



PULMONARY HYPERTENSION

Mariposa Journal

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

PHA EUROPE *for the patients*
European pulmonary hypertension association

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Editor's memo

SUMMER 2020 EDITION

Dear PHA Europe members, supporters, friends and family members!

Let me welcome you to the pages of our newest edition of Mariposa: you can learn more about this year's World Pulmonary Hypertension Day (WPHD).

WPHD has a long history of celebration: in the first year, in 2012 a conference was organized in Madrid. We have been organizing these series of events for the 7th consecutive year and thought we can build on the experiences we gained from the previous years.

... but suddenly, in the middle of the preparation for this year's activity, on Wednesday, the 10th of March, the World Health Organization declared the COVID-19 outbreak a pandemic. It changed not only the planning and implementation of the projects, but our whole lives. Most of the European countries introduced various measures sooner or later: borders were closed, workplaces, if possible, and schools went online, except for agricultural sector and strategically important industries, production was suspended and, in some countries, citizens were not allowed to leave their homes without profound reasoning. Sport events and public gatherings, our usual partners in WPHD activities and fields of work, were either cancelled or postponed.

Amid these challenging and unprecedented circumstances, the difficult decision as to the next steps

needed to be made. There were a lot of possibilities which included postponing the events to organize them as they were in the past; and the conditions were constantly changing country by country and day by day. Finally, we were brave enough and ran a series of online activities!

- O2kids video – the video which shows the isolation of children with PH and how you can help – was re-launched in our member countries with 22 (!) local language subtitles. This video is a good example of how PH is usually overlooked and misunderstood. The little kid in the video cannot play with his friends... Does it turn into a happy end? You can find the English version of the video at: [youtube link: www.youtube.com/watch?v=ixL9cj58bfU&t=10s](https://www.youtube.com/watch?v=ixL9cj58bfU&t=10s)
- Webinar on access to treatment: Achievements and future plans. It is challenging to find a good subject which most of our members are interested in: it should not be too specific and neither too general. This year we walked around the theme of access with the help of Dr. Stanimir Hasurdjiev, Secretary-General of PACT (Patient Access Partnership) and CEE4. You can learn more about the webinar on the coming pages.
- Photo contest continues to be one of the best awareness raising tools. Each year we introduce

some twist. This time two contests were running parallel: a group of professional photographers voted on the best photo and, simultaneously, everybody could vote and choose the best photos by using the “like” button under the pictures on Facebook. Do you think the same photo was the winner of both contests? You can find it out by visiting the following pages of the journal.



how our members have overcome the difficulties COVID-19 caused and despite these obstacles celebrated WPHD.

In addition to these activities the social media platforms were extremely busy and a lot of informational and eye-catching posts were made both by member associations and PHA Europe. Hundreds of photos were taken, posted and shared. A big applause goes to our members, patients, carers, friends and family members whose hard work and effort made this

year's WPHD celebration happen! We can be very happy with and proud of our achievements! Let me conclude with our appreciation to our medical partners, physicians, surgeons and researchers, who participated in the WPHD events. Without their dedication we would not be where we are now. We also warmly thank our industry partners, who make our work possible and support our projects. Looking forward to next years' WPHD celebration and collaboration!

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Looking forward to next years' WPHD celebration and collaboration!

Gergely Meszaros
WPHD project manager
PHA Europe



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PHOTO CONTEST

PHA EUROPE 2020

WPHD 2020 FACEBOOK PHOTO CONTEST



It became a tradition that we organize a photo contest as part of the World PH Day celebration. This initiative has a multiple purpose: to raise awareness of pulmonary hypertension, to boost our social media presence, to tempt our member associations to make hundreds of beautiful photos, and last but not least to generate a healthy competition. We kept what worked last years, only fine-tuned the technical requirements and made the application as easy as possible. Despite the lockdowns and restrictions COVID brought in 2020, it was a real surprise to see the great variety of the photos: buildings dancing in different colours, smartly caught moments what PH means, some fun with friends and relatives with blue lips and even animals shared our common theme.

This year we received the incredible number 16 photos for the contest – it means almost all of our members who participated in the WPHD celebration submitted a photo!

It is always difficult, if not impossible to choose the best photos from many excellent shots.

We took up this challenge this year in two different ways: a professional jury of photographers was setup from various countries and, at the same, we ran a contest on our Facebook page to see which photos collect the most “likes”.

Stephan Huger and Mike Lindtner from Austria, Evgeni Dimitrov from Bulgaria, Robert Szaniszló from Hungary and Hans K. Aspenerg from Norway had the challenging task to vote on the best photo from professional photographer point of view. For this purpose we launched a special platform (PollUnit) and the photographers could rate the photos from 1 to 5 stars and the photo which collects the most starts will be the winner.

The public voting followed a slightly different approach and we have relied on the identification processes of Facebook: everybody who has a Facebook account

winner

PROFESSIONAL
CONTEST



could vote by using the “like” button under the photos uploaded to the PHA Europe photo folder – it was possible to “like” more than one picture. The voting was open for almost two weeks and we saw big efforts from some of the countries to promote their photo. PHA Europe also promoted the photo album on various social media channels. With these continuous online activities, the total reach on Facebook was over the enormous number of 580.000!

I cannot say how excited I was about these parallel voting processes!

The professional voting was very close and the photo from Serbia emerged as winner.

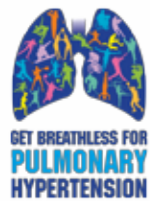
The winner photo in the Facebook contest collected almost 7.000 votes and was taken by Bulgaria PHA.

Portugal came to the second place having more than 1.000 likes and Bosnia and Hercegovina reached 400 likes which meant the third place for them this time.

Let me congratulate the winners and for their awards: the winner of the professional contest will receive EUR 1.000, the Facebook 1st, 2nd and 3rd places will receive EUR 500, EUR 300 and EUR 200 respectively! I would like to also thank for the member associations, who participated in the contest and made excellent photos and valuable work of raising awareness of pulmonary hypertension all over the world. It was a real fun and hope next year even more countries will join and more votes we will see!

Gergely Meszaros





WPHD 2020

ACCESS TO TREATMENT: ACHIEVEMENTS AND FUTURE PLANS

“Raising awareness of PH in the general public” – is always the main motto of the World PH Day celebrations. However, for years now, we provide capacity building opportunities to our members, carers, friends and relatives.

The most practical way of connecting each other is the way of webinars. Most of our members are very busy with their local events around the 5th of May and this year, due to COVID-19, it was the safest way.

Previous years we covered one of the sub-groups of PH, the chronic thromboembolic pulmonary hypertension (CTEPH) thanks to our key opinion leaders on the field. Patient perspective was also provided: we could listen to inspirational patient stories. The activities of ERN-Lung (European Reference Network for Rare Respiratory Diseases) was presented in details and the webinar was concluded by Q&As.

This year we followed a completely different approach: the webinar was rather not a lecture-type of event packed with presentations, but a thinking-together exercise. The webinar also served as a catalyst to our surveys: we are mapping the access, organ donation and transplantation situation in our members’ healthcare systems.

Our key speaker, who raised smart questions to generate lively discussions amongst the participants, was Dr. Stanimir Hasurdjiev, Secretary-General of PACT (Patient Access Partnership) and CEE4.

Stanimir introduced the PACT and CEE4 initiatives and

following that talked about the 5As principle:

- Availability
- Affordability
- Accessibility
- Adequacy
- Appropriateness

It means that those healthcare systems, which meet the above criteria at the same time provide high-quality and equitable access to treatments and other medical services.

We were witness of a lively discussion when the representatives from different countries – based on the above dimensions – endeavored to identify those difficulties and obstacles their healthcare system is suffering from. All of the participants could share their ideas and opinions – the chat box was also very busy! Everybody was surprised that even in case of Norway, due to long travelling times, e-health solutions were proposed to make patients’ life easier.

The webinar was concluded with the common understanding that a lot of work is before us and we need to systematically build it up step-by-step: if we are not aware of the current situation, do not have

enough data and cannot measure the

status quo, how we

plan to make the

system better and

how we can be sure that the changes will ultimately result in better quality of life of patients living with pulmonary hypertension.

Gergely Meszaros



WPHD 2020 - AUSTRIA

The World PH Day on May 5th 2020 was different to the one in the past. Because of the Covid 19 pandemic no events or gatherings were allowed in Austria. With people bound to their homes and enhanced communication through new media – like Facebook or Instagram – PH Austria revived the blue lips campaign from 2012, but this time focussing on Social Media.

PH Austria drew up a concept for the new “#bluelips campaign” and joined forces with PH Europe, which spread the idea to other European countries. The “blue lips campaign” was created to raise awareness for pulmonary hypertension (PH). The goal was to motivate as many people as possible to post a picture with blue lips on their social media channels with our hashtags.

“We wanted to get as many people as possible to take part in the campaign, so we did a lot of media work, made a press release and spoke to media representatives, and of course informed and motivated through our social media channels, f.e. Facebook and Instagram. “With a great success, as we can state today”.

PH Austria made a template and various instruction for

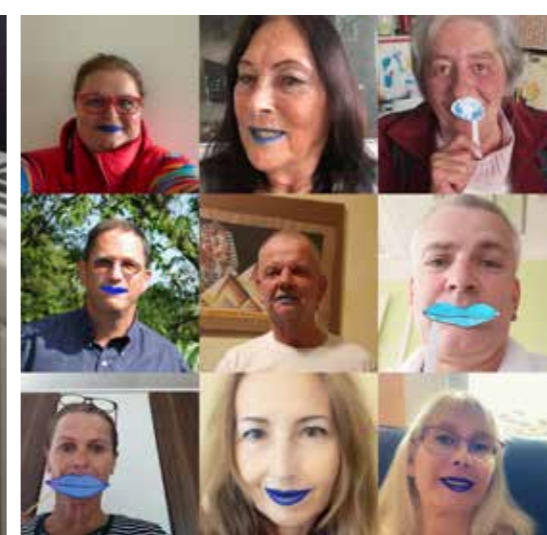
the participation in the #bluelips campaign. To enhance our reach, we collaborated with Austrian influencers. Not only bloggers and influencers have shown their solidarity with those affected with blue-painted lips or stencils. Our members, patients and supporters in particular have also set a sign for more attention, as you can see while looking at the beautiful pictures. In total we shared about 55 posts for the WPHD/#bluelips campaign on Facebook and Instagram and created various Facebook frames.

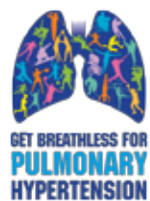
We were very honoured that Vienna's major attraction, the Giant Ferris wheel was illuminated blue on World PH Day to raise awareness for our cause.

PH Austria – Initiative Lungenhochdruck has been working for patients in a variety of ways for 20 years now and is a proud founding member of PHA EUROPE.

Gerald Fischer, PH Austria - Initiative Lungenhochdruck

www.phaustria.org - <http://on.fb.me/RzdEcb>





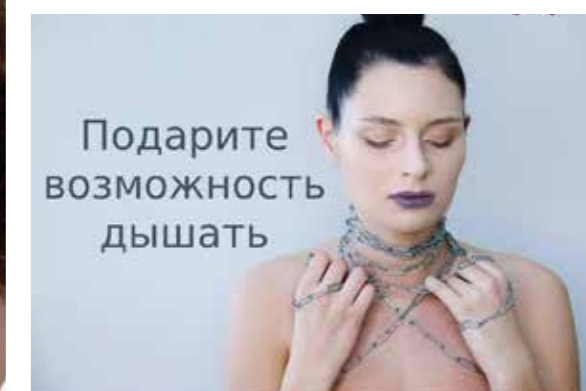
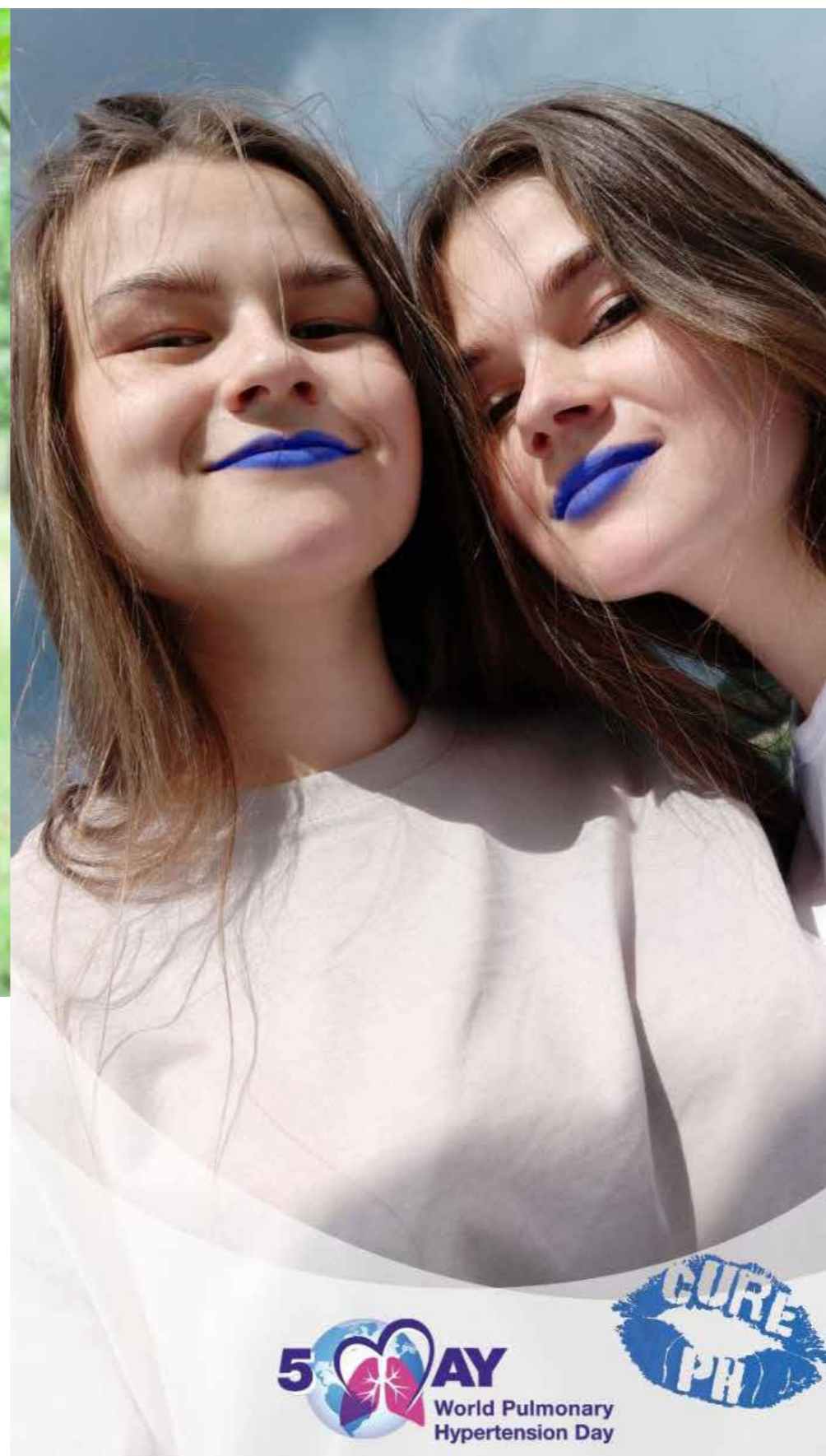
WPHD 2020 - BELARUS

Another nice activity was online yoga for PH patients in cooperation with Irina Sidorchuk from Ukraine who posted online classes for Belarus and Russia at ZOOM during quarantine.

association for Hunter Syndrome, conducted an open psychological lesson, to help patients to get rid of the feeling of anxiety; find peace; point their thoughts in a positive way; learn to deal with negative conditions.

