedonia "Moment plus"
<http://www.phmomentplus.com.mk/>



WPHD 2021 - POLAND



This year, during World Pulmonary Hypertension Day in Poland, for the first time, known places in 10 Polish cities flashed blue. It is a symbolic color of patients suffering from pulmonary hypertension who, in the advanced stage of the disease, have blue lips. As part of the "Cities in blue" campaign, buildings and structures were highlighted for PH patients:

- Pier and the Town Hall in Kołobrzeg
- Neptune's Fountain in Gdansk
- Philharmonic in Szczecin
- Sport and Entertainment Hall „Spodek” in Katowice
- Arena Stadium in Lublin
- Footbridge “Bernatka” in Krakow
- Palm House in Zielona Góra
- Wroclaw Stadium
- Water Tower in Bydgoszcz
- Częstochowa Museum
- Balancing Sculptures in the Old Market Square in Częstochowa

All cities posted a note about the action and information about PH on their website and social media portals.

Polish association also organized the online conference “Everyday out of breath – what should we know about pulmonary hypertension?”

The conference was chaired by Patryk Kuniszewicz – radio journalist. The association invited experts, who accompany PH patients in their struggles and help in the fight against the disease. First expert was Professor Adam Torbicki, from Department of Pulmonary Circulation, Thromboembolic Diseases and Cardiology of the European Health Center in Otwock. The subject of his speech was: “Treatment options for pulmonary hypertension: yesterday, today and tomorrow.” Professor gave a very interesting lecture, which showed the history of treatment of pulmonary hypertension. Information on the prospects for a near and slightly later tomorrow was particularly important: new drugs and lung transplants using porcine lung scaffolds. Doctor Małgorzata Żuk, from the Department of Cardiology at the Memorial Institute of the Children's Health Center, presented subject: “Pulmonary hypertension also affects children: diagnosis and treatment”. The lecture made the audience aware that children are not a small adult, that pulmonary

hypertension in children still remains a huge challenge for pediatric cardiologists, and that the treatment developed for adults requires appropriate modification. The last speech: "Living with pulmonary hypertension - the importance of psychological support for patients and their relatives" gave Ms Milena Dzienisiewicz, psychologist, from the European Health Center in Otwock. She pointed to the important role of psychological support for the purposes of psychological help and the symptoms that should prompt patients to seek such help.

The online conference was a big success. Not only PH patients watched it, also journalists. After that, association got inquiries about interviews on the radio and TV, including very popular in Poland, morning program "Question for Breakfast".

PHA Poland recorded a special video, when Marta Mrozek, vice president of association, played the main role. The video is to encourage all viewers to do the "straw test". This test is intended to show healthy people how patients with pulmonary hypertension feels. An English subtitled version will be available soon. This test did not only friends or members of family of PH patients. The Polish volleyball player and coach - Piotr

Gruszka - took up the challenge. Specially for patients with pulmonary hypertension, he made a video, when he made a "straw test". Piotr also posted the film on his profiles in social media.

At the end of the celebration of WPHD, PHA Poland was supported by Tomasz Mrozowicz, a personal trainer. During one of the training sessions, together with a group of participants, all of them did the "straw test". For a minute they did sit-ups, breathing only through the straw, their nose blocked. It was a great visible action.

The COVID-19 pandemic did not stop the association's efforts to spread information about the disease. "Pulmonary hypertension" was very visible in May in Poland, in addition to "Blue Cities", internet campaigns, conferences, recorded video, PHA Poland can add: 4 radio interviews, 4 TV interviews and almost 400 publications on the Internet. Thank you very much to all those who supported the Polish association in organizing the World Pulmonary Hypertension Day!

<https://www.phapolska.org/3916-2/>

Agnieszka Bartosiewicz, PHA Polska
www.phapolska.org - on.fb.me/1ORE2WJ



WPHD 2021 - PORTUGAL

To mark World Pulmonary Hypertension Day, the Portuguese Association for PH, with the support of Ferrer, Janssen and MSD, launched a campaign and a cycle of webinars, with the purpose of honoring patients and caregivers, as well as alerting the population to this pathology and to the importance of early diagnosis. In total, 932.628 people were reached!

"Heroes of the Air" was the motto of the campaign, which consisted of the production of a video and posters with testimonies of three people with PH who lost important moments in their daily lives as a result of the symptoms associated with the disease. We wanted the population to take a break in their busy daily rhythm to reflect on the importance of O2.



The campaign was publicized on social networks (Facebook, Instagram and Twitter) with the hashtags #heroisdoar (#airheroes) #diamundialdahopertensaopulmonar (#wphd) and #aphp.

Here are the numbers obtained: people reached: 45 964; views: 26 700; interactions (likes, comments, website hits): 2 842!

The initiative had the support of a local radio station (called "Radio Oxygen"), which produced a spot to publicize the campaign, alerting people to the pathology.

Two weeks before WPHD, radio announcers invited listeners to celebrate the event and to honor the Air Heroes, by viewing and sharing the video on social networks.

Also to celebrate World HP Day and to educate patients and caregivers on relevant topics to their health and facilitate the access to essential information, a set of three webinars was promoted. The events took place on May 5, 12, and 26,

and were watched by almost 2000 people!

The panel of speakers for each webinar was composed of specialists and health professionals in the PH field. After each webinar, patients and caregivers were given the opportunity to share their doubts and issues in a Q&A session.



Several opinion articles were written by PH experts about the impact of PH on the quality of life of patients and caregivers and the importance of early diagnosis.

The articles were published on regional media, sites and online magazines about health and wellness. Patients were also invited to be interviewed by press (daily and weekly newspapers and general and medical magazines).



Dulce, Sonia and Patricia are PH patients and were invited to be the campaign ambassadors. They wore the Lungs T-shirt and went on TV to raise awareness to PH and promote the World PH Day.

In the last day of our PH Awareness Month, Patricia was also invited to be on the talk show with the highest audience in Portugal. Unfortunately, due to our government's rules, sport



activities with more than 5 people were forbidden in our country. As such we had to develop online activities only. We can't wait to back on track of our WPHD sport activities...

However, we are proud of having been reached almost a million people. Some of them were people with PH that wanted to be part of our family.

Especially after the TV shows, we were reached by a lot of people saying they had the symptoms described by our patients. We guided those people to our reference centers to be examined.

We are proud of the possibility that we have saved these people's lives!

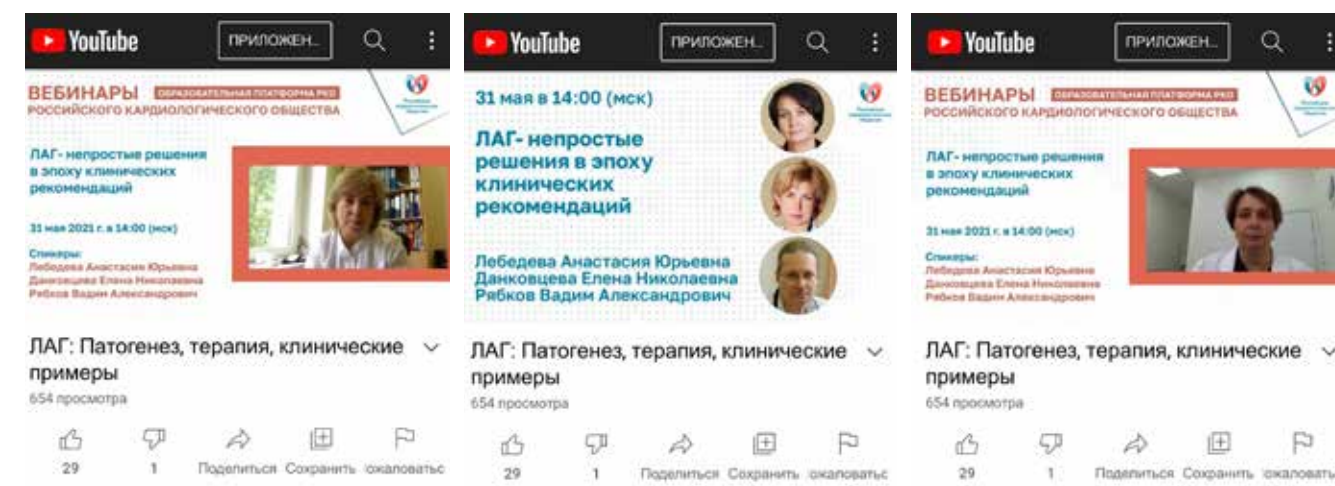
Teresa Carvalho
Associação Portuguesa de Hipertensão Pulmonar
<https://aphp.pt/>
<https://www.facebook.com/hipertensaopulmonarportugal>

World PH Day on TV

<p>Dulce Barbosa, a PH patient wearing the "Lungs T-Shirt" at the morning TV show with the highest audience in Portugal</p> <p>Audience (average): 307 296</p>	<p>Sonia Calado, a PH patient wearing the "Lungs T-Shirt" at a very famous talk show</p> <p>Audience (average): 151 357</p>	<p>Patricia Miranda, a PH patient wearing the "Lungs T-Shirt" promoting WPHD at a news station</p> <p>Audience (average): 189 634</p>
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WPHD 2021 - RUSSIA



Pulmonary hypertension expert center treatment that has been created on the basis of Moscow hospital #51 vascular department is widely known in and outside the Russian capital. Patients from all the country are willing to get help from the medical center experts. Doctors meet lots of interesting and unique patients with the PH pathology in their everyday practice. On 31 May 2021 in cooperation with Charity Association "Save and Protect" a webinar with participation of Deputy Head non-staff cardiology expert of Moscow - Anastasiya LEBEDEVA and Head of cardiology department for patients with Chronic Heart Failure and Pulmonary

Hypertension of municipal clinical hospital #51 – Elena DANKOVOTSEVA took place. They shared their clinical case studies from their personal practice. Online-event was dedicated to PH patient diagnostic, therapy and monitoring questions.

In order to see the webinar video, please follow the link:
<https://www.youtube.com/watch?v=7Zw275Q7SRw>

Lilya Yarullina, PHA Russia "Help and Save"
lilya-belle@yandex.ru

кардиолога г. Москва Анастасия Лебедева, заведующая кардиологическим отделением для больных с хронической сердечной недостаточностью и легочной гипертензией #ГК551 Елена Данковцева поделилась клиническим случаем из собственной практики.

Онлайн-мероприятие было посвящено вопросам диагностики, терапии и мониторинга пациентов с ЛГ.

Ссылка на видео — версию вебинара <https://www.youtube.com/watch?v=7Zw275Q7SRw>

Онлайн-семинар «ЛАГ-непростые решения в эпоху клинических рекомендаций»

Дата и время проведения: 31.05.2021 в 14.00 (мск).

Место проведения: www.savelife.ru

Спикеры:

- Лебедева Анастасия Юрьевна – д.м.н., профессор, заведующая терапевтическим отделением кардиологии, заместитель главного врача по медицинской части ГКБ №51 им. И.В. Давыдовского ДЗМ (Москва)
- Данковцева Елена Николаевна – к.м.н., доцент кафедры кардиологии, клинической и функциональной диагностики с курсом нефрологии ФГБУ ДПО «Центральный научно-исследовательский институт кардиологии» Управления делами Президента РФ (Москва)
- Рябов Вадим Александрович – к.м.н., доцент кафедры госпитальной терапии Медицинского института Петровского государственного медицинского университета (Петрозаводск)



WPHD 2021 - SERBIA

Behind us are a few very challenging years, and we all know how time is important for all PH fighters. That's why we were very happy as we managed to get our vaccines in time after the pandemic of coronavirus that has locked the whole planet, and not only that, during the same year we have successfully held not only a virtual but also a live event to mark the WPHD. You all know us quite well, and you are well aware that we are always striving to overcome all the limits, primarily our own ones because in doing so, we provide ourselves the necessary strength to persevere and to continue our fight. All that reminds us that there is hope for PH patients. You can read more about the events that we have organized during the marking of WPHD in the next article:

1. Scientific meeting on the occasion of the World Pulmonary Hypertension Day

To mark World PH Day in Serbia a great symposium has been held in the auditorium of the Serbian Academy of Science and Arts (SANU). The event was opened by the president of the aforementioned institution, academic Vladimir Kostić, together with honorary patron, great and true friend and companion of our association, spouse of the president of Serbia, Mrs. Tamara Vučić. Her truly inspiring speech has rendered all present in the

hall, especially those who are suffering from PH, as well as all those who are fighting for them and their lives... completely speechless. We were all deeply touched by the energy and emotion that Mrs. Tamara has literally transferred on us...