Thanks to the integration with the Russian group our patients were also offered online meetings with a psychologist. For those who needed psychological support, we, together with Republican charity public

*Alina Katsubinskaya
PHA Belarus team*



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As well as in many other countries World PH Day on May 5th 2020 was completely different from all the previous ones due to the COVID 19 pandemic. Although there were no strict precautions from arranging public events in Belarus we sensibly decided to protect our patients, guests and ourselves from the contagious disease.

Instead we tried to draw as much attention to online campaigns and raising awareness as possible. Some of our patients took part in Blue Lips campaign and helped us spreading awareness by sharing the posts. We also

launched an advertising campaign on the Instagram and Facebook and promoted both O2kids video and a picture of the model in chains to get views and followers.

As long as it was impossible to fit all the activities in one day we continued conducting online events throughout the month. We held two online conferences: COVID and PAH – precautions. These were lectures given by the pulmonologist Tsareva. The attendees listened to the information on therapy and safety methods during the epidemic.



WPHD 2020 - BOSNIA AND HERZEGOVINA



Another WPHD marking is behind us. For Bosnia and Herzegovina, this was the fifth participation in the campaigns dedicated to this day organized by PHA Europe. Although this year it was about online campaigns, the Association of Citizens Suffering from Pulmonary Hypertension „Dah” - in Bosnia and Herzegovina organized many activities that allowed us to raise awareness about the disease, a large number of new contacts and new members of the Association. The introduction to the organization of this year’s celebration was an invitation to the followers of our FB page and our friends to use the PHA Europe frames dedicated to May 5th in their profile pictures. The response was very good as over 70 people we know used the PH frame for the profile picture.

KIDS AND BLUE LIPS HAD A FANTASTIC FEEDBACK

From the beginning of May, the official campaigns „O2kids” and „Blue lips” start, and we also get fantastic feedback.

Two short films about the boy Thomas published on our FB page were seen by over 191,500 people. What is special about Bosnia and Herzegovina, and it is related to the „O2kids” campaign, is that we succeeded in the intention for this film to be watched by Thomas’ peers, elementary school students aged 8 to 11, who still do not use social networks. With the help of the school, teachers and parents, in addition to viewing on social networks where the film could be viewed as part of this year’s official campaign of the European Association of Pulmonary Hypertension, we also presented the film in online classrooms. The film caused attention and many

wonderful feelings among the students who transferred their impressions on paper, and sent us many drawings in which the youngest expressed a high degree of empathy for children with pulmonary hypertension. „Drawings as the support of the youngest” is our campaign that spontaneously emerged from the „O2kids” campaign. The campaign „Blue lips” was very interesting and in our country caused a lot of attention and attracted a large number of PH fighters, followers of our site and our friends who wanted to contribute to the celebration of WPHD 2020, but also to raise awareness about this disease in Bosnia and Herzegovina. We collected 136 beautiful photos of blue lips through social networks. The „Blue Lips” campaign caused media attention, so we talked about it, but also about WPHD 2020, during our participation in several TV and radio shows, emphasizing the difficult situation of patients with pulmonary hypertension in Bosnia and Herzegovina.

OUR CAMPAIGNS HAVE CAUSED THE PUBLIC’S ATTENTION

Along with the official „O2kids” and „Blue lips” campaigns for the World Pulmonary Hypertension Day 2020, we launched three more campaigns in Bosnia and Herzegovina: „Drawings as support for the youngest”, „Celebrities with us” and „Stay home”. In addition to the already mentioned support of the youngest, a large number of celebrities from public life gave their support to PH fighters. Doctors, athletes, actors, screenwriters, directors, singers, painters, rap musicians, entertainers, 43 of them supported the patients with short videos and messages „Get breathless



for pulmonary hypertension”. We posted photos of them and 28 short videos of celebrities who had 22,993 views. We are very proud of this support because it has given us a strong public response.

A large number of people from public life heard about pulmonary hypertension for the first time, the media showed interest, and new patients from all over Bosnia and Herzegovina contacted us. By giving unconditional support to the patients, people from the public scene of Bosnia and Herzegovina joined in the celebration of WPHD 2020.

Along with celebrities, we connect the song „Breathe together”, which we received as a gift from our friend and constant collaborator in our activities, author Saša Ristić. Saša, Bojan, Sara, Ester and Ilija surprised and delighted us to tears on the occasion of the World Pulmonary Hypertension Day. In their studios in London and Sarajevo, they made a fantastic song dedicated to the patients with pulmonary hypertension, which became our new anthem. The song was broadcast on the TV program of one of the most watched TV stations in our country, which talked about pulmonary hypertension, patients and WPHD, and how our cooperation and the song itself came about, as well as in the radio program. The „Stay Home” campaign came up as an idea because of the whole situation caused by the Covid 19 virus infection. We asked our page followers to send a message of support from their windows and the well-known slogan „Get breathless for pulmonary hypertension”. And our support came from a small town in Bosnia and Herzegovina, Zavidovici, to Dubai (UAE).

We were really pleasantly surprised where people follow and support us. Apart from Bosnia and Herzegovina, support came from Montenegro, Croatia, Switzerland, the United Kingdom, Finland, Germany, Canada ...

PUBLIC ATTENTION HAS RESULTED IN NEW ACTIVITIES AS WELL

The attention we have caused to our activities this year has resulted in great interest on social networks, but also in the media.

At the invitation of two numerous groups on social networks, we held two presentations on pulmonary hypertension, talking about the disease, symptoms, treatment, the difficult situation of patients in our country, the problems we face, but also the goals we have set. The reactions of the listeners were positive, and a large number of questions followed, which only confirms our claims that we need to work even harder to raise awareness about the disease, but also that people are showing great interest.

In addition to public online presentations, we must mention the attention of the media, which in Bosnia and Herzegovina this year was not absent. We shared information about pulmonary hypertension and this year’s campaigns with the B&H public through four TV reports, two of which were as articles in the main news programs on May 5th, and two were Skype inclusions in the live programs of highly watched TV stations information and interview in two radio reports and an article in the most widely read daily newspaper. We also attracted the attention of the public with

video LED banners on which the announcement of WPHD 2020 and the call „Get breathless for pulmonary hypertension” were displayed in two cities in Bosnia and Herzegovina throughout the whole month of May 2020.

OFFLINE CAMPAIGN

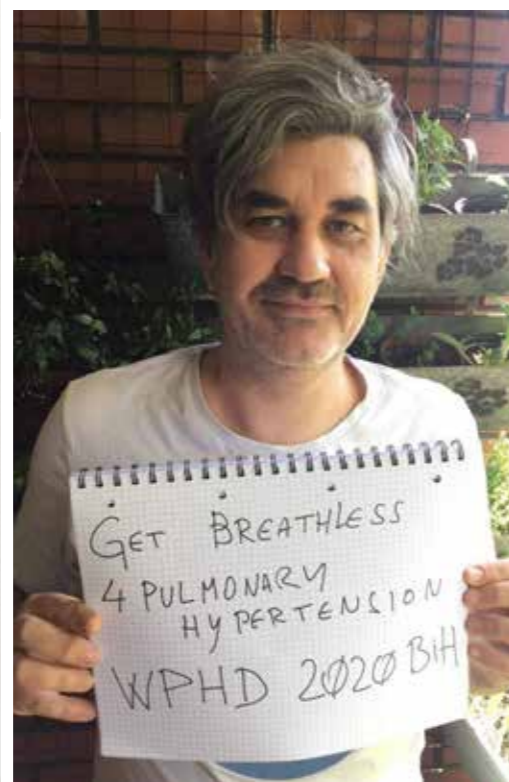
In addition to online campaigns, in Bosnia and Herzegovina we had offline campaigns that are equally important to us.

The constant support of the Association of Citizens Suffering from Pulmonary Hypertension „Dah” in Bosnia and Herzegovina is the support we have had for years from Ismet Škulj, a cyclist, marathoner, recreational athlete. He dedicated his daily route between two towns, Zavidovići and Žepče, to patients with pulmonary hypertension. The thirty kilometers

he drove that day is an easy training for Ismet, but at the same time he is preparing for the long journeys that await him, which will continue to be dedicated to those suffering from pulmonary hypertension. Ismet took this route with the characteristics of the European PH community.

Also, in the city Bihac, runner Enes Ibrahimagic dedicated his marathon in the length of 10.70 km to all patients with pulmonary hypertension. This is the first time we have collaborated with Enes, a long-distance runner, and recorded his races dedicated to the patients. We have agreed on cooperation for all future sports projects to raise awareness about pulmonary hypertension.

Vera Hodžić, Udruženje građana oboljelih od plućne hipertenzije „Dah” – u Bosni i Hercegovini
<http://bit.ly/2aiEJgO>



WPHD 2020 - BULGARIA BSPPH

THE NATIONAL PALACE OF CULTURE LIGHTS UP IN SUPPORT OF PATIENTS WITH THE “BLUE LIPS”

On the 5th of May 2020, for the eight time in our country, we are celebrating the World day of pulmonary hypertension, also known as the “blue lips condition”. Within the campaign entitled “Blue lips” organized by the Bulgarian society of patients with pulmonary hypertension, from 8 p.m. to 11 p.m. on the 5th of May 2020, the building of the National palace of culture in Sofia was lit up in blue. In this way, the capital city’s cultural center demonstrated its empathy with the problems of patients with this rare disease.



130 BULGARIAN PATIENTS WITH THE “BLUE LIPS” CELEBRATE THE WORLD PULMONARY HYPERTENSION DAY FOR THE EIGHTH TIME

About 300 people with pulmonary hypertension in our country remain undiagnosed and without access to expensive therapy.

The Bulgarian society of patients with pulmonary hypertension celebrates the World pulmonary hypertension day for the eighth time. The headline of this year’s initiative to raise awareness about the insidious disease will be “Blue lips”. The campaign is held online throughout the month of May with the support of the





opened doors on the 5th of May at 8 p.m., and his performance in support of the patients was broadcast live on the Facebook page of the Bulgarian society of patients with pulmonary hypertension. Actors Luiza Grigorieva-Makariev, Filip Bukov known from the TV Series "Stolen life", and Vladimir Zombori also supported the initiative with special video messages available for watching on the site and the Facebook page of the patient organization throughout May.

"Every patient with pulmonary hypertension needs two devices – one for at-home use and a portable one, so that he/she can remain physically active as long as possible and avoid the psychological consequences of isolation. Despite our efforts, the National health insurance fund still does not reimburse these medical devices. Most patients in the third and fourth functional class of the disease need expensive intravenous therapy which is within the so-called "compassionate treatment", because there are no drugs for them registered in our country yet. The only chance for patients at a terminal stage of the disease is bilateral lung transplantation. In our country, about 300 persons with pulmonary hypertension remain undiagnosed and without access to expensive therapy", says Natalia Maeva, chairperson of the Bulgarian society of patients with pulmonary hypertension.

Within the campaign O2Kids to help kids with pulmonary hypertension, a donation initiative was started aiming to raise funds for the purchase of a portable oxygen concentrator to be provided to patients in need.

The required amount is BGN 5,900. The first donation for the device was made by the musician Orlin Pavlov who gave BGN 500. The goal was achieved and a portable oxygen concentrator was purchased.



PATIENTS, PHYSICIANS AND MEDICAL STUDENTS TOOK PART IN A WEBINAR ON PULMONARY HYPERTENSION AND COVID-19

Unfortunately, Bulgarian patients are isolated, but this isolation is not unknown to us, patients with pulmonary hypertension. Very few people can understand the situation of a patient with pulmonary hypertension, because every move such a person makes requires immense effort. There are times when you find yourself wondering how to shorten your route or how many words to say to have enough breath. With this message, Natalia Maeva, chairperson of the Bulgarian society of patients with pulmonary hypertension, opened the webinar dedicated to pulmonary hypertension.

The event was organized to highlight the month when we celebrate the day of pulmonary hypertension – May 5. More than 50 participants took part in it, with presentations by Dr. Lyubomir Dimitrov, head of the pediatric cardiology department at the National cardiology hospital, ass. prof. Natalia Stoeva – head of the Pneumology clinic at "Acibadem City Clinic Tokuda Hospital", and Dr. Velislava Donkina – head of the Non-medical and psychological care unit at the National hospital for active treatment of hematological diseases. "I am happy that in these difficult times we are together, despite being apart. Pulmonary hypertension is curable when it is discovered at an early stage. It is important to ensure broad awareness, recognition of symptoms, and measures that need to be taken to fight the disease. The role of the EA "Medical supervision" is to intervene

when a transplantation is required. More efforts need to be made in our country to encourage the donation of organs. This is why we are working to coordinate efforts for donation of organs and to create conditions for more lung transplantations in our country", said in his greeting Rosen Ivanov, Executive Director of EA "Medical supervision".

In her turn, the chairperson of the Pulmonary Hypertension Association of Europe (PHAE), Danijela Pesic added that in the last two years, Bulgaria has shown significant progress in the treatment and care for its patients with pulmonary hypertension. In this way, it is becoming a leader in this area within the region. In her opinion, this is due to the activity of patient organizations, but also to the cooperation with institutions. She noted that panic is dangerous, although the complexity of the situation leads to feelings of fear. "Every virus is dangerous, but if we take good care, we will stay healthy", said Daniela Pesic.

"Anxiety among patients with pulmonary hypertension is great, because they know that an additional viral infection can have severe consequences. This is the question asked most frequently by patients – whether they are at risk of infection with COVID-19. Presently, there is no data indicating that this group has a higher risk of becoming infected. However, there is data showing unfavorable complications when the coronavirus disease is added", commented Dr. Lyubomir Dimitrov, head of the Pediatric cardiology department at the National cardiology hospital. He cited data showing that in the USA, 13 cases of patients with the disease have been reported, and only 1 death was registered. He cited an article investigating the question of whether pulmonary hypertension could lead to a reduced risk of becoming infected with COVID-19. The article, stated Dr. Dimitrov, is theoretical, and authors suggest that pulmonary hypertension therapy blocks the coronavirus and reduces the likelihood of infection.