Together with the most eminent experts in the field of PH, alongside prof Arsen Ristić, prof Slavko Simeunović, prof Jovan Matijašević, prof Seferović, prof Ilija Andrijević, dr Dejan Simeunović, prof Aleksandra Perić Popadić, many of the most influential people in the field of pulmonary hypertension in the world have also given their speeches to all the attendees via video link: prof Marc Humbert and prof Irene Lang, as well as academic prof Samaržija from Zagreb.

On behalf of all suffering from this disease, Danijela Pešić, president of the European association for pulmonary hypertension and the president of the patient association PH Serbia addressed all the attendees.

Besides excellent lectures, all the attendees were presented with the new National register for pulmonary hypertension in Serbia which will include all the persons with the diagnosis of PH in the whole of Serbia, and which will allow easier and faster gathering and analysis of all the relevant data.



Online Simpozijum | 25.5.2021. | 18:00h

SARADNJOM ZA BUDUĆNOST PLUĆNE HIPERTENZIJE

2. Expert symposium „Cooperation for the better future of Pulmonary hypertension“

May is dedicated to the raising of awareness of pulmonary hypertension. This insidious disease which affects the heart and lungs is very often misdiagnosed and it takes a lot of time to get a proper diagnosis. Because of all that, continuous education is of crucial importance.

An expert symposium under the title „Cooperation for the better future of Pulmonary hypertension“ has been held on 25th of May, and the following experts in the field of PH gave their speeches: dr Ivan Stanković - KBC Zemun, dr Jelena Marić Kocijančić - VMA, dr Sanja Dimić Janjić - KCS, dr Senka Milutinović Ilić - IPBV in Kamenica, dr Sandra Peković - IPBV in Kamenica and dr Ivana Veljić - KCS.

Participants of this tremendously important scientific meeting were doctors, internists, cardiologists, pulmonologists, rheumatologists, radiologists, ... and all those who are participating in the process of diagnosing and treating PH patients.

Organizing these kinds of events and meetings, which are more and more frequent in our country to our delight, is helping experts, doctors and scientific community to get more familiar with this disease and to contribute to the timely, and earlier diagnosis of patients with PH, which is of crucial importance to all of those who have to live with this dire disease.

We would like to express our gratitude to the MSD Serbia Company for giving us the opportunity to organize this event.



3. WPHD2021 – RACE #PHMatters

A terrific day spent with great people! We can try to describe in short lines what we have experienced on Ada Ciganlija on Sunday. Sixty different people from all across Serbia has gathered in one place around our Inspired by Hope team with a hope and a great desire to contribute to additionally spread awareness about pulmonary hypertension, so that others could learn what people with PH are facing.

Thank you all. We also have to thank all those who were prevented to be with us that day.

It is noteworthy to mention that a significant amount of funds were raised during this event, around 750 euros were collected, which we used to buy a modern electrical bicycle for our association.

All of us from the association can only thank you. We really gave our best to express our gratitude to you that day. You are one of us, and we are aware that you don't expect anything from us, that's clear to us...but nevertheless, you will always get an honest reaction from us, and great respect which you have certainly deserved.



Upbringing and the love that your parents have planted in your hearts together with a desire to help people around you makes you who you are. You are beautiful and noble human beings.

We are looking forward to new meetings, on track, in the forest, next to the river, or in the mountain... we are eagerly awaiting to hug you again. Slowly but surely, we are becoming a team, a family of completely normal people with a great hope beating in our chests.

Thanks to the Inspired by HOPE team, thank you not only for not giving up but also for being a part of our lives. Thank you on behalf of every person suffering from PH, on behalf of their parents, and on behalf of their doctors. And thank you so much from all of us.

Until next time!

*Danijela and Mirko
PH Serbia
www.phserbia.rs*



WPHD 2021 - SLOVAKIA

This year's campaign for World PH Day was really fruitful. Above all, we tried to provide information about PAH through social networks Facebook, Twitter, YouTube. In addition to the activities we have prepared, few of the unplanned ones took place, which we greatly appreciate. Top health professionals, but also the patients themselves, contributed to this.



1. Online press conference. The severity of PAH, diagnosis, symptoms, signs and treatment were discussed by top specialists MD Eva Goncalvesová and MD Milan Luknár. In their presentations, they mentioned the risks of Covid-19 coronavirus infection and the importance of vaccination in patients with PAH. MD Marta Hájková informed about lung transplants, statistically evaluated the current state and expressed the effort to establish a transplant center in Slovakia in the future. The president of PHA Slovakia, Iveta Makovníková, evaluated the activities of the association over the last 10 years and informed about the Call to Action petition for PAH. 19 articles were published in the media.

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

2. The Vademecum radio show targeted the topic of PH versus PAH. It was broadcast on May 25th. In the one-hour long session, the participants, cardiologist MD Milan Luknár (National Institute of Cardiovascular Diseases) and PHA Slovakia chairwoman Iveta Makovníková as an ex-PH patient after a lung transplant.

<https://www.rtvs.sk/radio/archiv/1690/1572378>



3. Podcast - PAH as Zebra. PAH and problems related to this disease were explained by the head of the Heart Failure and Transplantation department on National Institute of Cardiovascular Diseases and the head of the Center for PAH MD Eva Goncalvesová.

4. Podcast - Lung Transplantation in Slovakia focused on the current state of transplants and visions for the future from the point of view of the doctor Marta Hájková, the Head of the Center for Pre-Transplant Preparation and Post-Transplant Patient Care in University hospital in Bratislava.

5. Fundraising video. Reaching the public to gain support was a very important part of the campaign. Our four PH patient members of the association took part in this fundraising campaign. Thanks to them, we shot a concise video „Help us breath in“ and we received financial support in the amount of € 1006.

https://youtu.be/mcd4k_hv6I4

6. Campaign associated with the sale of cakes. A patient with PAH in her own confectionery did a campaign and took an action to raise some funds. During the WPHD week, she donated the entire revenue from the sale of the most popular dessert to our PH association.



7. Running competitions. We also appreciate the runners' initiative to support our campaign in the World Run and Mountain Park run on May 9 and 11. Runners are our excellent information spreaders about the existence of PAH already for a long time.

Thanks to this year's campaign, we reached out to more than 150,000 people, gained new followers, and provided

advice to people in need. The main partner of the campaign was Actelion / Janssen.

Iveta Makovníková
Združenie pacientov s pľúcnou hypertenziou
<http://www.phaslovakia.org/>



15,00KM 01:31:51



WPHD 2021 - SLOVENIA



This year situation was almost the same than last year due to Covid pandemic. We were in contact with our supporters and ask them to take a training day in our T-shirts and make the most of our event that is in normal situation held in beautiful resort Mostec in Ljubljana. So they actually create a group on Facebook and gather together in small groups and run for all patients with pulmonary hypertension. We must say that they make us proud and quite emotional. They were doing their thing and also raised awareness about our condition.

We send e-mails to everyone who were present on our events in the past. We asked to get some photos and different sports activity came out, from cycling to climbing.

We participated in an hour-long online interview at the Slovenian press agency (STA), the leading Slovenian provider of media content for domestic and foreign audiences. 3 members of our association were joined by Doc. Dr. Barbara Salobir, dr. med. to spread awareness of PH, the long periods required to get a correct diagnosis and to highlight the benefits of patients joining our association.



After the event STA made an exception by sharing our brochures to their entire medicine emailing list in an attempt to make the symptoms of PH more recognisable in the Slovenian medical community.

FLYING THROW THE CLOUDS

Luka Kobler, our Ironman, makes each paragliding jump with a big respect to PHAE community and to patients with pulmonary hypertension from all over the world. So, on the last day of awareness month our association organised a paragliding jump in the beautiful Gorenjska. It was magical and very emotional, because in our thoughts were also PH fighters who are sadly no longer with us.

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





WPHD 2021 - SPAIN ANHP

As every year, the National Association of Pulmonary Hypertension of Spain has run different awareness and fundraising activities to celebrate the World PH Day 2021. Due to the worldwide health crisis that we are living, our activities have been adapted to the current needs, all activities have been online.

From 30th of April to 31st of May, we organize the "Hipersensibilizate: Somos Hipertensión Pulmonar" (Hipersensitize: we are pulmonary hypertension) campaign with Oximesa and Janssen collaboration and the Support of the NeumoMadrid (Pneumology and Thoracic Surgery Foundation of Madrid), SEPAR (Pneumology and Thoracic Surgery Foundation) and Fundación Española del Corazón (Spanish Heart Foundation).

Pulmonary Hypertension Conference Cycles:

- May 5** - Social Perspective of Pulmonary Hypertension with the collaboration of Mr. Álvaro Lavandeira ANHP Lawyer, specialist in health law, Mrs. Laura Municio Fernández PAH patient and student of the Expert: Applied Nutrition in Clinic, Mrs. Sara Heras Mathieu ANHP social worker and Doña Juliana García Pascual patient.
- May 25** - Clinical Perspective of Pulmonary Hypertension with the collaboration of Dr. Iturbe Pulmonologist, specialist in Pulmonary Hypertension at the Hospital de Valdecilla (Cantabria), Dr. Escribano Cardiologist, specialist in Pulmonary Hypertension. Multidisciplinary Unit of Pulmonary Hypertension of the Hospital

12 de Octubre (Madrid) and Don Carlos Veneros patient. It was a workshop for families of children with pulmonary hypertension.

- May 7** - with the collaboration of Dra. del Cerro Head of the Pediatric Cardiology and Congenital Heart Disease Service of the Ramón y Cajal University Hospital, Madrid, Ms. María Morillo Soriano, nurse referring pediatric pulmonology of Child Hospital Vall d'Hebron (Barcelona), Ms. Jennifer Moreno Jiménez, ANHP Psychologist and Doña María Mateos, mother of a girl with Pulmonary Hypertension. In the workshop we addressed pulmonary hypertension, current treatments in the pediatric population, nursing care and the importance of caring for the caregiver.

HÍPERACTÍVATE: Physical exercise in PH

- On May 17 we organized a virtual physical exercise class for people with Pulmonary Hypertension. Made by the Siel Bleu Foundation - "Emotional support: Working negative thoughts"
- On May 27 we held a workshop coordinated by the Association's psychologist. Mrs. Jennifer Moreno, where techniques for dealing with negative thoughts were explained

I ANHP Virtual Race "Leave your footprint for PH"

- From May 28 to 30, this race was held through the Rockthesport application, with more than 80

participants.

- Short videos "Questions and Answers about Pulmonary Hypertension"

We have recorded 10 short videos, answering questions about Pulmonary Hypertension. All of them are available on our youtube.

Illumination of monuments Wednesday, May 5

San Mamés Stadium of Athletic Club de Bilbao (Bilbao)

- The 4 posts of Ávila
- The City Council of Gandía (Valencia)
- The Malaga City Council
- The City Council of Lorqui (Murcia)
- The fountain in the Plaza de España and the Plaza de D. Juan de Austria in Seville

The awareness and the sensitization are one of our

priority aims. It's transversal in our all activities. But around the 5th of May we increase our effort with this subject, and we are enormously proud of the result. We work very hard so that people know our pathology because having a proper diagnosis and treatment is very important to improve our quality of life.

Currently, the cure does not exist, but we will never stop until we find it.

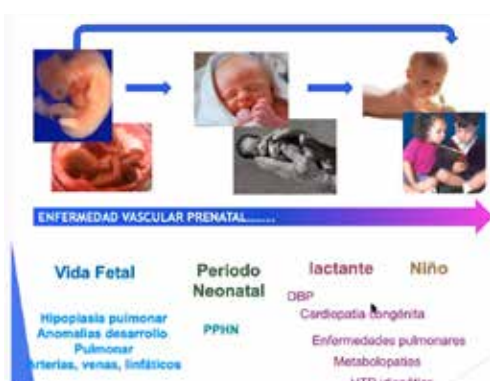
We would like to thank all the volunteers because their selfless work was amazing. THANK YOU.