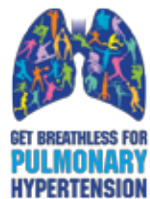
The statements, said Dr. Dimitrov, are speculative. He shared a hypothesis that it is possible that patients contract the disease less often because they are trained to observe strict rules when communicating with sick persons.

"When you can't breathe, nothing else is of any importance", commented ass. prof. Natalia Stoeva – head of the Pneumology clinic at "Acibadem City Clinic Tokuda Hospital". She also noted that especially for pulmonologists and cardiologists, difficulty in breathing is a major cardinal problem, for which it is important to find an explanation and ways to treat it. "Very often, patients and physicians associate difficulty in breathing with a lung disease. Naturally, COPD, asthma, and depression, anxiety, cancer, anemia, obesity are among the top causes", added Stoeva.

"Accepting the limitations is our only chance to be "normal" and have a good life. Limitations that the pandemic imposed on all of us are well known to persons with chronic diseases. Getting used to the disease is the challenge that a person can overcome, but with great effort", said in her presentation Dr. Velislava Donkina – head of the Non-medical and psychological care unit at the National hospital for active treatment of hematological diseases. "We are only afraid of things that have already happened", state Donkina. "In the uncertainty we find ourselves in, especially in this situation, people's inner fears germinate. And every time they encounter uncertainty, human beings create crises. We are less afraid of things that are known, even if we they make us grieve", added the psychologist.

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





WPHD 2020 - BULGARIA PHA

In the conditions of social isolation, this year's campaign went almost entirely online. Many Bulgarian patients supported it by changing their profile picture.

Our big success was the participation of Todor Mangarov in the prime time of the most watched Bulgarian TV in the health show "The Spirit of Health" for one hour together with Prof. Nina Gocheva on the topic of pulmonary hypertension and World Pulmonary Hypertension Day.

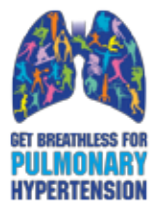
On May 5th at 5 pm we made an online presentation via ZOOM platform with a lecturer Prof. Gocheva in Bulgarian language with medical students and Bulgarian doctors. The aim of the online presentation is to increase the knowledge about PAH and to improve the diagnosis, because according to statistics the total number of patients with PAH should be about 350, and only about 170 are treated. This means that in the future we will focus on the spread of knowledge about the problem among an even larger number of doctors and

medical students. 74 people took part in the seminar. The future reporter Deyan, 10, also joined this year's campaign and supported patients with PAH. His photo traveled around the world and received 6,000 likes, winning first place in the PHA Europe competition. During the pandemic, we made an official note to the employer to support home office for patients and to their family members. We made also a note to be used for traveling (to the hospital if needed) to be used in front of police as in Bulgaria was not allowed to travel outside city of residence. 14 PAH patients benefited from a note to the employer and another 11 to travel note. We also helped with the purchase of disinfectants and masks. Over 20 patients received them for free. On June 11, after the cancellation of the quarantine, we had the first patient meeting of the year.

Todor Mangarov, PHA Bulgaria

www.apph-bg.org - www.facebook.com/aph.bulgaria





WPHD 2020 - CROATIA



Spring 2020 was certainly more than challenging, not only for the work of our association, not only for PH patients but for all of us globally.

Apart from Covid-19, which we have all talked about and written so much, Zagreb was unfortunately hit by a very strong earthquake on the 22nd of March, 2020, which left very big consequences right in the city center, damaging many buildings, museums, theaters, religious buildings and hospitals. Most of our hospitals are located in that part of the city. Images of mothers with newborn babies a few hours old, wrapped in blankets evacuated from the maternity ward, flooded our media. It was a cold Sunday morning, people on the streets had to adhere to distance measures because of Covid-19, and in moments like these we all know how important a human touch and a hug of support is. Sadness.

Among others, the Jordanovac hospital, the one where our PH center is located, was severely damaged. The staff and part of the equipment was transferred to another nearby hospital in order so that care for the sick can function to some extent. Unfortunately, they only had 34 beds there, cramped space and the feeling of being like refugees. Unfortunately, some of the fellow doctors treated them like that. During that period, it was impossible for our PH patients to come for examinations, the dates of already agreed hospitalizations and examinations were postponed, and are still being postponed. It was almost impossible to get the information on the phone because the lines were interrupted, and there was no entrance to the hospital, except for emergencies. We were taking medicine at

the gate. However, since last week, our doctors have returned to the part of the building that has not been damaged and started working with reduced capacities. It is very questionable when everything will return to its original condition, because the damage is great and repairs will be very expensive and time consuming. We remain patient in every way.

Still, hope never dies and we carry on to the best abilities we know. So I believe we successfully conducted the Blue Lips campaign and marked WPHD, and even the whole month of May as a month dedicated to pulmonary hypertension. We received a lot of pictures of citizens and patients with blue lips, it was impossible to publish all that.

The story of our PH fighter Valentino Belavić, who has been involved in music or rap since childhood, was also very positively accepted in the media, and he did not want to give up even when he fell ill. The song about his fight with PH as part of this year's campaign was translated into English, and the video was watched by over 35,000 people in Croatia alone.

Valentino was a guest on 4 radio stations with me during the month of May, and the listeners nicely accepted the message of his song and the struggle that despite the diagnosis with which he has difficulty breathing, Valentino manages to rap. The message is that you should never give up on your dreams.

Katica Mavračić and Zdenka Bradač
infoplavakrila@gmail.com - www.plavakrila.hr



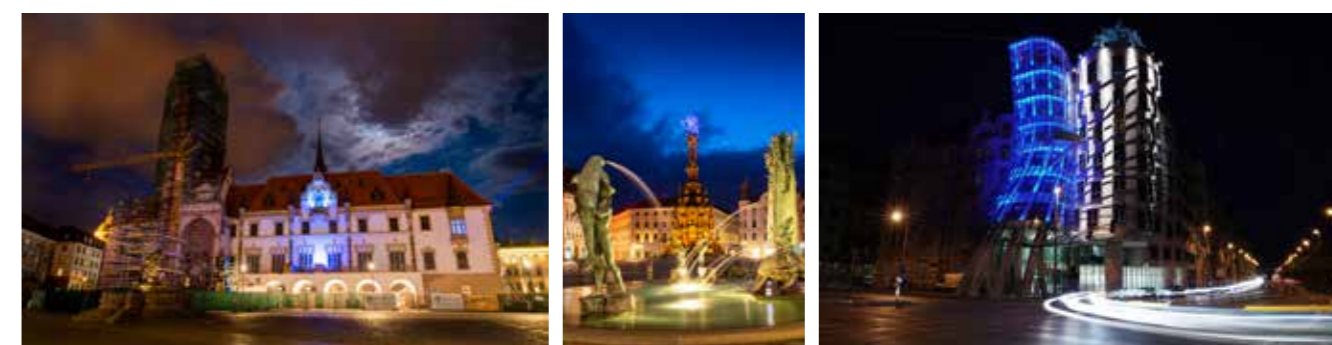
WPHD 2020 - CZECH REPUBLIC

This year, the celebration of World Pulmonary Hypertension Day was turned into an online campaign just like in other countries.

However, we were supported by the Dancing House Gallery and the City of Olomouc, and on May 5, monuments in the capital city of Prague and Olomouc were illuminated to support awareness of pulmonary hypertension. On this day, there were also two interviews on the radio and one on Czech Television, over 20 articles on the topic of pulmonary hypertension were written in newspapers and magazines throughout

the Czech Republic. On this day, a new website was launched for patients, full of important information and contacts needed for new and existing patients. At the same time, a new online counseling center with a specialist in pulmonary hypertension and a hotline for patients was launched.

Milena Kaftanová
[Sdružení pacientů s Plicní Hypertenzí www.plicni-hypertenze.cz](http://www.plicni-hypertenze.cz)





WPHD 2020 - DENMARK

In Denmark a temporary ban on holding or participating in events, happenings, activities or the like was introduced on the 18th March 2020, where more than 10 people were gathered. The ban was applied both indoors and outdoors and included both public and private events. Due to this The Danish PH association (PAH Patientforeningen Danmark) celebrated the 5th May 2020 online. This was done via our Facebook page,

homepage (WWW.PAH.DK) and by distributing the O2 Kids video through an ad campaign.

Bjarne Hoeg-Heise
<https://www.facebook.com/profile.php?id=100015455323402>
<https://pah.dk/>



PAH Patientforeningen
5. maj · 🌐
I dag er det international World PH Day og Pah Patientforeningen markerer dagen ved at dele denne video med jer. Del den gerne med andre.
[#bluelips](#) [#phaeurope](#) [#goodPHnews](#) [#WorldPHDay](#) [#pulmonaryhypertension](#)

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[#bluelips](#) [#phaeurope](#) [#goodPHnews](#) [#WorldPHDay](#) [#pulmonaryhypertension](#)



YOUTUBE.COM
O2Kids Danish version full video



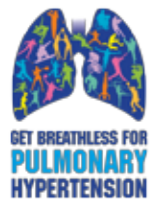
WPHD 2020 - FINLAND

Finland's Pulmonary Hypertension Association (Suomen PAH-Potilasyhdistys ry) joined the WPHD events by asking people to post their BlueLips photos in social media. We ran the campaign on our association's Facebook page as well as on a closed Facebook discussion forum. In addition, we posted the O2 Kids video to

the aforementioned sites and to our Youtube channel. We received BlueLips photos from eight patients.

Sonja Koski
suomenpahry@gmail.com





WPHD 2020 - HUNGARY



This WPHD in 2020 was unlike any other. Most of us quarantined ourselves from the beginning of March, stayed home to protect ourselves and others and not to burden the healthcare. We were facing new challenges. Suddenly we had to work from home, supervise the digital education of the children and we were trying to adapt to the extraordinary circumstances.

Our fellow patients and senior citizens needed even more help since they practically could not leave their home. As a result, the caregivers, family members had even more burdens to carry. The anticipated peak of the pandemic was 3rd May, there were strict limitations and a curfew was in effect. The whole country was at standstill. As the death-toll was rising people were panicking, tried to learn information about how to stay safe. It was not easy to catch the attention of the people and to organize any „celebration”.

Blue lips campaign was launched on 4th May. We have managed to convince some musician and sportsmen to support our cause. Besides Gergely running for those suffering from PH, a dragon boater team was also dedicating one of their training to us.

In the online magazines everything was about coronavirus, so it was not easy to find possibility to publish.

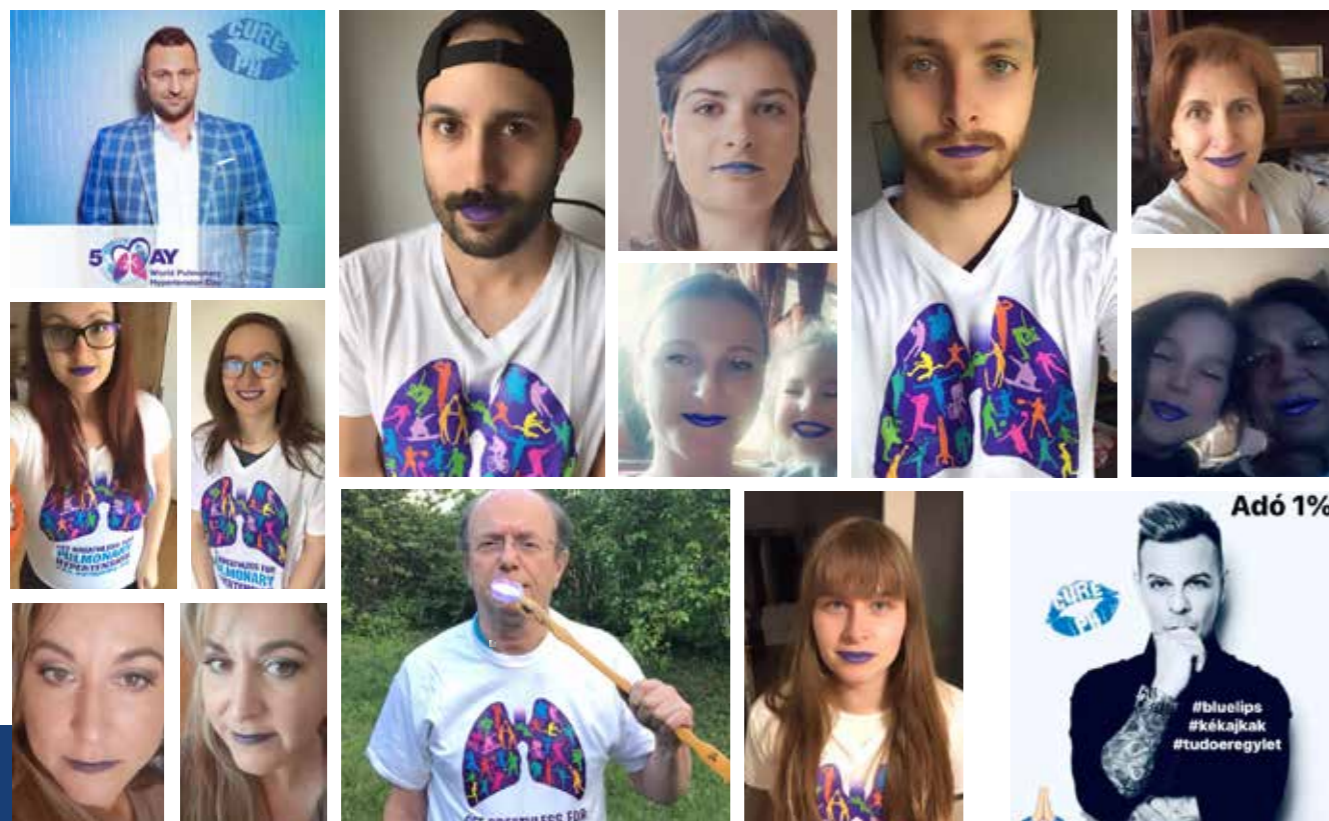
O2 Kids video was well received, just like, the World PH Day video address of Kristóf Karlócai, PH specialist. We had the opportunity to give a FB live awareness raising presentation about PH and lung transplantation on an event broadcasted by the Health Promotion Office of Zugló.

Life is slowly starting again, maybe carefully we can leave our homes, we can meet friends. Seems like the first wave was handled well and the biggest achievement is that based on current information we did not lose any fellow patients to COVID-19 thanks to their discipline and carefulness.

Eszter Csabuda, Tüdőér Egylet

www.tudoer.hu

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



WPHD 2020 - ISRAEL



2020 has proven a challenging year for the entire world and planet! Countries around the globe have faced fires, infestation, virus and protests and humanity has had to adjust to a new norm. And with that adjustment continues the challenge of creating awareness for Pulmonary Hypertension and finding ways of continuing to assist our members, their carers families and friends.

Life with PH can be stressful and adding COVID 19 to the mix created a huge amount of anxiety, fear for the unknown and concern for everyone concerned. The Israel Association for Pulmonary Hypertension has found our awareness focus this year to be centered around the tools needed to cope with PH, living with PH and caring for someone with PH. For once, the entire world has an insight into the fear of not breathing freely - the restrictions of wearing masks and the concerns when every second you are conscious of your surroundings and how they affect your health. We have found, through this unfortunate situation, an awareness which was created to not take something as “simple” as breathing freely for granted.

With this in mind we focused our efforts on online promotions and more so on connecting with current and new patients as well as with the general public. Every conversation with a masked colleague, friend, fellow shopper or passerby was suddenly an opportunity to mention to them how PH affects our members. We were excited to have participants for our #BLUELIPS



campaign from several schools and a local museum who kitted their animals in blue lips to raise awareness.

PH Israel are proud of the several situations which we would like to share. The first being a very touching and life saving story -it all started on MAY 5th!! A woman whose 11 year old son had just recently been diagnosed with PH reached out to us via Facebook messenger to ask for our help! She was desperate as she had not had any support - every doctor and specialist which she saw gave her the grave message that there was nothing to be done for her child. Through consultation with our CEO Aryeh who listened to her, checked all their medical information, consulted with doctors who are friends of our association and were able to refer the family to the one doctor who specializes in CTEPH in children. With the right connections, extensive years of involvement with PH and dedication we were able to assist in directing them to the correct treatment approach.

Another achievement which we are very proud of is the ongoing work we are focused on with our Portable Oxygen concentrators. The difference which these machines make in the life of every PH patient is immeasurable. No longer being stuck at home, limited in their time out, freedom to visit family, go to meetings, shopping, work and even travel is life changing! As part of our WPHD2020 efforts we promoted the request for support in funding these machines. We received a very generous donation of one machine and have an on-

going system working for rental which created income! We are very grateful to be able to purchase one more machine to add to our "team"

The next area of focus is the cooperation with medical centers and professionals. As we all know organ donation and transplant is the only solution for some PH patients. We were very honored to be working very closely with a team of experts who have trained extensively in Canada in order to bring the best possible transplant center to Israel. In our consultations with them we realised several issues from the patients perspective of the experience and were able to contribute with our knowledge and understanding first hand. The new center is being launched at Tel HaShomer medical center. As part of our World PH Day Activities we spent time supporting, educating and encouraging the development of this facility. We were very pleased to learn of

the centers high standard of preparation pre transplant, ensuring the patient is at his or her best possible condition pre transplant. The center makes use of previously unsuitable lungs which are rehabilitated. We are confident that having another competing transplant center will allow patients more access and greater care with regards to transplant options.

As a patient representation association we are honored to be able to assist medical companies, professionals and carers with a greater understanding of the needs of our members and ensuring they have the highest care possible.

Maayan Steele

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



WPHD 2020 - ITALY AIPI

AIPI Onlus, during the COVID-19 emergency, mobilized their connections and resources to find 2,800 surgical masks and 1,400 bottles of sanitizing gel. It proved to be very complex exercise in the midst of a pandemic emergency.

All this allow us to send an Anti COVID-19 kit to 1,400 supporters.

We have gone through a really difficult period, both for us with pulmonary hypertension and for those who are by our side it was challenging. Our life has suffered radical changes and some of these are likely to remain as such for a long time. We wanted, as always, to look into the future with a positive outlook and take courage with the latest epidemiological data, which seems to be improving.

The security measures remain unchanged, but we see daily many people adopt unresponsive behavior. It is important not to let your guard down to „keep us safe”. That’s why AIPI ONLUS has thought about this initiative ... to remain connected with our supporters in the severe particular moments in the life of our planet. In addition to our magazine, supporters will receive 2 triple-layer surgical masks and a pocket bottle of sanitizing gel.

With the total reopening of the Italian regions, we want everyone to be safe during the return to the pseudo-normal life and with this gesture we make this happen.

Leonardo Radicchi
www.aipiitalia.it
Presidente@aipiitalia.it





WPHD 2020 - ITALY AMIP

THE AMIP-ONLUS IN RECENT MONTHS HAS BEEN SEVERELY TESTED BY THE COVID-19 VIRUS

What we have done? First of all, we have strengthened our help line so as not to make the patients feel alone, we have sensibilized all our doctors to provide the necessary medical support, we have had countless meetings with the institutions to have regulations approved in favor of rare patients (approved regulations in record time), we had virtual meetings with other world associations and participated in 6 webinars, as well as in an international conference on web. We managed to make the semi-annual magazine with many testimonials of patients during the lockdown. Now, always looking to the future, and having had the good fortune so far that everything went smoothly, we are traveling around Italy for institutional meetings in the various Regions and ensuring that patients with pulmonary hypertension are not neglected or set aside. In this vision, we are part of the rare disease observatory.

In short, we were unable to make a social campaign, even if we realized that after a few weeks many were tired of being on social networks and preferred to hear the voice, but we took care of the fundamental aspects for the sick: safety, necessity, emergency.



insieme AMIP News

Luglio 2020

VIAGGIAMO INSIEME



VERSO UN FUTURO MIGLIORE

Laura Gagliardini, AMIP Italy
www.assoamip.net
<http://www.facebook.com/AssociazioneMalatiDiIpertensionePolmonare?ref=ts&fref=ts>



WPHD 2020 - LATVIA

PH: LEARN MORE, BREATHE MORE

This year we celebrated World PH Day with educational and awareness campaign "Pulmonary Hypertension: Learn More, Breathe More" from 16th April to 28th May on PHA Latvia's social media. We started with emotional and sincere story of Zane Lazdina about her way through double lung transplant in Vienna General Hospital 6 years ago. Until now, she is first and one Latvian patient with new lungs. The social media campaign concluded with brief story of PH patient Arina Bazarbaeva and her photo with PHA Latvia's Ginkgo Biloba tree, which PH Latvia members and friends planted celebrating World PH Day in 2017. These two stories of young PH patients underlined value of life, hope and encourage others to look for joy and to keep endurance fighting with this complicate and dangerous illness.

Educational part of WPHD 2020 campaign was popular among not only PH patients and their relatives but far beyond PH community. Videos of three lectures with practical tools and tips of physicians of Clinical University Hospital in Riga on PHA Latvia facebook page from 5th May till 5th June watched by 1579 people.

Most successful lecture is "Nutrition for PH patients" by nutrition specialist Nelda Karpenska-Allaza. Lecture of young cardiologist Dr. Santa Strazdina "Diagnostic methods for PH and CTEPH" and training session with physiotherapist Lina Butane also are useful tools to better understand and cope with pulmonary hypertension. All these lectures are available on PHA Latvia home page under section "PH library". PH patient Silvija Tumina about this year WPHD said: "It was big pleasure to see each other online watching together doctors' sessions. We fell united and stronger." As component of awareness and delight for PH community, we put in our facebook and twitter account four video greetings from doctors and members of PHA Latvia. Dr.med. cardiologist Ainars Rudzitis sent wonderful greetings: "We, PH community are part of all society; we will breathe deep and with joy. We will let spring come to our hearts!"

Ieva Plume

<http://www.phlatvia.lv>

<https://www.facebook.com/phlatvia/@phlatvia>



PULMONĀLĀS HIPERTENSĪJAS DIENA 2020
 UZZINI VAIRĀK, ELPO DZĪLĀKI!

- 05. MAIJĀ PLKST. 11:00**
 ĀRSTS REZIDENTS KARDIOLOĢIĀ SANTA STRAZDIŅA
 EHOKARDIOGRĀFIJA KĀ DIAGNOSTIKAS METODE PULMONĀLĀS HIPERTENSĪJAS PACIENTIEM
- 06. MAIJĀ PLKST. 11:00**
 UZTURA SPECĪALISTE NELDA KARPENSKA-ALLAŽA
 UZTURS PULMONĀLĀS HIPERTENSĪJAS PACIENTIEM
- 07. MAIJĀ PLKST. 11:00**
 FIZIOTERAPEITE LĪNA BUTĀNE
 FIZIOTERAPIJAS NODARBĪBA CILVĒKIEM AR PULMONĀLO HIPERTENSĪJU

Organizēt: PHB, 5 DAY World Pulmonary Hypertension Day, CURE PH





WPHD 2020 - LITHUANIA

ŽSPHA organized a competition „Blue lips” in commemoration of WPHD. Participants had to send photos with blue lips and were invited to vote for their photo.

The two photos with the most votes were awarded with handmade brooches „Blue lips”, the other two won face masks with „blue lips”. The WPHD frame was shared and invited to join the spread of the disease and at the same time support patients with PH.

On Facebook and Instagram was published „Skirtin-

gos spalvos“ („Different colours”) a patient’s story. The article mentions the importance of WPHD, Blue lips and donation.

Due to the fact that quarantine was announced for COVID-19, and it was only possible to gather in groups of up to 4 people, we were able to organize suping in the beautiful Lake Kertuoja.

Rima Gruodienė
rima.gruodis@gmail.com



WPHD 2020 - NORWAY

LHL PAH Norway had planned to implement the WPHD and a gathering early May for our members to educate, to celebrate and to highlight the day. Our plan was also to have stands around in some major Norwegian cities at the WPHD. Because of the Covid epidemic this of cause was not possible to complete.

The 22nd course April we started our campaign on internet. We chose to mainly use the Facebook and the Instagram platforms. We promoted the campaign at our pages and called on our members to help us to share all information on their pages and to engage as many people as possible throughout the whole campaign. In addition to the international slogans/hashtags we made up our own slogan in Norwegian, in rhyme; «Farg leppa blå for PAH» (Color your lips blue for PH).

The board used a whole lot of energy to try to get the most out of this period. Not only did we contact a whole lot of Norwegian influencers, journalists, celebrities and and the royal family we also spent a lot of time planning and to follow up our social platform activities. Sadly enough we didn't get a lot of response on our attempts on getting help from any «famous» people so again we had to concentrate on using our, and our members network.

One our most successful activities was a series of auctions. We bought in a stock of cheap blue lipsticks and had auctions on our Facebook page. This raised a lot of money, attention and fun. Not successful at all was our attempt to make a video to really get the attention on our day and work. We made a strategy in cooperation with the PR-staff in our «mother organization» and were some people working «day and night» to finish a

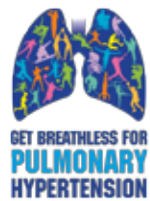
video with, pictures (mainly of members) information and promotion of our sponsors. We chose a beautiful norwegian «blue song» performed by a Norwegian «up and coming» artist to promote the video. Sadly enough after using so much time and energy we did not get the final permission from the rightsowner to use it in our campaign, that was «heartbreaking» and devastating. We ended up using just the clip with the artist calling for people to color their lips blue at the WPHD and naming our sponsors of course. We will continue with the concept for the coming years.

On the other side we were lucky to get a «covidpopular» artist to arrange a concert for us on his Facebook page raising both money and attention on our behalf. Several thousands NOK where raised and a lot of attention on the disease.

From what we can count only at our Facebook side we have around 20000 likes on our posts only on Facebook. We worked hard and well but could also see that our followers reached a point where the likes start to get less. Originally we had planned to continue with the O2kids campaign but decided to delay it till later not to lose followers. We will release our O2-kids film on our platforms in September. As said, we are very sorry that our video not could be released and hope to get it out in 2021. We are happy with our work in these special circumstances but do of course hope even more activities and attention to take place in 2021.

Sølvi Molnes
Odd Erling Børstad
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lhl.pah@lhl.no





WPHD 2020 - PORTUGAL

CHARITY MARKET

APHP works daily to disseminate Pulmonary Hypertension because it believes that there are many patients to be diagnosed. As the disease has no cure, we are fighting for an early diagnosis and the optimization of treatment.

Contacts with hospitals are made on a regular basis, so that all patients have access to the best possible treatment. It also has a line of social and psychological support that works 24 hours a day, 7 days a week. To ensure the sustainability of these services, APHP is now organizing a Charity Market to raise funds that will help maintain all the strengths of this Association.

A large part of the articles sold in this Market is handmade, by patients, family and friends who joined this initiative in May, the World Month of Pulmonary Hypertension.



#BLUELIPS CAMPAIGN

The #bluelips campaign ran throughout May. Dozens of people, of all ages, not only from Portugal but also from Latin America wanted to join us in this initiative. Some members of the Portuguese socialite also agreed to participate in the initiative and had published it on their social networks.

“PH IN TIMES OF PANDEMIC” WEBINAR

We planned to launch a webinar for the end of May, but due to the unavailability of some health professionals, we had to postpone it to 15th of June. It will be the first webinar organized by PH Portugal and will include the participation of two cardiologists from two PH treatment centres, a cardiopneumologist, a clinical psychologist, a patient and a member of PH Portugal. It is an open webinar and will be held on our Facebook page. Healthcare professionals will explain how PH treatment centres have adapted to this new reality, how they have kept in touch with PH patients, how they have guaranteed access to treatments and medication and what advice they can give to patients in this phase: in ‘tele-appointments’ (what the patient should take into account, how to prepare the appointment, etc.). The issue related with the post-lockdown phase currently implemented in our country will be discussed: if it is possible or not for patients to get out from lockdown and what is the behaviour they should adopt in this phase. The clinical psychologist will address the impact of Covid-19 on the mental health of PH patients and talk about the support provided to these patients during this phase. We could not fail to hear the patient’s perspective, how they adapted, what were the biggest difficulties he faced, if there was worsening of the symptoms or if the treatment was compromised. Finally, PH Portugal will provide feedback on all the support provided during this phase: logistical support in providing protection material, permanent information sharing via social networks and website, support in accessing medication at home, intervention with the media and health authorities to denounce the lack of legal protection for PH patients, etc.