Eva García

Asociación Nacional de Hipertensión Pulmonar

www.hipertensionpulmonar.es

<http://www.facebook.com/hipertensionpulmonar>



Conceptos relacionados con las distorsiones cognitivas.

CREENCIAS CENTRALES



Visión global del mundo, de uno mismo y otros, de carácter profundo y rígido que tiene su origen durante la infancia

CREENCIAS INTERMEDIAS

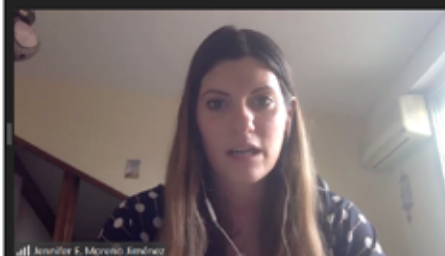


Nivel intermedio de creencias que suelen influir sobre la percepción de las situaciones. Un ejemplo serían las asunciones, actitudes, reglas

PENSAMIENTOS AUTOMÁTICOS



Nivel mas superficial de procesamiento cognitivo. Pensamientos puntuales ante situaciones puntuales (e.g. distorsiones cognitivas)





WPHD 2021 - SPAIN FCHP

Activities of the Foundation against pulmonary hypertension in Spain

The FCHP asks the Minister and the Autonomous Communities to consider Pulmonary Hypertension as a priority group in the COVID19 vaccination strategy. The FCHP has sent a letter to Ms. Carolina Darias, the new Minister of Health, asking that those affected by Pulmonary Hypertension be considered as a priority group in the COVID19 vaccination strategy. Letters have also been sent to the 17 Autonomous Communities, requesting urgent vaccination for those affected by Pulmonary Hypertension.

Enrique Carazo, president of the FCHP, points out that „the aim of this letter is to express our enormous concern about the situation that our patients are going through, and the lack of information about the COVID vaccination deadlines”.

Those affected by Pulmonary Arterial Hypertension (PAH) are a small but highly vulnerable group in terms of the pathology we treat. PAH is a rare, severe, progressive, chronic and fatal disease. It is characterised by high blood pressure affecting the blood vessels that carry blood from the heart to the lungs (the pulmonary arteries). All this added to the risk of being infected by COVID, has meant a very sudden change in the lives of those affected by this disease.

From the FCHP, we request and demand the commitment of this Ministry and the Autonomous Communities, so that we are considered as a priority in the COVID vaccination strategy. For all these reasons, we want to express the urgent need to know the date foreseen for the



vaccination of those affected by Pulmonary Hypertension. The vital risk of contracting COVID is too high for us.

XII pulmonary hypertension day for patients and families

In February we took part in the XII Pulmonary Hypertension Day for patients and families at the HU Clínic in Barcelona. The organisers are Dr. Joan Albert Barberá, Head of the Pneumology Service at the Clínic, Ana M. Ramírez, DUE of the Pulmonary



Hypertension Unit, and the Dr. Carme Hernández, head of the Hospitalisation at Home transversal device (HDOM) at the Clínic.

Webinar: the role of communication and the limits of the disease

In March we held a Webinar with an important topic for those affected by Pulmonary Hypertension. How to establish healthy limits with others, as it is necessary to feel good and respect ourselves, where we understood how important it is and how to communicate them, as Pulmonary Hypertension is a rare disease, and not very visible.

Some questions that we solved thanks to the Social Worker Ana Benlloch and the psychologist of the FCHP María Jiménez were: How do I explain to my doctor



what worries me, should I say my opinion when I am not happy, who should I tell that I have PH, do I always have to explain the same thing, and do I feel that I am constantly justifying myself? It was a success.

Online solidarity yoga class for world PH day

On World Pulmonary Hypertension Day, José Orta, a leading yoga teacher in Spain, organised a solidarity and informative online class to raise awareness of Pulmonary Hypertension through sport. The class taught how to control our breathing, relax and control our body. In this activity we raised funds for research through the BIZUM application with the FCHP number 02276. We thank Clínica Oséo for their selfless collaboration. www.clinicaoseo.com



Reception flat for people affected by PH

The FCHP continues to receive families with Pulmonary Hypertension in the reception flat it has to welcome and help families during their long stay treatments and transplants.

Some of the access requirements:

- To be a member of the FCHP.
- Affected by Pulmonary Hypertension on the transplant waiting list, or have an admission for long-term treatment.
- Be from outside the Community of Madrid.
- Do not receive aid from their Autonomous Regions for this purpose.

The Fundación Contra la Hipertensión Pulmonar works very hard every day to provide useful resources to those affected by pulmonary hypertension and their immediate family.

We are grateful to the Parla City Council that we can count on this flat which is so helpful to those affected by Pulmonary Hypertension in such complicated situations.



PHA Europe annual congress



FCHP participated in the Annual Online Congress of PHA Europe in commemoration of World Pulmonary Hypertension Day. We hope that soon we can all be together once again sharing unforgettable moments together. Congratulations to the organisers for the amazing staging.

Official act of world rare disease day

Once again this year, we attended and participated in the official Rare Disease Day Event, organised by the Spanish Federation for Rare Diseases (Federación Española de Enfermedades Raras). A very different year marked The needs of groups with these types of pathologies have been expressed.

Lighting up buildings in Spain

For World Pulmonary Hypertension Day, several cities lit up their most representative buildings in blue. We thank all the cities for the great welcome on our most important day.



La once coupon on world PH day

The Foundation against Pulmonary Hypertension is the protagonist of the ONCE coupon of Wednesday, May 5th. Precisely the world day against Pulmonary Hypertension. Five and a half million coupons and people will support research into this disease. Patricia Sanz, vice-president of the ONCE General Council, has given Enrique Carazo, president of the Foundation against Pulmonary Hypertension, a framed poster with this coupon that includes the phrase „Will you help us to research?”



The ONCE (NATIONAL ORGANISATION OF THE SPANISH BLIND) coupon is one of the most important games in Spain.

Multidisciplinary meeting MSD

We participated in the World Pulmonary Hypertension Day Conference, organised by @msd_es. In this way a true Multidisciplinary Unit in Pulmonary Hypertension is being created. To improve the quality of life of those affected and their families with Pulmonary Hypertension. Together we are more!



X. PH research meeting

The 5th Meeting of Research in Pulmonary Hypertension is held. The Foundation Against Pulmonary Hypertension is the only official collaborator of the EMPATHY project, since the beginning collaborating with funds for research.

Enrique Carazo in his speech representing our organisation, and thanking each one of you who support with your grain of sand to continue with the research of this cruel disease. The FCHP has given more than 360,000 euros to research since its beginnings, because it is one of its priority objectives. Dr. Barberá dedicated some moving words to the great work carried out by our organisation.



Presentation of a grant and a donation to research into pulmonary hypertension

During the first half of the year, the FCHP has given 48,000 euros to research into pulmonary hypertension.

A donation to the project of Dr. Diana Valverde from the University of Vigo, another donation to the PASION HP GENETICS Project to Dr. Jair Tenorio from the Hospital Universitario La Paz/ IMGEMM (Madrid) and a grant to Dr. Ángel Cogolludo from the Universidad Complutense de Madrid. We are very proud of these contributions, giving hope to those affected and families with PH. Because research is the solution.



Webinar: experience in pulmonary hypertension one year after covid_19

Pneumologists and cardiologists of first level in Spain, explained and solved doubts with the experience of one year with the COVID_19 in those affected in Pulmonary Hypertension. We are left with one sentence: „We can conclude that vaccines for COVID_19, not only are safe, but, in those vulnerable patients with chronic respiratory diseases, they are a priority”.



Making a difference in rare diseases: the value of research

Our President, Enrique Carazo, participated in the event organised by the Spanish Federation for Rare Diseases and Alexion Pharmaceuticals, 'MAKING A DIFFERENCE IN RARE DISEASES: THE VALUE OF RESEARCH'. Enrique discussed the importance of fundraising for research, one of the main objectives of the Foundation Against Pulmonary Hypertension. For this very reason, we are a reference point with several mentions and prizes awarded. In addition, we have been granted several research projects by our Pulmonary Hypertension researchers.



Enrique Carazo Minguez
FCHP Fundación Contra la Hipertensión Pulmonar
<https://www.fchp.es/>
www.facebook.com/fundacionhpe



WPHD 2021 - SPAIN HPE



World PH Day 2021

Throughout the month of May this year, HPE-ORG carried out a series of activities under the slogan "A responsible patient: the key to self-care". In addition to our own activities, we have joined the worldwide #PHMatters campaign. Due to the special circumstances caused by COVID-19, almost our entire campaign was conducted in online format, although we finally managed to carry out a sporting activity in person.

Our actions during this month have consisted of three online webinars in which we have put on the table the needs of people affected by PAH, focusing on the co-responsibility of the patient's health care together with the health staff, considering the health of the person/family as a whole, meaning inherently from the three basic aspects of health: biological, psychological and social. The webinars were moderated by two journalists with experience in medical/patient communication, Loreto Silvoso and Luís Fraga, with the participation of patients: Carmen Buján, Sagrario Pérez, Sofía Di Stefan and Pere Ballbé and with specialists in each subject: Ms. Mar Sevillano, supervising nurse at the Hospital La Vall de Hebrón in Barcelona, Dr. in social psychology María Palacín, the dietician-nutritionist Cristina Lafuente and Dr. Closa. in rehabilitation Coxita Closa,

who explained to us, from a human point of view, everything that we, as the main interested parties, can do for ourselves, not only to take care of our health, but also how to improve it, to take responsibility for it, to get involved in the processes with the disease, to be more autonomous, safer and more confident in the management and its processes, always with the aim of gaining years of life with quality. Being an active patient involved in self-care is our responsibility and taking care of our health is our duty. It is of utmost importance that we become involved in the knowledge of the disease and its management, knowing how different factors such as: belonging to a social group with a common nexus PAH, taking care of our emotions, what we think of ourselves and our situation, maintaining social relationships, the importance of a good diet and a good rest, as well as the importance of taking routine and regular physical exercise in a controlled way, affect our health.

As a complement to these webinars, we have launched, together with FENAER, a monographic Podcast on Pulmonary Hypertension, in which all the agents directly involved in pulmonary hypertension speak, such as patients, the president of Pulmonary Hypertension Spain María Rodríguez, as representative and spokesperson of a patients' association, Dr. Manuel López Meseguer,

pulmonologist specialising in pulmonary hypertension and lung transplantation at La Vall de Hebrón Hospital in Barcelona and Ana María Ramírez, nurse at the pulmonary hypertension unit of the Hospital Clínic in Barcelona.

Both the webinars and the podcast, as well as being available online via registration and our website, have been recorded and are available for viewing on our YouTube channel through the following link: <https://tinyurl.hu/qi0U/>

Finally, and after having to suspend it twice, we have been able to carry out in person, although with limited capacity, the Yoga masterclass that we had planned by Lluïsa Lozano, Yoga teacher at the Ananda Kanda Centre.

Besides that, we have also participated in the worldwide campaign #PHMatters by publishing in our social networks the materials provided by PHA Europe, which have had a great impact and very good acceptance among all our followers in social networks.

With this World Pulmonary Hypertension Day campaign, we have achieved great growth in all our social networks. Our Facebook followers have increased by 3%, our Twitter followers by 6% and our Instagram followers by almost 5%. We have also strengthened our presence on LinkedIn during the month of May and the videos of the webinars held on the occasion of WPHDay 2021 have had more than 250 views.

In addition to the impact we have had on our own, we have managed to get other entities such as FENAER, Corporación Fisiogestión and Somos Pacientes, among others, to echo our publications by sharing our content on social networks to support us and help us to give visibility to Pulmonary Hypertension.

All in all, we can conclude that we are very satisfied with the work done, since one more year we have achieved that at the end of May, more people knew about Pulmonary Hypertension, that they became aware of the importance and seriousness of this pathology and that they knew us as an association and as a fundamental part to consider in the treatment of Pulmonary Hypertension.

María Rodríguez, Hipertensión Pulmonar España
www.hipertension-pulmonar.com
www.facebook.com/pg/HPSpain.org

Campaign clipping

[HPE-ORG](https://tinyurl.hu/so0n/)

<https://tinyurl.hu/so0n/>

[HPE-ORG YOUTUBE](#)

[SOMOS PACIENTES](#)

[PODCAST FENAER](#)



WPHD 2021 - SWEDEN

The frustration of patients who have been forced to self isolation for more than a year due to the pandemic has been in centre this spring. Many patients have contacted media to tell their story and the result is quite amazing. PH have never had this kind of media coverage in Sweden before. Major newspapers, TV and radio have

all published interviews with PH-patients. We want to give a big shout out to all these brave people!

Patrik Hassel

<https://www.pah-sverige.se/>





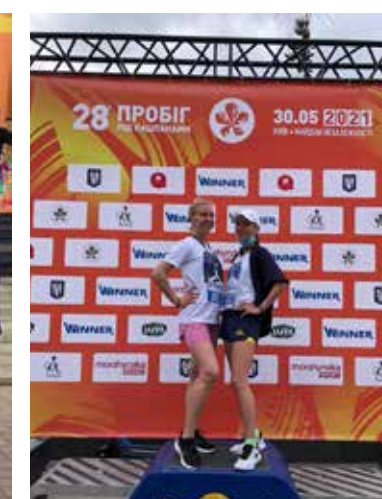
WPHD 2021 - UKRAINE PHA

On the WPHD 2021 the PHA Ukraine organized and held a number of events:

In mid-April 2021, the PHA Ukraine announced a children's drawing contest "What I Dream About" and an essay competition for adults "My Life with Pulmonary Hypertension" for WPHD 2021. And although there were few participants, the contest aroused great interest. The young participants shared their dreams, and the stories of adult patients made it possible to learn more about their life stories and get to know them better. The winners of the contests were determined on the WPHD and awarded with cash

prizes, which, undoubtedly, made them happy, and in return we received many words of gratitude from our young and adult participants. We hope in the future to hold similar contests on an ongoing basis.

On April 26, 2021, we held an online meeting of PH-patients with well-known Ukrainian PH-doctors, dedicated to a topical issue in the modern world - vaccination of patients with pulmonary hypertension from Covid-2019. During the meeting, issues of concern to many patients were discussed - the need for vaccination, contraindications, risks, possible consequences. The meeting was timely and very productive, as many



of the patients found answers for themselves and, we hope, made the right decision regarding vaccination. On May 30, 2021, the largest sports and charity event in Ukraine and the true tradition of the Ukrainian capital - the "Running under chestnuts" took place in Kyiv. This is the 28th time that such a mass run through the central streets has taken place, and representatives of the PHA Ukraine took part in it, dedicating their race to the WPHD 2021.

All funds raised during the Run are used to save young patients of the Scientific and Practical Medical Center

for Pediatric Cardiology and Cardiac Surgery of the Ministry of Health of Ukraine (purchase of necessary equipment and consumables). It is on the basis of this center the only Pulmonary Hypertension Center for Children in Ukraine was established, so in recent years the PHA Ukraine has always joined this event to be able to contribute to this noble cause.

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



WPHD 2021 - UKRAINE PHURDA

5 MAY 2021
World Pulmonary
Hypertension Day

**МИ ПІДТРИМУЄМО
ПАЦІЄНТІВ ІЗ
ЛЕГЕНЕВОЮ ГІПЕРТЕНЗІЄЮ**

5 ТРАВНЯ
Міжнародний день
легеневої гіпертензії



PHA EUROPE
European pulmonary hypertension association
for the patients

In spite of Covid 19 the WPHD celebration was filled with support and emotions. To mark WPHD 2021 PHURDA organized few activities.

First one was photo sessions with participation of singers, musicians, a TV channel director, a scientist in the field of medical law, a leader of a religious community, a director of the regional center of social services, heads of hospitals, doctors and educators. Photos were used for PH promotion campaign.

During May, there were placed 20 billboards and city lights. They all depicted famous people of Ukraine supporting PH patients as well as WPHD 2021 and PHURDA hotline number. Lviv City Council and Lviv Regional State Administration supported us with placement of billboards and city-lights. This is a great way to draw public attention to PH issues in the context of the COVID-19 pandemic, braking the information barrier.

On May 5, famous people of Ukraine on their own social pages in Facebook and Instagram called on their subscribers and friends to support WPHD 2021 and patients with pulmonary hypertension. Among them are singers, musicians, artists, a TV channel director, a scientist in the field of medical law, a leader of a religious community, director of the regional center of social services, heads of hospitals, doctors and educators.

As a part of WPHD 2021 celebration a session of psychological rehabilitation for PH patients took place.

It was a long-awaited and family-friendly meeting. This was a new format due to Covid19. And, even, the theme of the session was inspired by this phenomenon. The meeting began with a welcoming speech from Oksana Skåra-Kulish and a representative of PHA Europe Hall Skåra. Than Andriy Guley spoke about the new opportunities to receive NoLag drugs from Microchim as a part of supporting program. The presentations made by Vilena Kit and Roman Andriievskiy were extremely useful. They contributed to better understanding how it is possible to live flexibly and fully. Participants shared memories and worries that began a year ago due to Covid, and many still suffer from it. There also were discussed significant topics for today including some changes that might happen in future after Covid 19.

In terms of WPHD 2021 PHURDA filmed short videos with commentaries of singers, musicians, artists, a TV channel director, a scientist in the field of medical law, a leader of a religious community, a director of the regional center of social services, heads of hospitals, doctors and educators in support of PH patients and made a short movie to make PH patients in Ukraine more visible and to spread information about PH in society.

As a part of WPHD 2021, we also filmed two informative videos. One tells about the problems and opportunities for PH patients with medicines. Another one discovers the problems and needs in transplantation and rehabilitation in Ukraine. Our informational partner The Pershyi Zahidnyi TV



Channel elucidated WPHD 2021 on TV and radio. It was very important for us to continue «O2Kids» project in the frame of WPHD 2021. We filmed video starring young PH patient Artem who had got e-scooter for St. Nicolas Day. We have «O2Kids» advertisement on radio. We are also planning to collect funds for other kids. It is a wonderful project that brings childhood emotions to every PH child patient.

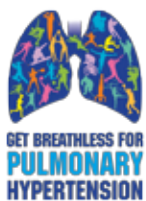
Not less important winning for us as organization is to see how grow the possibilities and projects of our wards. We've supported the project of our PH patient Myroslava Dziubinska. It consists in creation of short social film "Other life". The aim of the project is popularization of PH through the example of strength and brave of the PH patient Myroslava, in the frame of WPHD 2021. "The aim of this film is to inspire, to motivate, to add more hope to the same patients like me. It is important to understand that in spite of longevity of life it depends only on you how you will live with

it: in happiness or in suffering..." – shared Myroslava Dziubinska. In addition, in the frame of legal assistance services for PH patients project that started in May, our patients get legal assistance from the lawyer of PHURDA Andrii Hulei. And Myroslava Dziubinska works on the legal registration of her own organization. Here we also speak about group and individual consultations as for increasing of legal awareness among PH patients and their families.

The support from PHA Europe is very precious and strengthens every patient individually and all together. A pleasant bonus of recognition of our activity is receiving a diploma for the contribution into charity development.

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





WPHD 2021 - ALL OVER THE WORLD: CANADA



Again this year, World PH Day was celebrated virtually. Nevertheless, PHA Canada's #PaintCanadaPurple campaign raised awareness of pulmonary hypertension and highlighted the strength of Canada's PH community. The Canadian PHamily marked the occasion by wearing purple, sharing photos online, and spreading messages of hope and determination! Stories of Canadians living with PH were also featured by several print, radio, and TV news outlets.

Since 2014, PHA Canada's #PaintCanadaPurple campaign has aimed to illuminate monuments and landmarks

across the country in purple to highlight World PH Day and raise awareness of pulmonary hypertension. Canada's PH community answered the call again this year and was successful in getting 17 monuments lit up for World PH Day. Sites like Vancouver's BC Place, Calgary's Reconciliation Bridge, Toronto's CN Tower, and Halifax's City Hall all shone bright purple on May 5th in a demonstration of the strength, unity, and resilience of the global PH community!

PHA Canada
<https://phacanada.ca>



WPHD 2021 - ALL OVER THE WORLD: JAPAN



"6 Minutes Together" for PAH

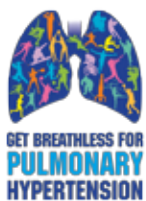
Janssen Pharmaceutical Japan launched the Spotify playlist, "6 Minutes Together" in the aim of transforming the PAH patient's 6-minute walk into 6 minutes of progress together. By collaborating with Spotify, 40 artists from around the world have offered their 6-minute songs. Every song can be used to match patients' walking speed. The playlist also gained endorsement by one of Japan's most well-known artists, Yo Hitoto, who wrote a new song, "6 Minutes" for PAH patients specially in the playlist. Please listen to and follow the playlist.

"6 Minutes Together" - Spotify Playlist for PAH patients
<https://spoti.fi/3x5MKhX>

Furthermore, "60 Minutes Together - PAH Virtual Camp -" was held for PAH patients, their families, and doctors to gather on a virtual platform to learn and think together about the present and future of PAH.

6 Minutes Together Secretariat
JP-PR@ITS.JNJ.com





WPHD 2021 - ALL OVER THE WORLD: TURKEY

To mark the celebrations for World PH Day, all throughout the month of May, our Patient Association organized a number of activities focusing on Pulmonary hypertension along with others concentrating on scleroderma, rare diseases, lung transplants and educational sessions.

We represented our Association in a booth set up at the Virtual WPHD Center. The banners prepared for the occasion by PHAEurope were translated into Turkish.

We also took part in an event organized by the Turkish Cardiology Association providing them with questions supplied by our members with PH and prominent physicians in their fields answered them on-line.

Along with a press-release, our own video filmed by

ourselves on early diagnosis, the risks of living with PH, an invisible disability and lung transplant for PH patients was shown on the 5th of May.

We also started an on-line pulmonary rehabilitation series supervised by an expert. We organized a meeting on nutrition to fit the needs of our members who have been inactive during the lock-down period.

Last but not least, pulmonary hypertension was fictionalized for a game on mobile phones to raise awareness. Thus, for the first time in the world a disease has become a game for mobile phones.

Deger Kesimoglu
www.pahssc.org.tr



WPHD 2021 - ALL OVER THE WORLD: USA PHA



US Connects Digitally for World PH Day

In May, the Pulmonary Hypertension Association (PHA) joined 80 pulmonary hypertension (PH) organizations to raise awareness for World PH Day. This year, PHA launched a new social media campaign, "Together, We Can Fight COVID-19." The campaign promoted the importance of COVID-19 vaccinations. Because of the pandemic, World PH Day festivities were virtual this year, as they were in 2020.

PHA's World PH Day web pages received more than 4,300 views in May, including a toolkit with social media cover images, profile photos and graphics in English, Spanish and French. PHA created and shared 22 World PH Day social media graphics between April 29 and June 1 with the #WorldPHDay2021 hashtag. Support groups were urged to focus on World PH Day during May virtual meetings.

PHA's social media posts included information about PH symptoms and types. In addition to World PHA Day on May 5, PHA participated in International Nurses Day on

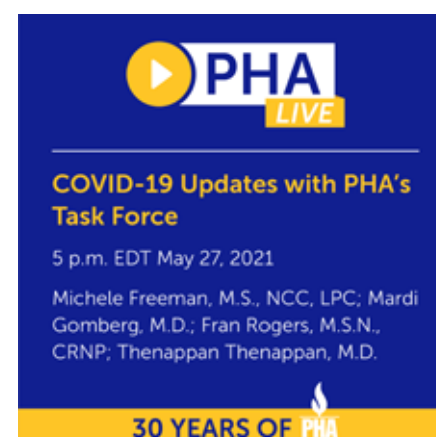
May 12. Social media posts thanked nurses across the globe for taking care of our lungs.