PH EUROPE’S PHOTO CONTEST

PH Portugal competed for the Photography Contest organized by PH Europe with a photo that won the second place! A photograph contains a story of a young

woman who was only a child when she was diagnosed with PH and how she learnt to live with a disease in such a positive way. This is the story behind the photo:

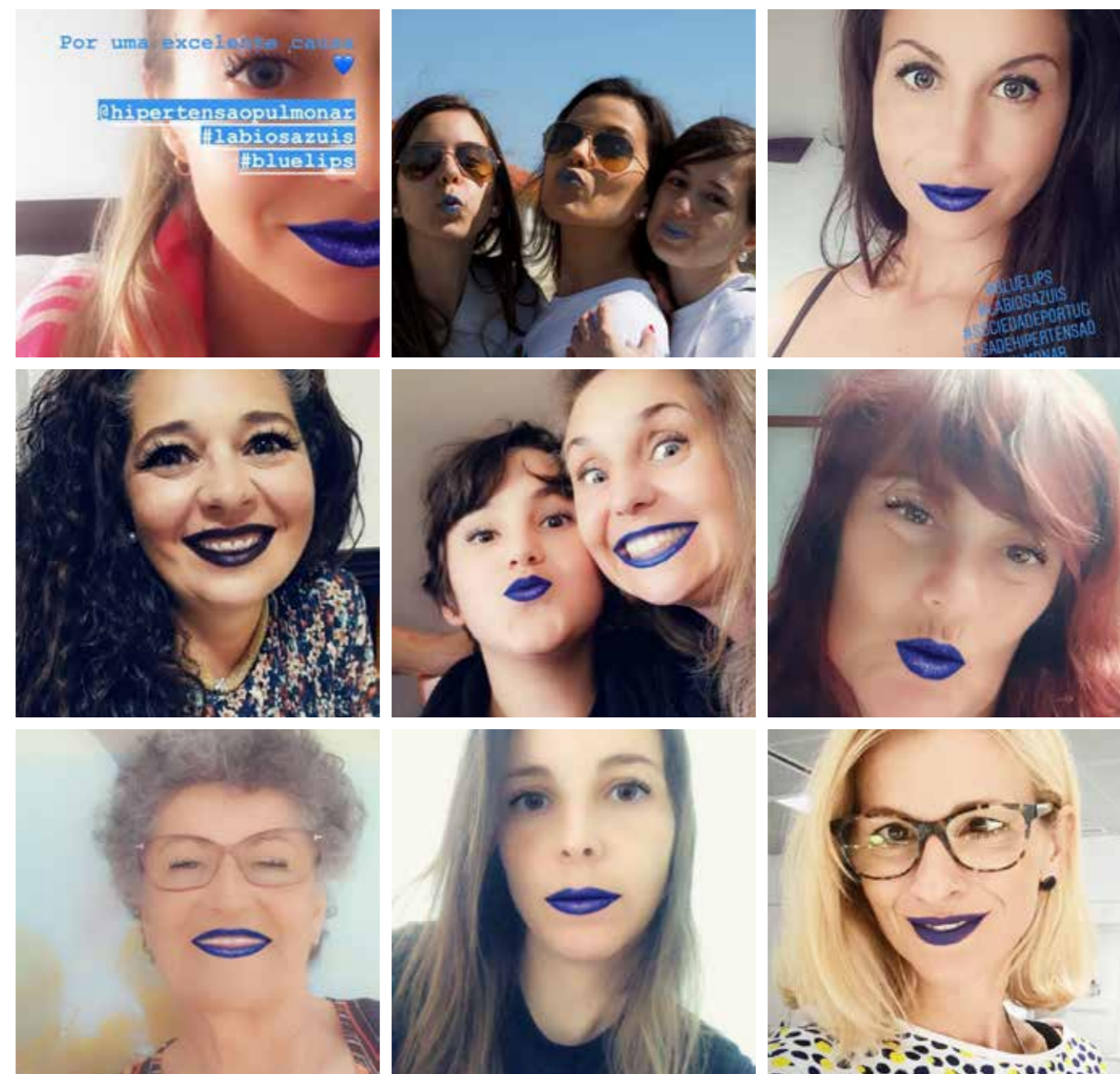
„This photo contains a lot of information about me, my values and beliefs: calm, light, peace and the joy of living. In addition to the oral medication, I take Treprostinil portable infusion pump since December 2018 - the initial impact was quite negative, both on a psychological and physical level.

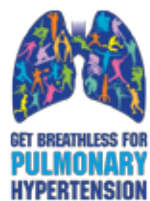
I felt very insecure, with low self-esteem; I had a lot of pain as a side effect of the medication. However time has passed and I can say that I am 100% adapted to this new reality - I continue to do my normal life, doing what I like the most, both professionally and personally. I am a nurse at the Hospital and University Center of Porto and I love what I do! I love walking, going to the beach going to the pool, rollerblading, camping, traveling. Anything that provides me contact with nature and people, is where I am happy. Of course, I feel much better,



much less tired, and I can do things that I couldn’t until I started this medication. It was wonderful for me to see how little things make such a difference - for example, not having to stop in the middle of the hall whenever I got up in the middle of the night to go to the bathroom; not having to stop in the middle of a flight of stairs; don’t feel tired just talking! Taking into account my profession combined with my condition, I am sure that every day I learn to know how to deal better with adversity, helping myself and others. So, the choice of the photo is based on everything good that this change brought to my life - learning, growth, improving the quality of life. Life is colour, light, loving and being loved. It is the heart beating. And I want to enjoy it as best as I can, in the way that makes me happy.”

Teresa Carvalho
teresapmcarvalho@gmail.com





WPHD 2020 - RUSSIA



In honor of the WPHD and the 5th anniversary of the Pulmonary Hypertension Association Russia, we had the online StandUpShow just for us. The stars of show were stand-up comedian Arthur and MC-Comedian. There was a festive atmosphere, a lot of jokes, competitions, gymnastic exercises and a lot of positive emotions to dispel sadness from the virus and the impossibility to meet in person. It was wonderful warm and positive online meeting, which lasted an hour and a half. Within the framework of the World Pulmonary Hypertension Day a meeting was held between the lawyer of PHA

Russia and the board of the Ministry of Health. They discussed the most important questions for PH patients - constant and undisturbed medications and their reimbursement. The medications delay has a negative impact on PH patients and it has to be unacceptable. We hope to have strong and productive liaisons with the representatives of the Ministry of Health going forward.

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



WPHD 2020 - SERBIA



World Pulmonary Hypertension Day in Serbia is, although in specific quarantine conditions, celebrated again by a series of events. The first of these is the Blue Lips campaign. The blue-lips campaign really set fire to social networks in Serbia. In addition to great attention and interest, we have an unprecedented visit to the page of Pulmonary Hypertension of Serbia. Our friends from the pharmaceutical company MSD support us with their pictures. Everyone wanted to hear what it was about and they heard.

The point is not that they have participated, but how they did it. Twenty-seven of them, they all came prepared, having read something about pulmonary hypertension on their own, and something with the help of their parents, and with the use of their imagination they painted something on paper, while some of them painted their shirts. Those guys, 27 of them with their coaches, are already champions! Their parents and the city of Čačak should be proud of them, proud of them and of their coaches who understand life with their hearts.

Another interesting event happened in a beautiful city in Serbia in Athletic Club "ČAČAK". Coach Srđan and children from that club participated in a race that we have organized on the occasion of World Pulmonary Hypertension Day.

Also, one of the biggest events was Race „Get breathless for pulmonary hypertension” 550 runners and 8.600 km for Pulmonary Hypertension! On the occasion of World Pulmonary Hypertension



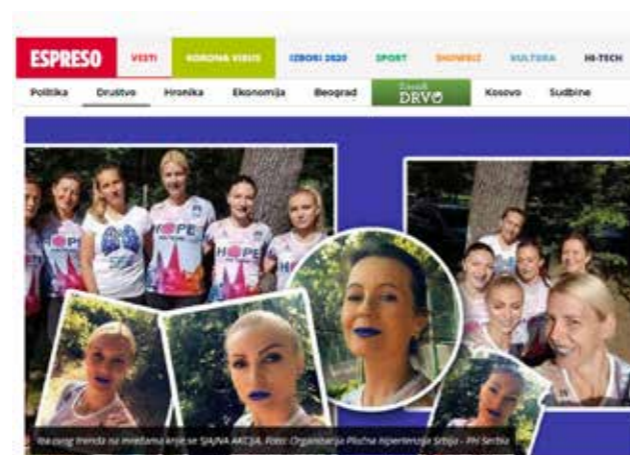
Day, a large scale individual race took place in Serbia. Respecting all the recommendations of the World Health Organization about avoiding and banning public gatherings, association PH Serbia, came up with the original way to mark World PH day. More than 550 runners, participated in this race that took place in more than 150 cities in Serbia and more than 5 countries from region and USA, Spain, etc, under one slogan „ Get breathless for pulmonary hypertension“. Participants crossed more than 8.600 kilometers for all suffering from pulmonary hypertension. All those racers who crossed the longest distances were awarded trophies, shirts, and medals.

Webinar - World Pulmonary Hypertension Day, Serbia On the occasion of World Pulmonary Hypertension Day, patient association- Pulmonary hypertension Serbia, has organized a very important webinar, that gathered our most eminent experts from three PAH centers in Serbia alongside representatives for PH Serbia association. Members of the associations asked questions and we all talked about the most significant themes related to PAH and all the challenges that are ahead of us. The webinar was Live-streamed and everyone interested could follow it via our Facebook page. The webinar had more than 1,700 views! High interest of Major Media regarding the World Pulmonary Hypertension Day in Serbia

On the occasion of World Pulmonary Hypertension Day, all major press agencies in Serbia showed great interest. Three most important TV stations (RTS 1, TV PRVA nad N1) dedicated a very prominent place in TV schedule to Pulmonary hypertension. On two national TV stations, pulmonary hypertension was a topic of the day. President of the association PH Serbia Danijela Pešić and prof. Arsen Ristić appeared on the most important national TV station – RTS (Radio-television of Serbia) together, and they spoke about PH each from their own point of view. Danijela, as the president of PH Europe and as a patient suffering from PH, and prof. Arsen Ristić spoke from a professional standpoint.

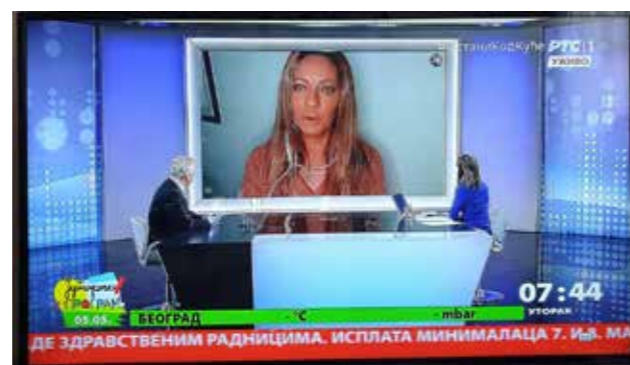
On the other major national TV station, PH was also a topic of the day. A representative of the association, Mirko Glavinić spoke, for more than 25 minutes, about all the challenges that persons with PAH here in Serbia face each day. During his appearance, a direct broadcast of a special race that was organized in Serbia with more than 550 runners on the occasion of World Pulmonary Hypertension Day was shown.

Danijela and Mirko
PH Serbia
www.phserbia.rs



LEPE SRPKINJE SE OVIH DANA SLIKAJU SA PLAVIM USNAMA! Iza ovog trenda na mrežama krije se SJAJNA AKCIJA (FOTO)

Ako se ova retka i teška bolest ne leči, pacijenti od nje mogu da...



WPHD 2020 - SLOVAKIA

Due to the COVID-19 pandemic, we had to adapt to the new situation. We have issued a press release for the media. We adapted the planned activities for World PH Day to the conditions and since mid-April we have been running an online campaign on social networks. The faces of celebrities - actors of the Puppet Theater and singers of the State Opera - helped us to present the signs and manifestations of PH with Blue Lips lollipops. Paid advertising was a very big success. During the campaign, we provided lot of information and recommendations to people who wanted to verify their suspicion of PH. We also gained new members of the association. The campaign helped our association to increase financial funds from income taxes. We received a grant from the Liptov Community Foundation for the purchase of a portable oxygen device. PHA Slovakia supported their patients members in the fight against coronavirus by providing them with surgical masks and disinfectants. One of the members of the association contributed to the help package, by tailoring cotton masks for patients with the association's logo. The partner company AOP Orphan also supported our patients safety by donating additional masks.

The public also joined our campaign. Several sent us photos from their own sports activities, which they completed in Get breathless for PH T-shirts. Five runners joined the Wings for life run. For May 16, the Slovak Pulmonary Hypertension

Association (Združenie pacientov s pľúcnou hypertenziou, ZPPH) was planning a climb to Vápenná („the Limestone Mountain“, 752 m above the sea level) in the Little Carpathians mountain range in Western Slovakia as a part of activities for the 2020 World Pulmonary Hypertension Day. Unfortunately, much to our disappointment, the COVID19 pandemic changed the plans and prevented the organization of mass undertakings. But physicians and nurses from the National Cardiovascular Institute in Bratislava, the largest PAH centre in Slovakia, decided to resist the unfavourable epidemiological situation and express their solidarity with PAH patients and their relatives. Recent alleviation of anti-epidemic restrictions made possible a gathering of 30 or so physicians and nurses and their relatives who climbed the Vápenná Mountain. Then, they hiked the lush greenery, meadows and lime stone rocks of Little Carpathian crest down to the romantic Plavecky hrad castle ruin. Wearing PAH T-shirts, they spread the awareness of PAH on their way. This expression of compassion from PAH health workers was just a taste to the official activities of ZPPH to the World PAH awareness day in 2020. We hope we will be able to organize the main event later this year.

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





WPHD 2020 - SLOVENIA



We are proud to say that this year's WPHD event was a success.

We managed to get some successful Slovenian sportsmen to join our online event. Klemen Bauer, Slovenian biathlete, Denis Šketako, Slovenian triathlete, and Anže Bašelj, who is a Slovenian sports journalist, all showed their support by participating in our blue lips campaign. In addition to our online event, great support was shown from our friends and colleagues, who were traditionally participating in all our previous WPHD events. As soon as the quarantine in our country was canceled, they went running in our T-shirts in the Slovenian capital city of Ljubljana representing and raising awareness of pulmonary hypertension. They »even made their own blue lips« and took several photos.

2 magazine articles were published in 2 well-known health magazines. One of them elaborated on what PH is in detail. In the other one, our association's president

presented her personal story and promoted the importance of organ donation.

The pharmaceutical company Medis, which we have been collaborating with for many years now, asked us to share their video. This beautiful video they made showcases the difficulties that PH patients face on a daily basis.

Another one of our partners, Slovenia Transplant, collaborated in our campaign by sharing all our posts on their Facebook page.

Thanks to the campaign, we were able to reach a lot of new patients. In the next few days, we will reach out to them and invite them to join our association.

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



WPHD 2020 - 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 2020. Due to the worldwide health crisis that we are living, our activities have been adapted to the current needs and we are enormously proud of the result.