A live webinar event, "COVID-19 Updates with PHA's Task Force," featuring several clinicians who are members of PHA, addressed vaccinations and other issues in the ongoing pandemic and answered questions from the PH community on May 27. All monthly webinars can be watched as videos on the PHA website at PHAssociation.org/PHALive

Throughout the month, PHA encouraged the community to share PH journeys and hopes for the future of PH research, support and care.

PHA reached 63% more people on Facebook than in 2020, and Twitter engagements were up 44%.

Karen Smaalders, Pulmonary Hypertension Association USA
<https://phassociation.org/>
<https://Facebook.com/PulmonaryHypertensionAssociation>



2-3 YEARS
Average time to get an accurate diagnosis for U.S. pulmonary hypertension patients.

75% have progressed PH when they are diagnosed.



Media clippings
Austria

Ihr wurde geholfen, nun macht Maleen Kinderwünsche wahr

Vor sieben Jahren hatte die schwer kranke Maleen Fischer nur einen Wunsch: Pop-Star Justin Timberlake treffen! Der Traum wurde dank „Make-A-Wish“ wahr – nun arbeitet sie selbst für die Organisation.

Seit 23 Jahren erfüllt „Make-A-Wish“ in Österreich die Wünsche schwer kranker Kinder. Auch Maleen Fischer – sie leidet an der seltenen Erkrankung Lungenhochdruck – hatte vor mehreren Jahren ein großes Anliegen: Justin Timberlake treffen! Aus dem Wunsch wurde dank der Organisation Realität. „Ich habe ihn vor seinem Kon-

zert in der Stadthalle backstage kennengelernt und wir haben uns richtig nett unterhalten. Er war total herzlich und abgerollt. Es war eine wunderbare Erfahrung“, so die heute 25-jährige, die das Ergebnis nie vergeißt.

Maleen Fischer traf vor sieben Jahren Justin Timberlake.

von Christine Ziebert

Als „Make-A-Wish“ dann vor einem Jahr Mitarbeiter für das Digital Media Team suchte, war zusehends klar: „Das will ich unbedingt machen, weil der Prozess so toll war.“ Neben ihrem „Fern-Studium“ Creative Writing & Literature in Harvard – ist die Wienerin nun wie 130 ehrenamtliche Mitarbeiter tätig und verfasst Beiträge für Facebook, Instagram und Co. make-a-wish.at

Die Presse am Sonntag
Wien, am 28.02.2021, 52./Jahrg. Seite: 25
Druckauflage: 57.160, Größe: 66,6x96, easyAPC
Auflage: 1348, Clog: 13412852, 58, PH Austria

BRANCHENGESPRÄCH

Alleingelassen zu werden, ist das Schlimmste

Diskussion: Für Personen mit seltenen Erkrankungen hat die Corona-Pandemie eine bereits schwierige Therapie- und Versorgungssituation noch weiter verschärft. Mehr Sichtbarkeit wäre dringend wünschenswert.

Im Interview mit der „Presse am Sonntag“ spricht Dr. med. Barbara Kerschbaum, Leiterin der Abteilung für Seltene Erkrankungen am Universitätsklinikum Wien, über die Herausforderungen für Patienten und Ärzte in der aktuellen Situation. Sie betont die Wichtigkeit von Vernetzung und Austausch zwischen Fachleuten, um die Versorgung der Betroffenen zu verbessern. Ein zentraler Punkt ist die Notwendigkeit, die Sichtbarkeit dieser Gruppe zu erhöhen, um politische und gesellschaftliche Unterstützung zu gewinnen.

Medin

Medin ist eine innovative App, die die Lebensqualität von Kindern mit chronischen Erkrankungen verbessern soll. Die App bietet Eltern und Kindern Werkzeuge, um Symptome zu tracken, Arztbesuche zu planen und sich gegenseitig zu unterstützen. Durch die Digitalisierung von medizinischen Daten und die Einbindung von Experten wird eine ganzheitliche Betreuung ermöglicht.

Leistung: App-Neuheit zur Ermittlung submaximalen Belastungsfähigkeit von Kindern und Jugendlichen entwickelt

Das Projekt ist Teil eines größeren Vorhabens, um die Diagnostik und Therapie von Kindern mit Lungenhochdruck zu optimieren. Die App wird in Zusammenarbeit mit Kliniken und Forschungsinstituten entwickelt und soll in naher Zukunft für eine breite Gruppe von Patienten nutzbar sein.

Belarus

Новости

Турнир в поддержку людей с легочной гипертензией

В Беларуси прошел турнир по волейболу в поддержку людей с легочной гипертензией. Соревнования прошли в спортивном зале, где собрались спортсмены из разных городов. Турнир был посвящен поддержке людей, страдающих от этого редкого заболевания. В ходе мероприятия были собраны средства на лечение и реабилитацию пациентов. Организаторы отмечают высокий уровень мастерства участников и надеются, что турнир поможет привлечь внимание общества к проблеме легочной гипертензии.

Bosnia and Herzegovina

Zavidovići

Zavidovićanin na biciklu već treći put putuje do Albanije za oboljele od plućne hipertenzije

on 26/05/2021

Ismet Škulj, biciklist iz Zavidovića vozio treću vožnju u Albaniju za PH pacijente

Ismet Škulj je biciklist, rekreativac, Zavidovićanin koji svake godine sam organizuje jednu ili više vožnji kroz cijelu Bosnu i Hercegovinu, region ili Evropu. I ove godine je sedam dana vozio do Albanije i nazad za sve oboljele od plućne hipertenzije.

Ruta duga 1.200 km specifična je i po tome što je Ismet na ovom svom putovanju i planinario.

Ovo je Ismetova treća biciklistička vožnja do Albanije za pacijente oboljele od plućne hipertenzije, a peti put da to radi povodom Svjetskog dana plućne hipertenzije – WPHD, – rekla je Vera Hodžić, predsjednica Skupštine Udruženja koje okuplja...

Biciklom od BiH do Albanije u znak podrške plućnim bolesnicima

Prešao 1.200 kilometara. Tokom putovanja pričao sam s ljudima davalu su mi podršku i ispitivali o bolesti, kaže Škulj

Autor: Autor: L. Memić
11. juni 2021, u 06:15

Zeljo sam biti obaveštajac

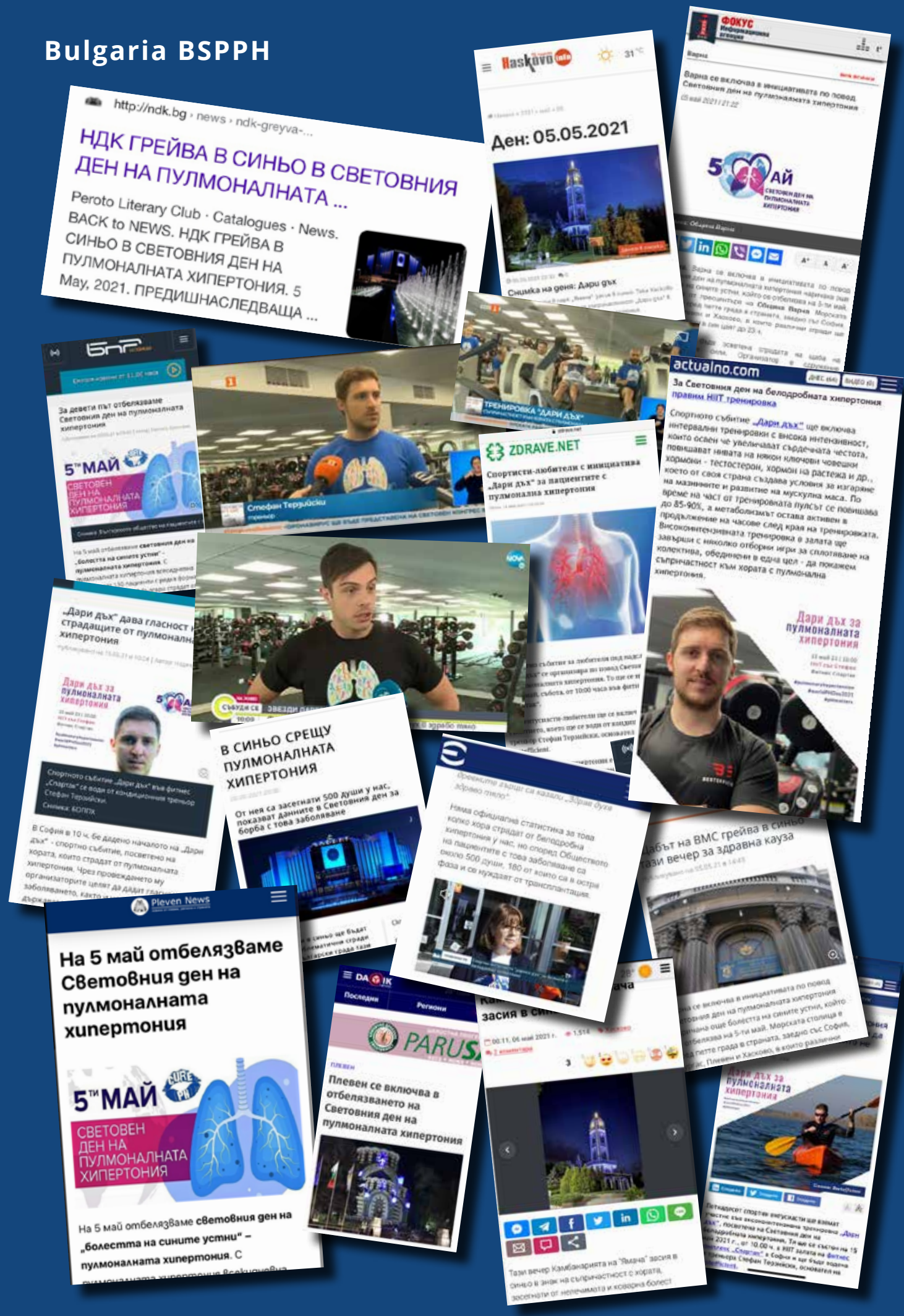
Prijava za "Mars mira" do 1. jula

Škole terapije

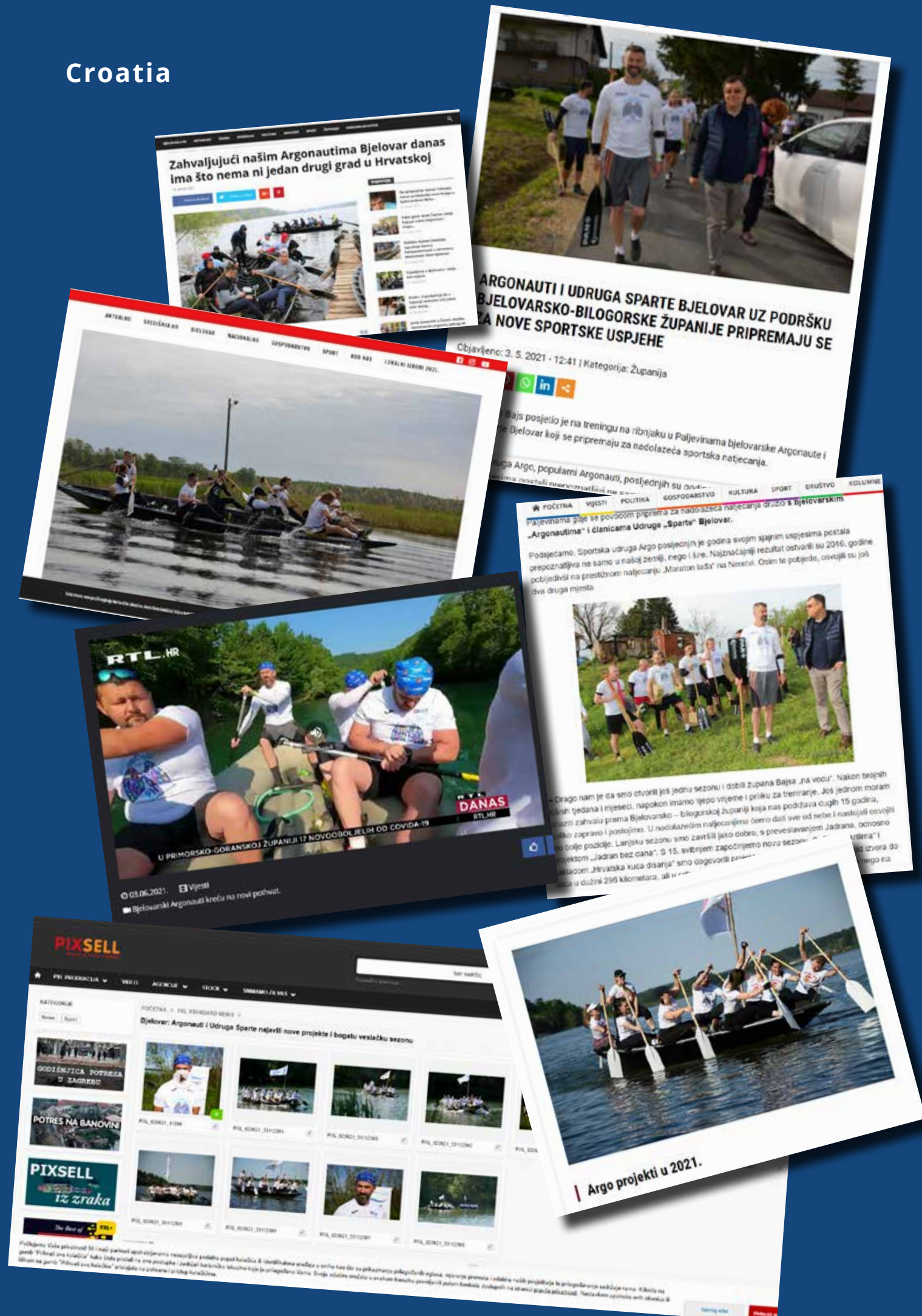
Prilika za memorijalnu manifestaciju

Prva informaciona "Avaz"

Bulgaria BSPPH



Croatia



Czech Republic



POZITIVNÍ ZPRÁVY

Na nebezpečnou nemoc upozornila modrá barva

Na připomínku Světového dne plicní hypertenze se ve středu modře rozzářila řada významných budov v Česku. Modrá je totiž barvou této nemoci, protože pacienti mívají často modré rty. V Česku touto chorobou, která způsobuje zúžení plicních cév a projevuje se dušností při fyzické námaze, únavou či bolestí na hrudi, trpí desítky tisíc lidí. Mnozí však o tom nevědí a riskují vážné zdravotní potíže, kterým lze přitom včasnou léčbou zabránit. V Praze se modře rozzářila fontána Národního muzea, budova ČVUT v Dejvicích, ministerstvo zdravotnictví i nedaulek Tančící dům. V Brně modře zazářilo Mahenovo divadlo, v Olomouci pak tamní radnice.

Typy a fotky do rubriky posílejte na pozitivnizpravy@lidovky.cz



„Plicní hypertenze má řadu příčin, nejčastěji ji lékaři diagnostikují jako komplikaci jiného onemocnění plic a srdce“

několik tisíc lidí o své diagnóze vůbec neví. Tromboembolická hypertenze se léčí chirurgicky nebo angioplastikou a farmakoterapií. Ročně se v Česku provede kolem 30 operací a kolem 80–100 angioplastik pro tromboembolickou plicní hypertenzi.



MEDICAL TRIBUNE

Nemocných s plicní hypertenzí bude přibývat

Brno, 30. dubna 2021 – Dušnost při fyzické námaze, únava, případně bolest na hrudi – to vše může signalizovat plicní hypertenzi, tedy zvýšený krevní tlak v plicích. Tato nevyčleptelná choroba trápí desítky tisíc Čechů, ale řada z nich o své diagnóze vůbec neví nebo se jí dozví pozdě.

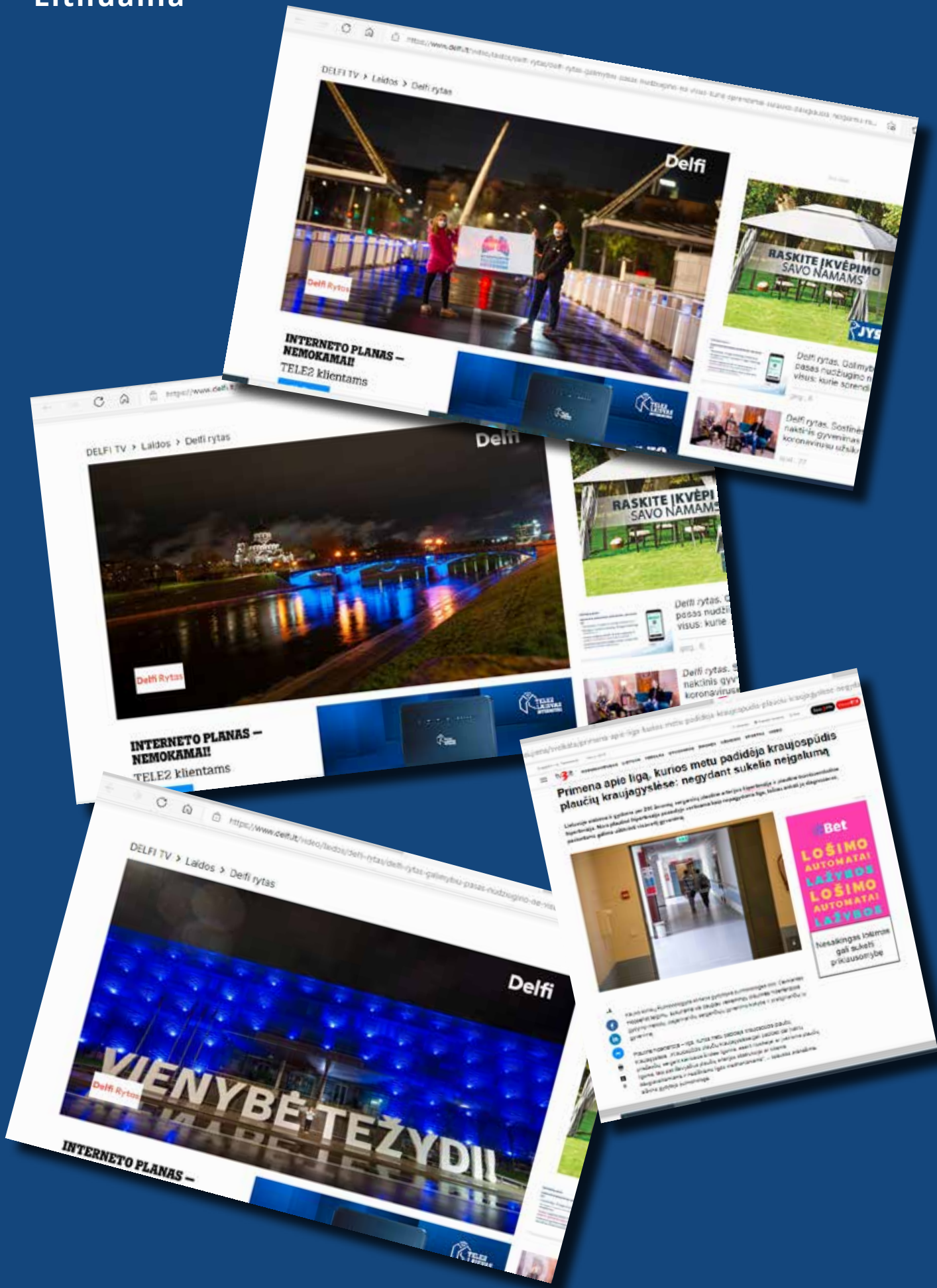


Lékaři jí dávali dva roky života, dvacetiletá Bára ale nemoc porazila a pomáhá ostatním

Hungary



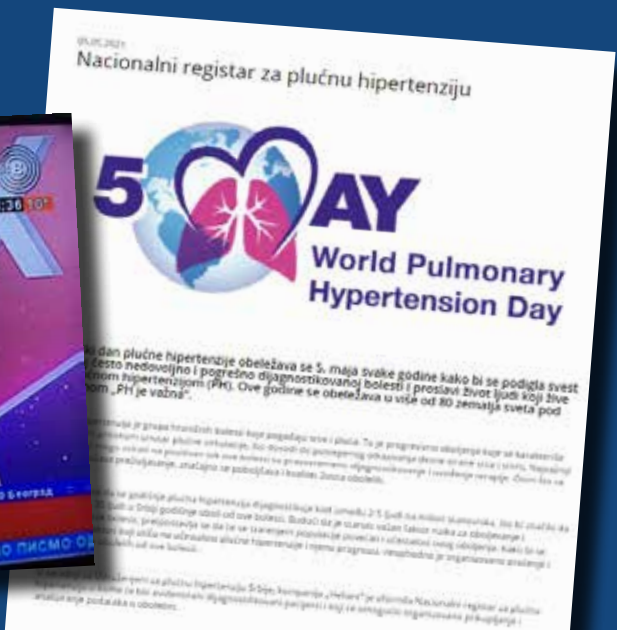
Lithuania



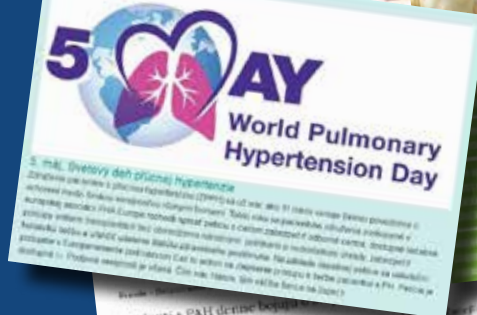
Portugal



Serbia



Slovakia



Slovenia

Spain ANHP

Kaj morate vedeti o pljučni hipertenziji?

Piljučna hipertenzija je ime za skupino bolezni, do katerih pride zaradi različnih vzrokov. Vsi imajo skupno to, da povzročijo težave pri dihanju in s tem povezano slabšo kakovost življenja. Če ne pride do pravega zdravljenja, lahko privede do smrti.

Piljučna hipertenzija - simptomi:

- težav pri dihanju, zlasti pri aktivnosti
- otekanje nog, zlasti zvečer
- utrujenost, zmanjšana zmogljivost
- bolečine v prsih, zlasti pri aktivnosti
- izguba telesne teže
- izguba apetita
- izguba splošnega dobrega počutja

Do diagnoze pride po 12 letih...

Piljučna hipertenzija: ko postane hoja po stopnicah mislija nemogoče

Prenekaterega otroka ali mladostnika se vse prehitro in boleče nekritično primemo ozave, češ da je preveč len ali predebel, da bi bil kos aktivnostim, ki jih njegovi vrstniki opravijo z lahkoto. Ključno napreduje, ki ga je dosegla medicina, je namreč misel, da piljučna hipertenzija še vedno na vrsti med zadržimi – pa ne le v lažni javnosti, ampak tudi v strokovnih krogih, tudi med osebnimi zdravniki, kajti piljučni hipertenziji še vedno vse predolga, po drugi strani pa je zaradi povzročene krvnega tlaka v pljučnem žilu bolnikovo srce vedno bolj obremenjeno. Zgodnja postavitev diagnoze je dobesedno vitalnega pomena, in čeprav znanost še ni odkrila zdravila za to bolezen, zdraviljenje upoštevni napredovanje te sicer usodne bolezni.

Piljučna arterijska hipertenzija

Piljučna arterijska hipertenzija je pogosta pri sistemskih boleznih vezivnega tkiva (zlasti sistemski skleroziji), ki jih sprožijo nekateri toksini (kokain, metamfetamin, alkohol), napredovala jetrna ciroza ali dedna genska mutacija. Zanj je značilno zoženje manjših arterij ter odebelitev in preoblikovanje sten, kar vodi do togih žil, v katere desni prekat srca ne more več normalno pretlačiti krvi. Zaradi tega se krvni tlak v pljučnih arterijah poveča, kar povzroča težave pri dihanju in s tem povezano slabšo kakovost življenja. Če ne pride do pravega zdravljenja, lahko privede do smrti.