From 27th of April to 5th of May, we organize the "Blue Lips for PH" campaign with Oximesa collaboration. We flooded social media with photos of blue lips. People were very engaged. Thanks to the broadcast tools of our association, more people took part than other campaigns.

On the 4th of May we held an online meeting with our lawyer, Álvaro Lavandeira, with the target of solving PH patients' questions about work, certificated of disability etc. COVID-19 was an important topic because there were different questions about government pandemic measures.

On 5th of May, with the collaboration of the Andalusian Patients School, we organized an online meeting with Dr. Lázaro (head of PH Monographic Unit at Hospital Virgen de la Salud in Toledo) and Dr. Del Cerro (head of the pediatric cardiology and congenital heart disease service at the Ramon y Cajal University Hospital in Madrid). Our president Eva Garcia took part in the event.

On 5th of May, the Getafe City Hall and our organization joined to celebrate the World Pulmonary Hypertension Day, coloring fountains and emblematic buildings of the municipality from 9pm to 11pm.

Besides we organized two online meetings for members, one of them for families with children with pulmonary hypertension, in order to celebrate this day of which we are very proud because our association was the

host and organizer of the first world day celebration of pulmonary hypertension in Spain in 2012.

From 27th of April to 31st of May, we published different videos as O2 Kids, news, information, etc. on our social networks about pulmonary hypertension its causes and consequences to increase the awareness of the population.

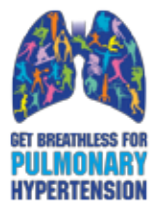
This year we organize our crowdfunding event in Facebook. The aim of the campaign was get medical material for the unit of pediatric for several hospitals in Spain: the maternal and Child Hospital of the 12 de Octubre University Hospital (Madrid), the Vall d hebron Hospital (Barcelona) and Ramon y Cajal University Hospital (Madrid). We sent glasses, personal protective equipment, protective screens and masks for adults and children.

The awareness and the sensitization is one of our priority aim. It's transversal in our all activities. But around the 5th of May we increase our effort with this subject. We work very hard for what people know our pathology because have a diagnostic and a proper treatment is very important to improve our quality of live. Actually, the cure doesn't exist but we will never stop until we find it.

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

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





WPHD 2020 - SPAIN FCHP



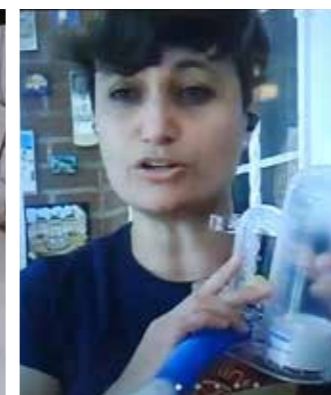
During this unusual month of May due to the COVID-19 pandemic. The FCHP has adapted to online outreach activities. The official campaigns endorsed by the association have been "Blue Lips PH" and "O2 kids". The campaign of the blue kisses is carried out in all the countries of the World to spread the bluish color of those affected by Pulmonary Hypertension. It is one of the symptoms that characterizes the disease, due to the lack of oxygen. The FCHP had the Guinness Record of blue kisses a few years ago.

Because face-to-face outreach actions were not possible due to the pandemic, the Foundation Against Lung Hypertension organized, together with the Flyz 401 Triathlon Club and the City of Parla, an online Solidarity Bike "Pedals Solidarity Class HP solidarity." We have the presence of the Olympic paratriathlete and European Champion Eva Moral, a point of reference for her fight and courage after a traffic accident. Dani García Lara former player of Real Madrid C.F., and the actress María Pedroviejo, patrons of our entity, did

not want to miss the event. In addition to the mayor of the city of Parla who participated with more than 40 national triathletes.

Respiratory physiotherapy workshops have been organized for people affected by pulmonary hypertension. They have been done online using the Zoom platform. Exercise and nutrition workshops are designed for those affected by pulmonary hypertension and remain physically and mentally healthy and active during this confined time. The workshops were divided into two parts for affected children and adults, with different themes. All this has been possible thanks to Encarna Valero, physiotherapist, Sergio Corbalán, nutritionist, both from the Oslo Clinic, and Dr. Paz Sanz, Rehabilitation Physician of the Cadiac Unit of the HU 12 de Octubre.

The Foundation against Pulmonary Hypertension, with the help of our friend Joaquín (3D designer), has handed over to the professionals of the Pulmonary Hypertension Units protective shields COVID-19.

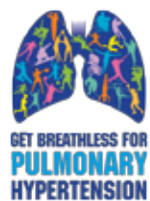


The target hospitals have been the followings: HU Virgen del Rocío (Seville) HU Virgen de la Macarena (Seville) HU Clinic (Barcelona) HU Virgin of Health (Toledo) HU Puerta de Hierro (Madrid) HU Gregorio Marañón (Madrid) HU October 12 (Madrid) HU Ramón y Cajal (Madrid) HU Montecelo (Pontevedra) HU Doctor Negrín (Gran Canaria). This equipment has the toilets that are in the front line of contagion to be more protected against the threats of COVID-19. Thus we attend to the health emergency and the needs of our professionals. With this donation, we want to thank the efforts that the health teams are committed to during these days to end the pandemic, and to be able to recover the people who have been affected by this situation. At the Pulmonary Hypertension Foundation, we would like to take care of those who always take care of us.



To end a month full of activities, Sergi Arola, one of the most media chefs in Spain, has prepared a dish to commemorate World Pulmonary Hypertension Day. Sergi Arola has been collaborating with our entity for years. In this atypical year with the Covid-19 pandemic, he wanted to delight us with a wonderful dish dedicated to those affected by pulmonary hypertension

Enrique Carazo Minguez
FCHP Fundación Contra la Hipertensión Pulmonar
www.fchp.es/es
www.facebook.com/fundacionhp



WPHD 2020 - SPAIN HPE

During the campaign, work has been done to generate synergies with entities in other countries, many of which have shared our contents. We have achieved a large growth in all our social networks. Thus, our Facebook followers have increased by 30%, our Twitter followers have increased by 6% and

We also achieved repercussions by obtaining the social endorsement of the scientific society SEPAR patients and other prestigious entities, publishing our campaign on their web page and on the web pages of these entities that wanted to support and accompany us to give visibility to pulmonary hypertension.



„FEEL THE PULMONARY HYPERTENSION, PUT YOURSELF IN MY PLACE”

During the whole month of May, HPE-ORG has carried out the campaign „Feel the Pulmonary Hypertension, put yourself in my place” on the occasion of the celebration of the World PH Day on May 5th. This year, due to the special circumstances caused by COVID-19 and by the lockdown, our entire campaign has been celebrated on social networks. Our actions during this month have consisted of carrying out publications worked on by the campaign team of WorldPHDay in Spanish and English. This material, with its own graphic image made for the occasion, has been represented with pictures and videos where disclosed it's made about what this disease is and it's available for everybody on our YouTube channel. In addition to these pictures and videos, we

wanted to show rather the human side of pulmonary hypertension, explaining the day-to-day work of our association and publishing patient testimonials to convey a positive and hopeful message.

All the testimonies received can be consulted on our website:

<https://www.hipertension-pulmonar.com/tu-historia-ayuda/>



our Instagram followers have increased by almost 13%. We have also strengthened our presence on LinkedIn during the month of May and in particular, the videos of the campaign of the WPHDay 2020 have had 101,443 reproductions. So we are very proud to have been able to reach so many people because that means that at the end of the campaign, more people knew about Pulmonary Hypertension and about us as an association, which is one of the main objectives of World Pulmonary Hypertension Day.

On May 5th, we asked our fans to take a picture or video of themselves breathing through a straw and upload it to their social networks with the tag #BreathWithAStaw. The response was incredibly positive because we get a lot of videos and photos and the social networks were plenty of people breathing with a straw, more than we expected.

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

"Feel the pulmonary hypertension, put yourself in my place"

5 MAY
Día Mundial de la Hipertensión Pulmonar

#BreathWithAStaw
#WorldPHDay2020

1. Hold your nose and breathe with a saw.
2. Do any activity of your daily life or any sport at home.
3. Take a photo, video or gif.
4. Share it on your social networks.
5. Challenge 10 friends by tagging them in your post with the hashtag:

HIPERTENSIÓN PULMONAR



WPHD 2020 - UKRAINE PHA



MAY 6, 2020

ONLINE CONFERENCE DEDICATED TO THE WPHD

COVID-19 made its adjustments to the annual patient meeting, dedicated to the WPHD. But on the other hand, it opened up new opportunities - after all, it was possible to connect to an online conference organized by the PHA Ukraine from any corner of Ukraine.

For 2.5 hours, we managed to discuss many issues with our doctors - Yuriy Sirenko, Iryna Zhyvylo, Vlodymyr Zhovnir. Oksana Aleksandrova, the head of the PHA Ukraine, spoke about the organization's work over the past year, achievements and problems. It turned out to be an interesting dialogue with Iryna Zaslavets, Head of IDonor: All-Ukrainian donation platform, which spoke about the prospects for the development of lung transplantation in Ukraine. With Iryna Sydoruk, a member of our Association, we discussed the importance and necessity of continuing the yoga program for patients with PH.

The guest of our conference, the head of the Latvian LH patient organization Ieva Plūme, spoke about the organization of patient care and rehabilitation programs for

Latvian patients.

The main issues, of course, are the timely delivery of drugs, the lack of a clear delivery schedule, and an information vacuum on the quantities and delivery times. But most importantly, we were able to spend this time together, feeling each other's support!

Easy breathing for everyone!

May 23, 2020-ONLINE WEBINAR

„Current opportunities and current issues of pharmacotherapy of patients with PH”

The webinar was conducted by the head of the expert group on pulmonary hypertension, a doctor of the PH Center at the Institute of Cardiology, Ph.D. Iryna Zhyvylo answered the questions that always interest our patients. The Chairman of the Association, Oksana Aleksandrova, also spoke about the situation with the supply of medicines for PH patients.

Oksana Aleksandrova

Ukraine Association of Patients with PH

www.pha.org.ua - info@pha.org.ua



WPHD 2020 - UKRAINE PHURDA



For the first time, we had to give up a patient meeting and interesting mass events. We went online. The situation with Covid-19 has affected each of us. During May, the “Sister Dalila” Charitable Foundation was involved in raising funds for the purchase of medical supplies. The Ukrainian Philanthropist Forum supported the CF “Sister Dalila” by creating a special video. We managed to raise funds and purchase some protection gears to use by health personnel handling corona patients. Furthermore, PH patient made 150 reusable masks that were given to PH patients and doctors.

Link for video:

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

We started celebrating WPHD 2020 with participation in a tv program. Due to the quarantine rules, it happened online. Representative from PHURDA, Oksana Kulish, noted the importance of timely procurement of medicines by the state. Special guests were present at the program: staff member of PHA Europe Gergely Meszaros and members of the Supervisory Board of the CF “Sister Dalila” Jurij Klufas and Oksana Rubay. Gergely spoke about the experience of European countries and the importance of fundraising campaigns. We talked about the patients' condition, treatment and lifestyle of PH patients in Ukraine and in Europe. Jurij Klufas summed it all up, emphasizing the fashion project „Butterfly in Blue”, which took place in Toronto, as an example of a mega successful awareness campaign that has potential for the world. We thank our guests for their support and sharing the experiences.

Link for the program:

https://www.youtube.com/watch?v=tn9e7c8Ro-eA&fbclid=IwAR3sw3fEig7AtSyrM_SGX2Ln7ARxJd-fuDDTIyuclZGjxdl1l6bFPih5V60M

https://www.youtube.com/watch?v=_b4JacUp3g-c&t=48s (interview with J.Klufas)

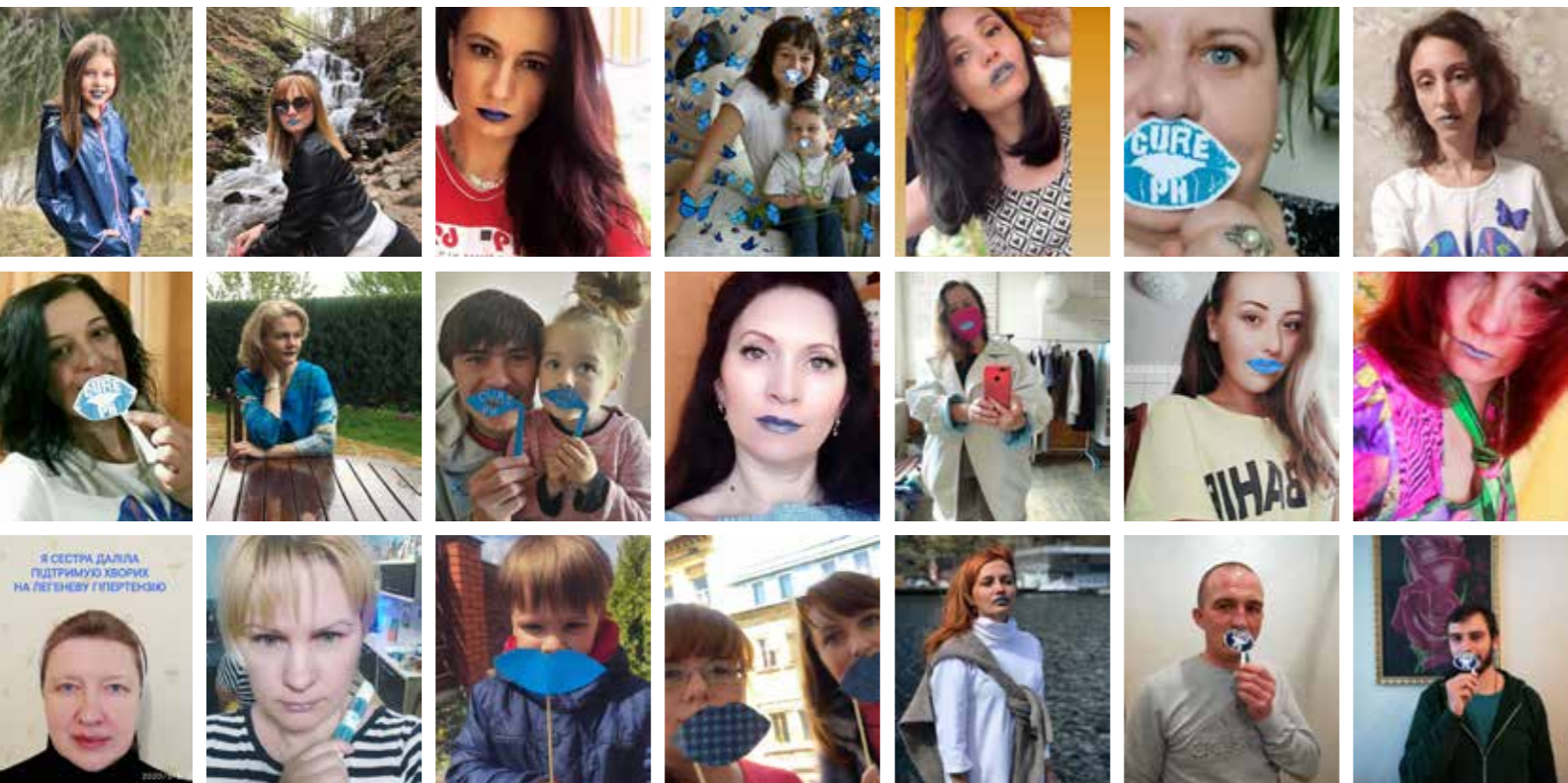
https://www.youtube.com/watch?v=M1_d0M-eyy-M&t=131s (interview with G.Meszaros)

The online WPHD celebration campaign was also filled with a broadcast of a PHA Austria video about Thomas. This is a simple and at the same time very informative video with a fundraising element. We broadcasted it on TV channels, on YouTube and social networks (the video gained a lot of views) and covered a large part of the audience in Ukraine, as it was broadcasted on Channel 5, and with repeats on the First Western channel. The video is well suited as a YouTube video and it is posted on our YouTube channel. In addition to receiving a lot of views there, it was also viewed by thousands during live broadcast on tv. We thank PHA Europe and PHA Austria for creating the video and subtitling it and thus making it understandable to Ukrainians. This helps people more easily and better understand what pulmonary hypertension is.