Descubre las actividades de sensibilización por el Día Mundial de la Hipertensión Pulmonar

5 MAYO Día Mundial de la Hipertensión Pulmonar

Asociación Nacional de Hipertensión Pulmonar

GRACIAS HÉROES EN APOYO A TODO EL PERSONAL SANITARIO

Gandía se adhiere a la campaña del Día Mundial de la Hipertensión Pulmonar

05 Mayo 2021

Gandía se suma al Día Mundial de la Hipertensión Pulmonar

El Día Mundial de la Hipertensión Pulmonar (DHP) es un evento mundial dedicado a crear conciencia sobre esta patología, una elección grave y compleja que pone en peligro la vida de los pulmonares y el corazón. El 5 de mayo de cada año, las organizaciones y grupos de la salud de todo el mundo participan en una gran variedad de actividades para reducir el riesgo y ayudar a mejorar la vida de las personas con esta enfermedad. La Facultad del Ayuntamiento de Gandía se suma al mayor día del año para contribuir a la sensibilización.

Hipersensibilizate: somos hipertensión pulmonar

DEJA TU HUELLA POR LA HIPERTENSION PULMONAR

CARRERA VIRTUAL ANHP

Deja tu huella por la hipertensión pulmonar

Día Mundial de la Hipertensión Pulmonar 2021

5 MAYO Día Mundial de la Hipertensión Pulmonar

Asociación Nacional de Hipertensión Pulmonar

El Día Mundial de la Hipertensión Pulmonar (DHP) es un evento mundial dedicado a crear conciencia sobre esta patología, una elección grave y compleja que pone en peligro la vida de los pulmonares y el corazón. La Asociación Nacional de Hipertensión Pulmonar (ANHP) se suma hoy orgullosa de ser parte de esta celebración del Día Mundial de la Salud.

El Registro Español de Hipertensión Arterial Pulmonar (REHAP) ya ha incluido a más de 840 pacientes con hipertensión arterial pulmonar de toda España. Actualmente, esta enfermedad afecta a personas de una edad relativamente joven, de los treinta a los 40 años de edad. Y es que, en España, la prevalencia es de 1,5 casos por 100.000 habitantes y año y la incidencia de 4,3 casos por 100.000 habitantes y año.

Spain FCHP

Infosalus

Investigan nuevas dianas terapéuticas par tratamiento de la hipertensión pulmonar, un enfermedad rara y sin cura



Grupo de investigación del CIBERES liderado por Francisco Pérez Viscaino (UCM) al que pertenece Ángel Cogolludo (primera fila izquierda) - CIBER

PORTADA NOTICIAS ÚLTIMA HORA DIÁLOGOS QUIÉNES SOMOS

Monumentos de toda España se iluminarán mañana para conmemorar el Día Mundial de Hipertensión Pulmonar

04 MAYO 2021 | 10:24H | MADRID



Monumentos de toda España se iluminarán mañana para conmemorar el Día Mundial de Hipertensión Pulmonar, según informó este martes la Fundación Contra la Hipertensión Pulmonar.

Así, la Puerta del Sol de Madrid, y monumentos de Toledo, Valencia, Badajoz, Sevilla y Jaén se iluminarán mañana para recordar que la hipertensión pulmonar es una grave enfermedad que no tiene cura.

Asimismo, en el marco de la conmemoración de este día mundial, se celebrará la semana de la investigación donde se entregarán tres cheques a los médicos seleccionados por ser los proyectos más destacados de investigación sobre hipertensión pulmonar.

La ONCE dedica un cupón a la Fundación contra la Hipertensión Pulmonar, para apoyar la investigación sobre esta enfermedad

En el sorteo del 5 de mayo

Fecha: 30/04/2021



La Fundación contra la Hipertensión Pulmonar protaga ONCE del miércoles, 5 de mayo. Precisamente el día Hipertensión Pulmonar. Cinco millones y medio de investigación sobre esta enfermedad.

Patricia Sanz, vicepresidenta del Consejo General Enrique Carazo, presidente de la Fundación contra la Hipertensión Pulmonar, recibe una lámina conmemorativa con este cupón que invierte en la investigación.

Hospital Universitario La Paz

La Paz recibe una beca para un proyecto de diagnóstico genético de la Hipertensión Pulmonar

De la Fundación contra la Hipertensión Pulmonar



El Grupo de Hipertensión Pulmonar del Hospital Universitario La Paz (CIBER-IPAZ) ha recibido una beca de 24.000 euros por parte de la Fundación contra la Hipertensión Pulmonar (FCHP). Este proyecto liderado por los doctores Lázaro y ambos investigadores del Instituto de Genética Médica y Molecular (INGEMM), tiene como principal objetivo el diagnóstico genético de todos los pacientes identificados en España con esta enfermedad poco frecuente.

Universidade de Vigo

Diario da Universidade de Vigo

diana valverde



Para conmemorar la celebración de la semana de la investigación sobre hipertensión pulmonar, la Fundación contra la Hipertensión Pulmonar (FCHP) ha entregado un cheque a la Universidad de Vigo. Este cheque, por el valor de 12.000 euros, será destinado a la investigación sobre la enfermedad.

Spain HPE

Corporación Fislogestión

3 de mayo a las 12:17

JORNADAS VIRTUALES

Con motivo de la celebración hoy 5 de mayo del Día Mundial de la Hipertensión Pulmonar, se han organizado estas charlas enfocadas en mejorar la calidad de vida de los pacientes haciendo hincapié en la corresponsabilidad y el autocuidado, atendiendo a los tres pilares básicos de la salud: el biológico, el psicológico y el social. En el marco de estas jornadas vinculadas a la clave del autocuidado del paciente, la Dra. Conxita Closa realizará, el 14 ... Ver más

WEBINAR "Beneficios y aplicabilidad del ejercicio físico en pacientes con HP"

14 de mayo a las 18h

Dra. Conxita Closa



5 MAYO Día Mundial de la Hipertensión Pulmonar

HPE Janssen

Actividades

Día mundial de la Hipertensión Pulmonar



5 MAYO Día Mundial de la Hipertensión Pulmonar

HPE Janssen

somos pacientes

HPE-ORG Hipertensión Pulmonar España Organización de Pacientes

Día Mundial de la Hipertensión Pulmonar

5 MAYO

5 MAYO Día Mundial de la Hipertensión Pulmonar

HPE Janssen

Fenaer Pacientes

4 de mayo a las 14:00

En el Día Mundial de la Hipertensión Pulmonar, Fenaer Pacientes y Pulmonar España ORG organiza una sesión online con pacientes y charla sobre cómo afectan las relaciones a afectados. Con el apoyo de Janssen. Más información: https://hipertension-pulmonar.com/_/257-dia-mundial-de-hipertension-pulmonar

Masterclass "Convive y mejora tu salud: ¿Cómo afectan las relaciones en tu salud?"

Maria Palacin Doctora en Psicología Social

Moderadora: Loreto Silvestro

5 MAYO Día Mundial de la Hipertensión Pulmonar

HPE Janssen

Un paciente responsable: la clave del autocuidado



5 MAYO Día Mundial de la Hipertensión Pulmonar

HPE Janssen

Un paciente responsable: La clave del Autocuidado

Mesa de discusión hablan los pacientes

Mar Sevillano, Sofia Distefan, Carmen Bujan, Sagrario Pérez, Pere Ballbé.

5 de mayo 16:30

Convive y Mejora tu Salud: ¿Cómo afectan las relaciones en tu salud?

Dra. María Palacin Doctora en Psicología Social

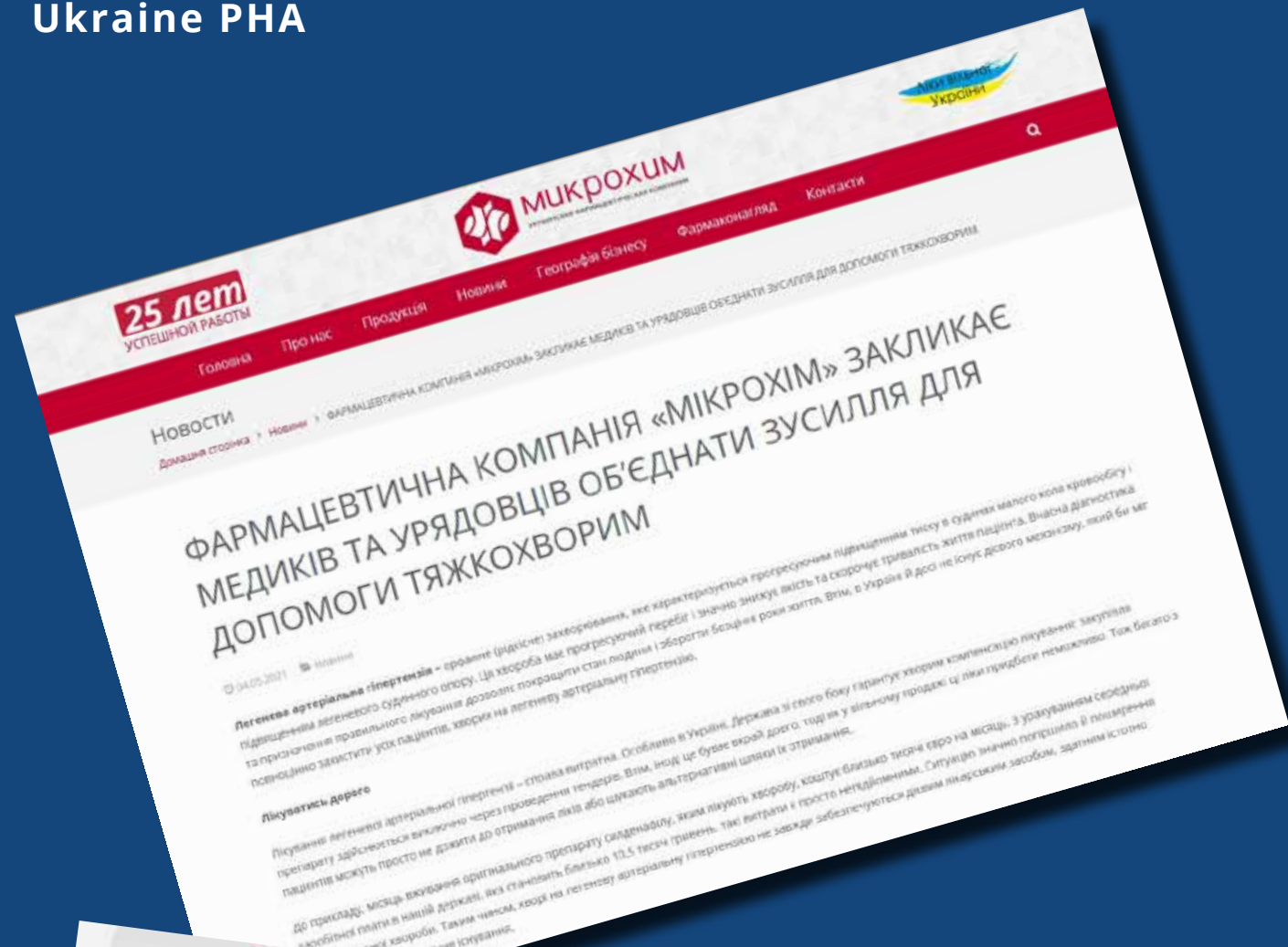
5 de mayo 18:00

Moderadora: Loreto Silvestro

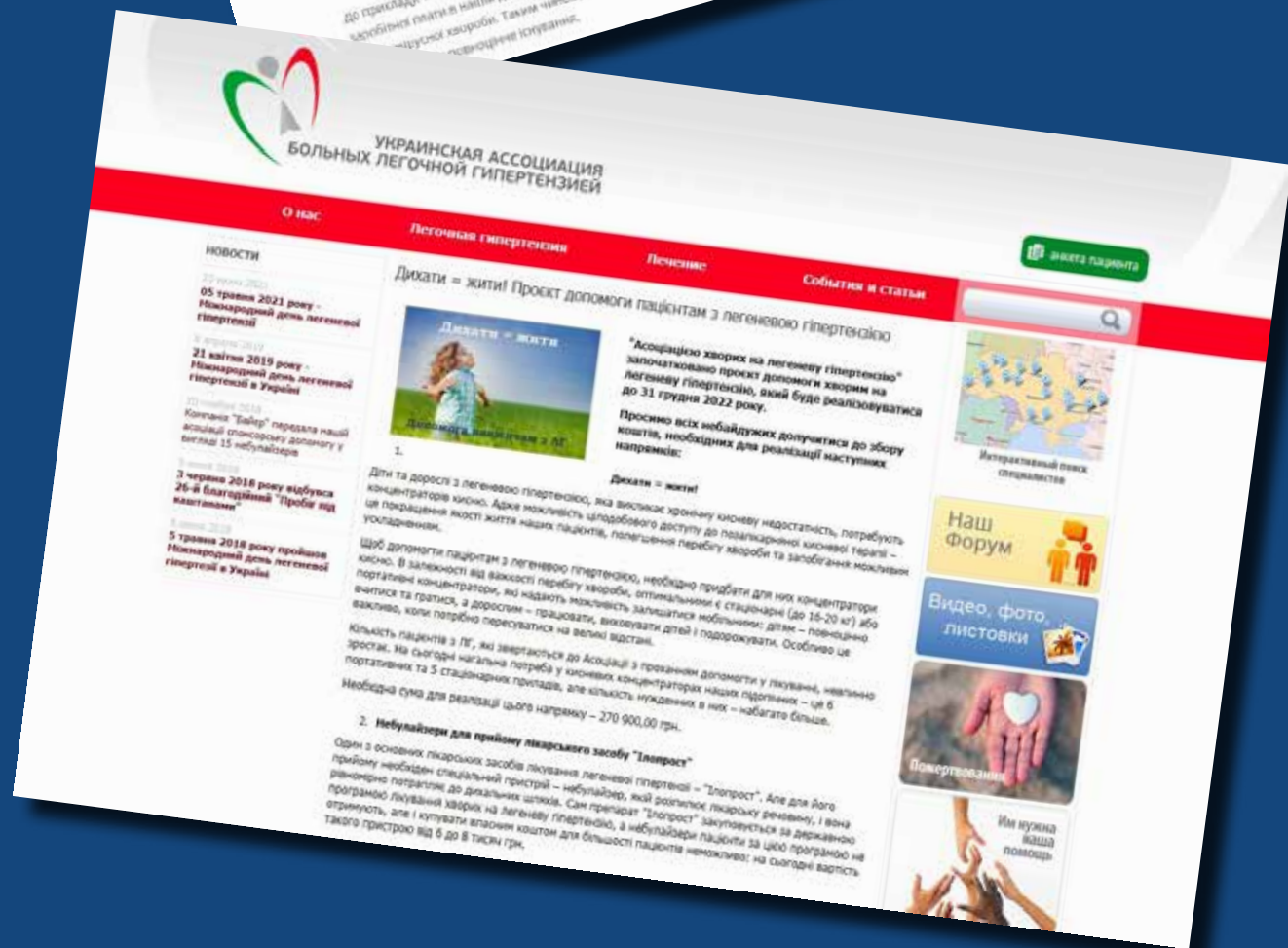
5 MAYO Día Mundial de la Hipertensión Pulmonar

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Ukraine PHA



Ukraine PHURDA



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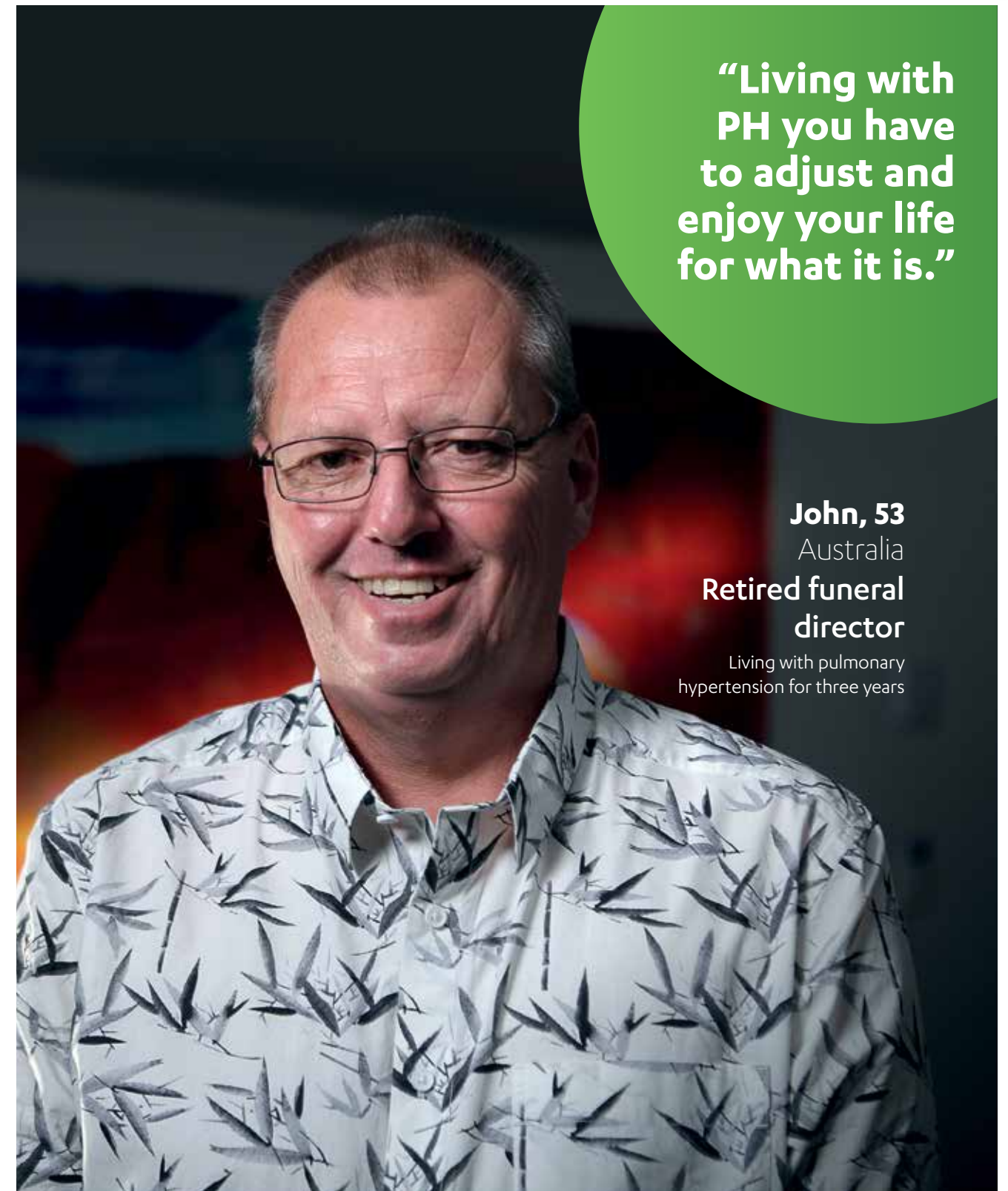


Silver



Sponsors' corner

“Living with PH you have to adjust and enjoy your life for what it is.”



John, 53
Australia
Retired funeral director
Living with pulmonary hypertension for three years

PHuman™



This content has been developed by Actelion Pharmaceuticals Ltd, one of the Janssen Pharmaceutical Companies of Johnson & Johnson.

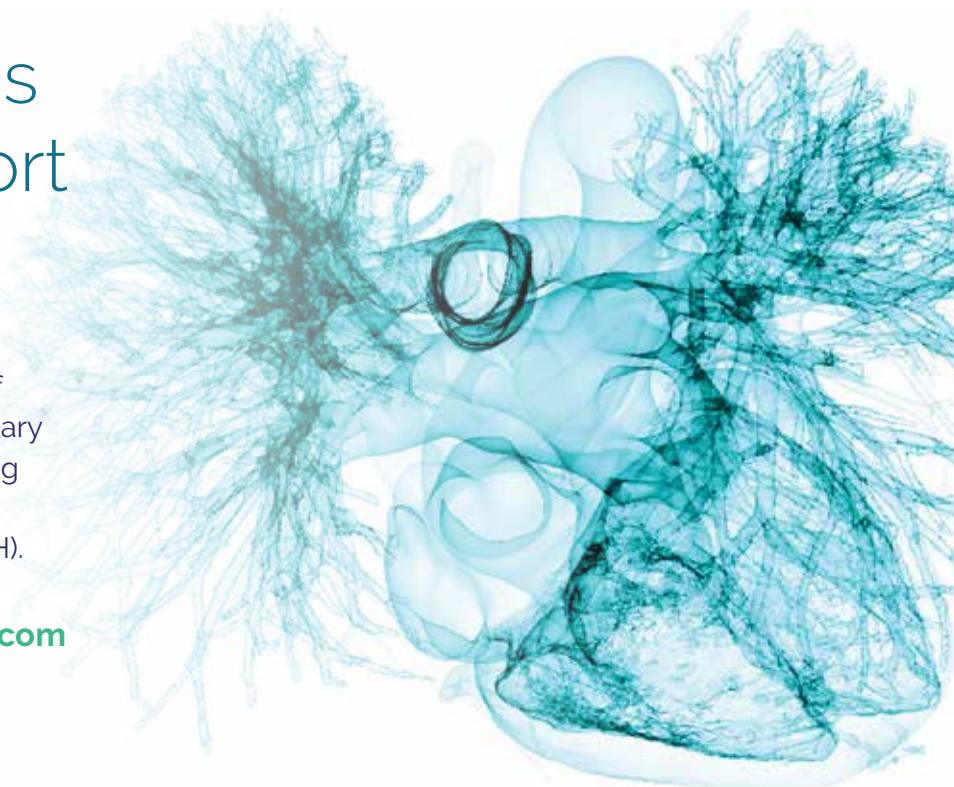
Date of preparation: October 2018

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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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.

Date of preparation: June 2021

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

[@GossamerBio](https://twitter.com/GossamerBio)

Collaboration with Bayer and MSD Making a difference, together

Throughout this issue of Mariposa, the positive impact of projects throughout PHA Europe – on patients, their carers and families – has never been clearer.

At Bayer and MSD, we are committed to supporting patients throughout their entire pulmonary hypertension (PH) journey, and to truly making a difference to patients' lives.

Collaborations between industry and patient organizations ensure our work continues to deliver what patients really need. In the past year alone, financial sponsorship from Bayer and MSD has helped PHA Europe to:



TRACEY HUDDY

Head of Pulmonology
and Established
Products, Bayer

"We won't rest until patients who suffer from pulmonary hypertension can forget their disease and return to a normal life"



ERIC COX

Global Marketing
Head for Heart
Failure and Orphan
Indications, MSD

"Through the work of our local and global teams, we are committed to making a continued difference to the lives of people with pulmonary hypertension"



Reach over **115,800 people** on social media to raise disease awareness in the PHA community¹



Facilitate **public, healthcare professional-led lectures and patient-focussed webinars** to help patients understand their disease



Develop resources and fund over **50 local events** with over **276,600 attendees** to support those living with PH¹



Fostered collaboration with **non-PH groups** across Europe to increase the **impact of awareness activities**

¹ Bayer AG. Data on file: World PH Day 2019 evaluation report. 2019. PP-ADE-ALL-0197-1

Acceleron is dedicated to the discovery and development of innovative, life-changing medicines for patients with a wide range of serious and rare diseases



At Ferrer we are dedicated to working for people with **Pulmonary Hypertension** to improve their physical and emotional wellbeing.

#FerrerForGood



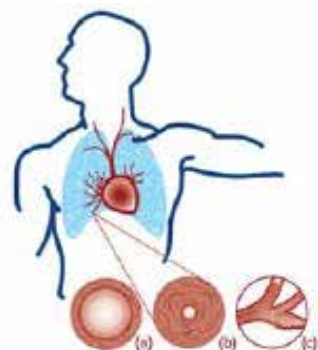
www.ferrer.com

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

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BOSNIA AND HERZEGOVINA



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ugphbih@gmail.com

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ITALY



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CROATIA



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infoplavakrila@gmail.com
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Associazione Malati di Ipertensione Polmonare Onlus



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CZECH REPUBLIC



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