Link for video:

<https://www.youtube.com/watch?v=SFRF73S9GKs>

The Blue Lips campaign was launched a long time ago and became very relevant during Covid-19. We wanted to involve different groups of people plus families in the project. The photos with blue lips are very descriptive since it shows a possible symptom of PH. Patients were not ashamed to show this symptom and also accepted the challenge. They showed by this their strength and will to fight for their lives. Among the large number of participants who supported the flash mob, we chose only three, and our master PH patient Nadia Nus awarded the winners with beautiful memorable gifts.



Link for the video:

<https://www.facebook.com/ksenia.zubriy/videos/3371505212884444/>

Representatives of PHURDA and the CF “Sister Dalila” took part in a TV program on “Channel 5”. During the broadcast, we talked about the limited PH budget for 2020 and the potential and problems with the supply of drugs in 2021. Furthermore, we discussed the absence of one of the drugs for the 2019 budget due to incomplete registration of the drug in Ukraine, which won the tender. All these issues are now of great concern to all patients.

Link for program:

https://www.youtube.com/watch?v=Pc5uvzf58_g

Our friends, supporters and colleagues remember the days that are special to us (like WPHD). The “Vinks” advertising and production center, which was forced to postpone the realization of the „Other Life” show as part of the „Butterfly in Blue” project due to the coronavirus. In its “FiFi Fashion” magazine they very constructively described CF “Sister Dalila” and PHURDA as well as the projects that we jointly implement in the future in order patients could be heard as much as possible.

Oksana Kulish is a member of the All-Ukrainian organization „Patients of Ukraine”. On May 18th there was an online briefing, where the «Patients of Ukraine» reported a number of problems to the new Minister of Health, including orphan nosologies and PH in particular.

Link for the briefing:

<https://www.facebook.com/patients.org.ua/videos/3038261872898147/>

PH patient Mira Dziubinska, with the support of the “Sister Dalila” Charitable Foundation and PHURDA, created a special video „Another Life” to celebrate the WPHD and to honor the memory of those who have passed away due to PH. Another life and life style is what every patient is forced into after receiving a diagnosis. This is what the PH patients have to live with every day.

P.S: This video has become a good tool to illustrate the problems with the lack of PH medication. As of today, the vast majority of patients in Ukraine have been left without medication. A girl with medicine in her hands is a symbol of Ukrainian patients who live with this uncertainty every day. Because without medicine, tomorrow may not come.

Link to the video:

<https://www.youtube.com/watch?v=dOjtRuB-Nf7k&t=35s>

We experience difficult times at the moment. There is a war in eastern Ukraine, the coronavirus pandemic is not receding, the financial situation is not the best, we have to deal with a new government including a new Minister of Health. At the same time, we want all patients to experience a tomorrow, including all our PH patients.

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



WPHD 2020 - ALL OVER THE WORLD: CANADA

COVID-19 & PH

The COVID-19 global pandemic presents significant challenges for all of us, and unique challenges for those living with chronic illnesses, such as pulmonary hypertension. PHA Canada is committed to ensuring the PH community has access to trustworthy information, tools for staying mentally and physically well, and a sense of belonging in the face of increased physical isolation. The Canadian PH community can visit our website for general information about PH & COVID-19, video resources, such as a Q&A session with PH specialist Dr. Sanjay Mehta, and support resources: phacanada.ca/COVID-19.

PH BUDDY PROGRAM

PHA Canada created this program to reduce social isolation for people affected by PH during COVID-19. Life during a pandemic can be stressful, especially for people already concerned about their health or the health of a loved one. Visit phacanada.ca/PHBuddy.

PH BLOG

Read articles from health care professionals, researchers, advocates, and PH patients about diverse subjects such as “Research Update: ‘Implications of EZH2 in PAH’”, “Advocating for the PH Community: There is Hope”, and “Meditation For PHers, From A PHer”. Visit phacanada.ca/PHBlog.

POSTPONED: PHA CANADA’S EASTERN REGIONAL PH SYMPOSIUM

PHA Canada takes physical distancing measures very seriously and is committed to the safety of PH patients and their families. All community events and fundraisers, including the Eastern Regional PH Symposium scheduled to take place in Ottawa this September, have been postponed or canceled.”



MEET PHA CANADA’S FIRST BOARD CHAIR LIVING WITH PH

It’s an honor to have Nicole Dempsey as the first person living with PH to be appointed Chairperson of PHA Canada’s Board of Directors. Nicole has been a key leader within the PH community for several years. She served as a PHA Canada Ambassador from 2014-16, before being elected to the Board of Directors in 2017. She is also active on social media where she uses every opportunity to raise awareness and educate others about PH. A passionate advocate for access to PH treatments, Nicole has participated in media conferences and meetings with government decision-makers. To learn more about Nicole and the Board of Directors, visit phacanada.ca/Board.

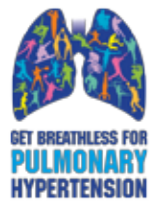


WORLD PH DAY 2020



World PH Day was very successful this year with great engagement with the #PaintCanadaPurple campaign on social media and an increase in traditional media attention. 23,582,191 Canadians were reached through the media and heard about pulmonary hypertension on May 5th. For more details, visit phacanada.ca/WorldPHDay.

PHA Canada
phacanada.com
facebook.com/PHACanada



WPHD 2020 - ALL OVER THE WORLD: USA PHA



Marking World PH Day Digitally During the Pandemic

The Pulmonary Hypertension Association (PHA) joined the global pulmonary hypertension (PH) community May 5 and throughout May to recognize World PH Day 2020. In years past, global organizations conducted walks, gatherings and festivals to bring the community together and raise PH awareness. But due to the COVID-19 pandemic, World PH Day festivities went virtual. PHA shared facts about the five PH groups and common symptoms on its social media platforms with the #WorldPHDay2020 hashtag.

PHA also launched World PH Day social media campaigns and shared posts that addressed safety measures PH patients can take to protect themselves from COVID-19.

One campaign encouraged the PH community to thank health care professionals who work to protect the lungs of people with PH. The campaign used the hashtag #PHoreverThankful. The #FlauntYourMask

campaign asked the community to share selfies of themselves wearing handmade face coverings.

All of PHA's campaigns, social media posts and graphics were available on WorldPHDay.org for the global community to use on their own social media platforms. Social media graphics were also available in Spanish and French. WorldPHDay.org received nearly 2,400 page views May 5.

Some PH community members celebrated World PH Day in their own ways. Jack Bartky, a licensed ham radio operator from New Jersey, created a radio station. He promoted PH awareness in honor of his wife Jessica, who was diagnosed with PH in 2013. From May 4 to May 6, the couple heard from 400 amateur radio operators from 20 countries.

PHA is grateful to be among the global health organizations that raised PH awareness for World PH Day 2020.

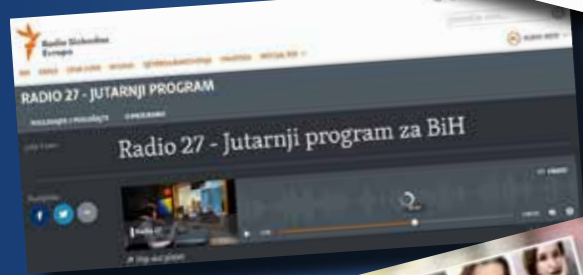


Media clippings

AUSTRIA



BENEFIZAKTION
Vespafahrer für Kinder
Das Perchtoldsdorfer Vespatreffen unterstützt „PH Austria – Initiative Lungenhochdruck“. Hunderte Fahrer helfen Kindern, die an der unheilbaren Krankheit Lungenhochdruck leiden, und spenden die Startgelder.





ZVONČEK KOMENTAR NA SVIJETU ZVONČEK ŠKOLSKO ZVONČEK ZVONČEK ZA VRIJEME

Križa sa zoraom virusom SARS CoV-2 skrenula je pozornost na plućne bolesti, iako taj virus razara i druge unutarnje organe, a današnji dan, 5. svibnja, na međunarodnoj sceni skreće pozornost na jednu drugu plućnu bolest – plućnu arterijsku hipertenziju. U Hrvatskoj je obilježava udruga bolesnika i članova obitelji Plava krv.

Od te rijetke bolesti u Hrvatskoj boluje otprilike 200 osoba, a ona pogada ljude bez obzira na starosnu dob. S obzirom da se teško otkriva pretpostavlja se da je obilježila više struku više. U medicinskim statistikama piše da su prognoze te bolesti bez terapije vrlo loše te većina takvih bolesnika premine u roku od pet godina.

Dok vlastita pluća doživljavaju samo disanje, gutanje zraka koje nam nedostaje npr. dok ronimo na dalj, vrlo često čemo zaboraviti glavnu ulogu pluća, da venoku krv provučemo kroz kapilare u plućima obogaćujući krv kisikom i kroz plućnu arteriju dostavi je srcu koje će kisikom osvijetliti mišićima i drugim organima koji bez nje ne mogu preživjeti. Plućna arterijska hipertenzija, kao kroničnu zlokvastvenu tegobu, uzrokuje sužene male žile koje vode do pluća pa u njima raste tlak. Kada se one privremlo začepe ili začepi, srce je prisiljeno da snažnije i brže pumpa krv što ga opterećuje i skraćuje mu vijek.

Plućna hipertenzija teško se posuđano dijagnosticira, tim više jer su simptomi vrlo slični nekim drugim tegobama. Oni kojima je plućna hipertenzija indicirana dak pri napornu, bol u prsima, lupanje srca, umor, oticanje nogu, stopala i rebuka, teškoće otklapanju i kratkotrajno gušćenje svjesti. Bolest je moguće liječiti, a moguće biti i smrtonosna, pa je važno da je što na vrijeme otkrije.

Odbornici upozorjuju na zaluđnu plućni hipertenziju: Včasna dijagnoza zachraní životy

Zadýchávejte se při chůdi do schůdi a bojí vás při fyzické námaze na hrudi? Může být příčinou plućní hypertenze, velmi závažné onemocnění v plicích, které může být smrtelné. To vše se může stát, pokud se vám objeví příznaky, jako je dušnost, únava, otoky nohou a bolesti v hrudi. Pokud máte tyto příznaky, je důležité, abyste se obrátili na lékaře, který vám pomůže s diagnózou a léčbou.

Vysoký tlak mohou mít i gluce. V boj s plućni hypertenzí pomůže včasná diagnóza

Zadýchávejte se při chůdi po schůdi a bojí vás při fyzické námaze na hrudi? Může být příčinou plućní hypertenze, velmi závažné onemocnění v plicích, které může být smrtelné. To vše se může stát, pokud se vám objeví příznaky, jako je dušnost, únava, otoky nohou a bolesti v hrudi. Pokud máte tyto příznaky, je důležité, abyste se obrátili na lékaře, který vám pomůže s diagnózou a léčbou.

Špičkový chirurg Lindner o umělé plicí a mozku zchlazeném na dvacet stupňů

Špičkový chirurg Lindner o umělé plicí a mozku zchlazeném na dvacet stupňů. Tento článek popisuje inovativní chirurgické postupy a jejich význam pro pacienty s těžkými onemocněními plicí.



5. SVIBNJA, MEĐUNARODNI DAN PLUČNE HIPERTENZIE

Bez terapije oboljeli živi do pet godina

Od te rijetke bolesti u Hrvatskoj boluje otprilike 200 osoba, a ona pogada ljude bez obzira na starosnu dob

Plicni hipertenzije

- anemotični testovi krvni tlak v plicích, očividně
- dochází při ní ke zvýšené námaze při fyzické námaze
- zhoršuje se postavení v plicích, v plicích
- příznaky: dušnost, únava, otoky nohou, bolesti v hrudi
- příznaky: dušnost, únava, otoky nohou, bolesti v hrudi



Den 5. května je Světový den plicní hypertenze

Plicni hipertenzije je rakovina. Přitom není vidět

O plicni hipertenzii řada lidí ani neví. Na vážnou chorobu upozorňují příznaky, které není dobré podceňovat. Zadíchněte se při chůdi do schůdi a bojí vás při fyzické námaze na hrudi? Může být příčinou plućní hypertenze, velmi závažné onemocnění v plicích, které může být smrtelné. To vše se může stát, pokud se vám objeví příznaky, jako je dušnost, únava, otoky nohou a bolesti v hrudi. Pokud máte tyto příznaky, je důležité, abyste se obrátili na lékaře, který vám pomůže s diagnózou a léčbou.



Světový den plicní hypertenze

ES HODNOCENÍ DENNÍ S NEGATIVNÍM TESTEM JEDNOU ZA MĚSÍC. OCHRANA

Obilježava se svjetski dan plućne h...

Dve godine zbog pandemije Covid-19 priljubljeni smo Svjetskoj a...

Zbog spomenutih razloga odložili smo ovogodišnju kampanju...

Kampanja "Plave usne" zamišljena je na način da vrlo lako možete sudjelovati u njoj. Dovoljno je da u aplikaciji Snapschat pronađete filter Glatkor lips, odaberete od ponuđenih boja plavu i tako se slikate. Slike nam šaljite putem naše fb stranice PH-Plava-kralja-Croatia i koristite hashtag #plaveusne #plavakralja #blueclips #phneurope #phcroatia #plucnahipertenzija #goodphnews #WorldPHDay #pulmonaryhypertension

Ista kampanja provodi se i u ostalim zemljama Evrope koje su članice Evropske unije. Ukoliko želite sudjelovati u ovoj kampanji, možete se obratiti na našu fb stranicu PH-Plava-kralja-Croatia.



Den 5. května je Světový den plicní hypertenze

Den 5. května je Světový den plicní hypertenze. Světový den plicní hypertenze je mezinárodní akce, která se koná každoročně 5. května. Cílem této akce je zvýšit povědomí o této závažné a často neznámé nemoci. Akce se koná ve více než 100 zemích po celém světě. V České republice se akce koná pod patronací Ministerstva zdravotnictví. Akce se koná ve spolupráci s Evropskou asociací pacientů s plućní hypertenzí (EAPHC).

deník.cz

Na 5. května v modrých barvách

Den 5. května let v 2022 oslavujeme Světovým dnem PH. Plicni hipertenzije je chronická, potenciálně smrtelná nemoc, která se v České republice vyskytuje u asi 200 osob. Akce se koná pod patronací Ministerstva zdravotnictví. Akce se koná ve spolupráci s Evropskou asociací pacientů s plućní hypertenzí (EAPHC).

Česke novinky1.eu

Vysoký tlak mohou mít i gluce, varují lékaři

Vysoký tlak mohou mít i gluce, varují lékaři. Tento článek upozorňuje na plućni hipertenzii jako na onemocnění, které může být smrtelné, pokud se neléčí včas.

HUNGARY



ITALY AIPI



ITALY AMIP



LATVIA



ISRAEL



AŠ SERGIU 05/05

PLAUTINĖ HIPERTENZIJĄ

Man meilmos rūpos – tai tarsi žinutė ir kvietimas įkvėpti daugiau, kvėpuoti pilniais plaučiais. Juk pirmą kvėpimą yra gyvybiškai svarbus kiekvienam. Šiuo paskutiniu atodūsiu iškeliaujam iš šio pasaulio. Visą gyvenimą mes kvėpuojam nesusimąstydami, kokią dovaną turim, nes kvėpuoti yra savaimė.

Gegužės 5 dieną, minima Pasaulinė plautinės hipertenzijos diena (World PH Day). Žmonės, „meilmy rūpų“ iniciatyvos. Taip pat prie iniciatyvos paskiestume žinutę apie šią retą ligą. Kuo anksčiau žmogui diagnozuojama liga, tuo didesni šansai, kad jis galės grįžti į normalų gyvenimą. O pati liga nespės padaryti didesni žalos sergantiesiems.

#skirtingosSpaivos #skleiskiznia #WorldPHDay #bluelips #goodPhiness

Jūs ir Dar 71 žmogus

Patinka Komentuoti Bendrinti

Comment as ŽSPIVA

Músico André Sardet lança "Ponto de Partida"

Single lançado ontem, no dia em que os portugueses deram o primeiro passo para o regresso à normalidade, tem o também um novo "ponto de partida" para o músico de Coimbra

Debate online sobre agricultura familiar

UMA nova iniciativa de produção online vai abordar a produção agrícola familiar em Portugal. O debate, que será transmitido em vídeo, terá lugar no dia 22 de maio, às 19h, no canal de YouTube da Associação Nacional de Agricultores e Pequenos Empresários (ANAP). O debate será moderado por António Aguiar, presidente da ANAP, e terá como convidados o agricultor português António Aguiar e o espanhol José María Martínez, presidente da ANAP espanhola.

Campanha alerta para hipertensão pulmonar

HOJE é o dia mundial de luta contra a hipertensão pulmonar. A campanha "Ponto de Partida" tem o objetivo de sensibilizar a população para esta doença rara e grave. A campanha é liderada pela Associação de Hipertensão Pulmonar e conta com o apoio de vários parceiros.

Hipertensão Pulmonar: A doença 'invisível' que afeta a qualidade de vida

A Hipertensão Pulmonar é uma patologia progressiva, grave e rara que afeta mais de 25 milhões de pessoas em todo o mundo. Em entrevista ao Lifestyle ao Minuto, o médico cardiologista do Centro Hospitalar Universitário Lisboa Norte (CHULN) Rui Plácido, desmistifica a doença.

Associação de Hipertensão Pulmonar lança campanha nas redes sociais

30 de maio de 2020

médico

Hipertensão pulmonar: uma doença rara explicada por um médico

A hipertensão pulmonar é uma doença rara e grave que afeta os pulmões. O médico explica os sintomas e o diagnóstico.

Hipertensão Pulmonar: A importância de vigiar e valorizar sintomas

23 de maio de 2020

NEWS FARMA

HIPERTENSÃO PULMONAR NA ERA COVID-19: Condição rara e tratada de forma diferente

23 de maio de 2020

Hipertensão pulmonar na era COVID-19: como estamos a tratar os nossos doentes?

Sabe-se que a Hipertensão Pulmonar é a complicação mais frequente de quem sobrevive aos sintomas pulmonares e que pode surgir por vários motivos, desde logo a presença de infeções da via aérea inferior. Assim sendo, o tema "Hipertensão Pulmonar na era COVID-19" é de grande importância.

Campanha online "Lábios Azuis" pretende sensibilizar população

KONSERT FOR SIKKULASJONSYKDOM/LUNGESYKDOM (PAH)

Dansbandradioen er sammen med Bare1 og Me2 DanseDuo. Geir Iørgen som er Bare1 Informerer litt om tirsdagens støttekonsert for Sirkulasjonsykdom/Lungesykdom (PAH)

88 Amøll personer nådd 6 Engasjement Fremming ikke tilgjengelig

5 Likes 3 Kommenter Del

Kommenter som LHL PAH Pulmonal Hyper... Trykk Enter for å publisere

Hipertensão pulmonar: A importância de vigiar e valorizar sintomas

NEWS FARMA

HIPERTENSÃO PULMONAR NA ERA COVID-19: Condição rara e tratada de forma diferente

Hipertensão pulmonar na era COVID-19: como estamos a tratar os nossos doentes?

Campanha online "Lábios Azuis" pretende sensibilizar população

Máte modré pery?

Môže trvať mesiace a roky, kým sa zistí, že za zadychávaním a únavou nie je choré srdce, ale iný dôležitý orgán. Dnes z komárna za vyše roka preveril život hore nohami.

Naši odborníci



Mgr. Dana Cziborová, farmaceutka



MUDr. Milan Luknár, kardiológ



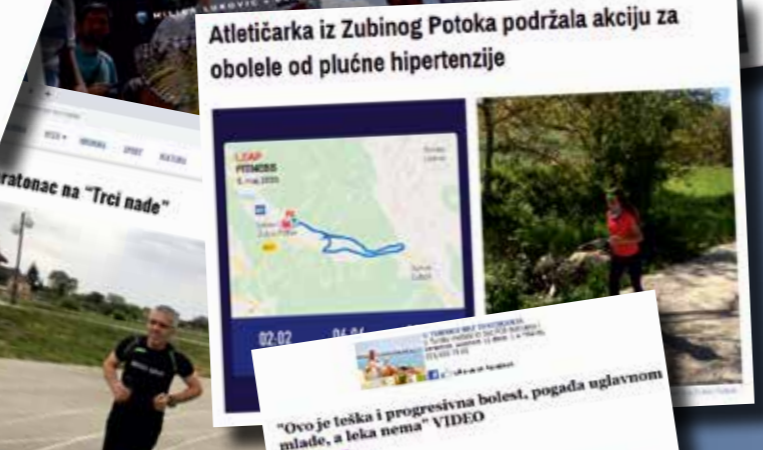
Veľké novy

Všimli som si, že sa zadychavam. Za svojho strážnika som vedel, a všetko ochotne som vedel o svojom ochorení. Všetkým som povedal, že som zdravý. Všetkým som povedal, že som zdravý. Všetkým som povedal, že som zdravý.

SRBIJA NA DLANI



KAŽE DA NEMA TRKA? ISTRČI SUTRA VANREDNU INDIVIDUALNU TRKU KAO PODRŠKU SVIMA KOJI BOLUJU OD PLUČNE HIPERTENZIJE



LEPE SRPKINJE SE OVIH DANA SLIKAJU SA PLAVIM USNAMA! Iza ovog trenda na mrežama krije se SJAJNA AKCIJA (FOTO)



"Ovo je teška i progresivna bolest, pogađa uglavnom mlade, a leka nema" VIDEO



Tadejine modre ustnice - osebna zgodba o pljučni hipertenziji

Pljučna hipertenzija je redka, izuzetno teška, progresivna i smrtonosna bolest, pogađa uglavnom mlade osobe. Prvi simptom koji se javi je pojava umora. Ono što ste mogli juče ili prošle nedelje da uradite više danas ne možete... imate nesvesnice, sredina vas eliminiše... može da razume da ono što ste mogli juče danas ne možete", rekao je glavni stručnjak na TV Prvoj Mirko Glavinčić iz Udruženja pacijenata Plućna hipertenzija Srbije.







UKRAINE PHURDA



Sponsors



Platinum



Gold



Silver



Sponsors' corner

“If you’re living with PH or not, do what gives you pleasure in life. For me, embroidery helps to relieve stress and gives me a sense of comfort and balance”

Nadiya, 26
Ukraine

Embroidery enthusiast

Living with pulmonary arterial hypertension for 18 years



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for more information

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:

-  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**



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"

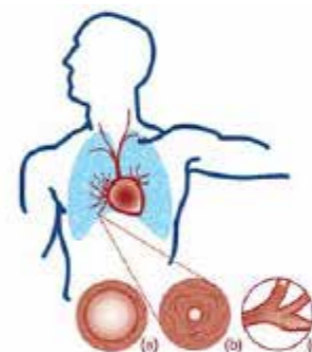


AIMS OF PHA EUROPE

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 Hypertension patient associations across Europe. The primary objective of PHA EUROPE is to establish a narrow cooperation between the members and the European institutions, international organizations and public institutions worldwide and work towards achieving the best possible standards of care for all European pulmonary hypertension patients.

WHAT IS PULMONARY ARTERIAL HYPERTENSION?

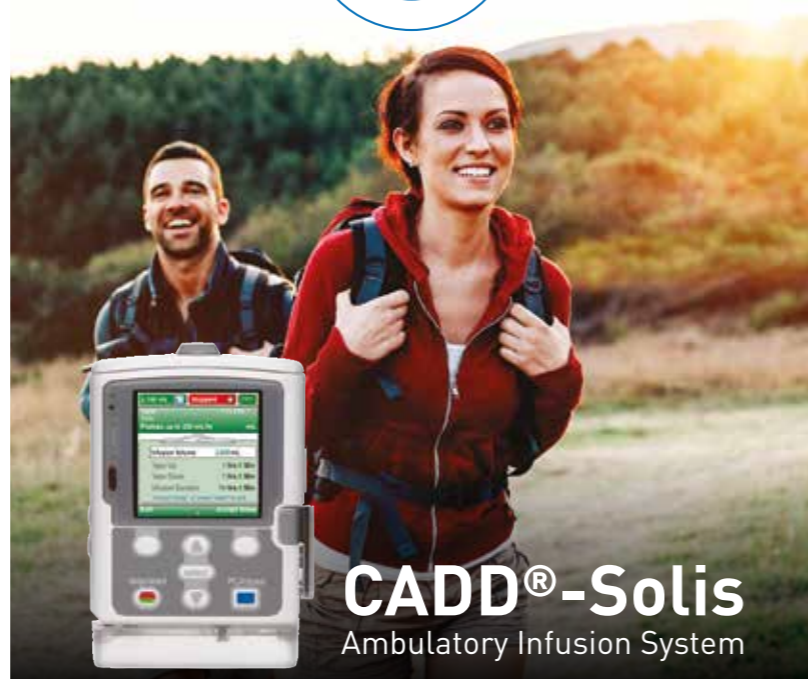
In patients with Pulmonary Arterial Hypertension characteristic changes occur within the pulmonary circulation, which include thickening of the linings and obstruction of the small pulmonary blood vessels. They are both structurally and functionally abnormal. In severe cases up to 80% of these very small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



- a) Cross section of normal pulmonary artery
- b) Reduced lumen of pulmonary vessels due to cell proliferation and remodelling in advanced pulmonary arterial hypertension
- c) Longitudinal section with pathological changes within the vessels proliferation, deposition of blood clots, thickening) causing difficulties for the heart to pump blood through the lungs

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

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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 hypertension, which improve the quality and length of life. The aim for the present should be to ensure that all patients with pulmonary arterial hypertension have access to centres of excellence in the diagnosis, management and ongoing treatment of this disease.



1. Bayer AG. Data on file: World PH Day 2019 evaluation report. 2019.

PP-ADE-ALL-0197-1

Members of PHA Europe and contact details

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www.phbelarus.by - phbelarus@yandex.ru

BOSNIA AND HERZEGOVINA



Udrženje građana oboljelih od plućne hipertenzije "DAH" - u Bosni i Hercegovini
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The Bulgarian Society of Patients with Pulmonary Hypertension - BSPPH
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www.bspph.net - bspph@gmail.com

CROATIA



Plava krila - Udruga pacijenata oboljelih od plućne hipertenzije
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CZECH REPUBLIC



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ESTONIA



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FINLAND



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ITALY



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ASSOCIAZIONE MALATI DI IPERTENSIONE POLMONARE ONLUS



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LATVIA



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LITHUANIA



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

MOLDOVA



Asociația Obsteasca
"Asociația persoanelor cu hipertensiune pulmonară din Republica Moldova"
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NORWAY



PHA Norway
LHL PAH - Pulmonal hypertensjon
Vitaminveien 1A
0485 Oslo, Norway
www.lhl.no/trenger-du-hjelp/interessegrupper/lhl-pah
lhl.pah@lhl.no

POLAND



Polskie Stowarzyszenie Osób z Nadciśnieniem Płucnym i Ich Przyjaciół
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ROMANIA



Association of pulmonary hypertension patients
Sinaia/Prahova Carol I, nr 11 street
www.phader.eu

RUSSIAN FEDERATION



Natasha Charity Fund
c/o Evgeniy Komarov - Kondratevsky prospect
House 57, apartment 6 - St.-Petersburg
www.community.livejournal.com/fond_natasha
otzovitesnam@mail.ru - www.nurm.ru

SAVE AND PROTECT



Save and Protect
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SPAIN



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www.hipertensionpulmonar.es informacion@hipertensionpulmonar.es

FCHP



FCHP Fundación Contra la Hipertensión Pulmonar
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<https://www.facebook.com/fundacionhp>
<https://twitter.com/fundacionhp>

HIPERTENSIÓN PULMONAR



Hipertensión Pulmonar España Organización de Pacientes (HPE-ORG)
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<http://www.hipertension-pulmonar.com/presidencia@hpe-org.com>

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