

PULMONARY HYPERTENSION Mariposa Journal

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GETTING BREATHLESS FOR PULMONARY HYPERTENSION ON WPHD 2019

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

PHA EUROPE *for the patients*
European pulmonary hypertension association

Mooslackengasse 17 • A-1190 Vienna • AUSTRIA • +43 1 4023725 • +43 1 4093528 • info@phaeurope.org • www.phaeurope.org



Editor's memo

SUMMER 2019 EDITION

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

I am delighted to welcome you on the pages of this issue of Mariposa dedicated to our World Pulmonary Hypertension Day (WPHD). The first WPHD was organized in Madrid on 5 of May, 2012 and we are happy that since then we have managed to organize our "breathtaking" series of events in each year under the theme of "Get Breathless for PH". The idea behind this concept is to help the whole society in understanding the everyday life of PH patients: how they manage with the challenges of their condition and what they are really feeling during even a simple activity like ironing or climbing the stairs. Such feeling is very similar to the one man can feel during sports: minutes or even longer periods of time of stalemates, when no more step is possible to make, when your body does not obey due to shortness of breath.

Thanks to the continuous support, dedication and hard work this year was again a big success with a great variety of events, which raised the awareness of pulmonary hypertension not only in Europe, but well beyond, all over the world.

2019 highlights



Activities were organized in the USA and Latin America, in Canada and Australia.

From Europe 20 countries and 24 member patient

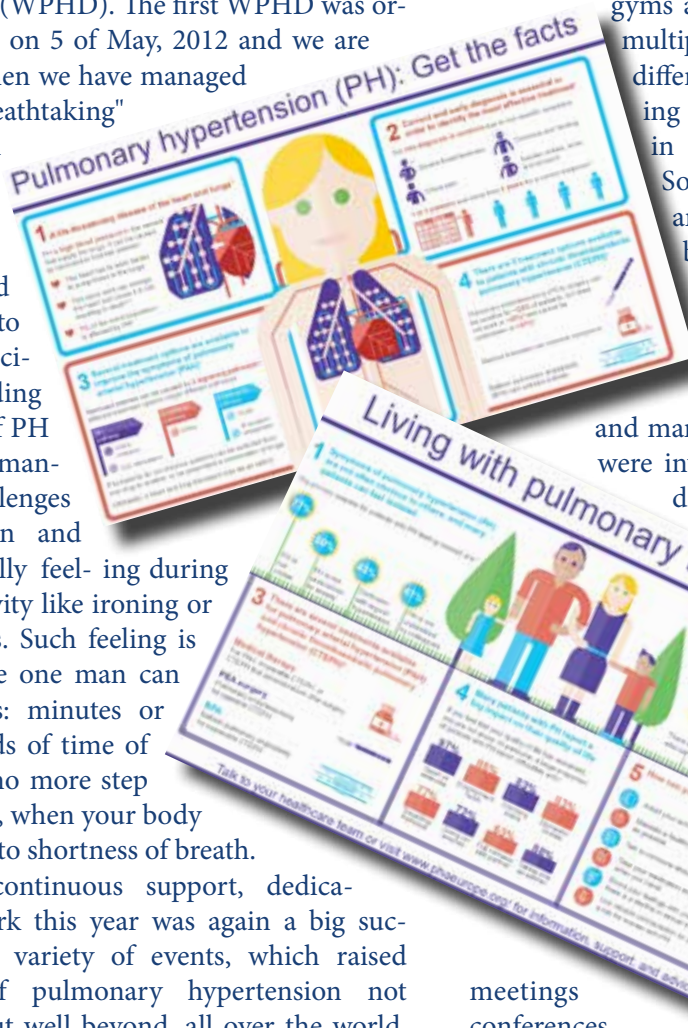
associations joined the project: organized and participated in different sport events, held educational programs, gave TV and radio interviews. We could witness hundreds of kilometer long bike rides, inside the gyms and outside on the roads, through multiple countries and continents (!), different trail running contest crossing hills and forests, running contests in very nice historical urban areas. Somebody was brave enough to swim amongst sharks, but wearing our branded T-shirt. Others took the challenge and climbed high mountains. There were dancing, which moved all parts of the body, horse riding, cheerleading master class and many more activities. Lots of children were involved in different activities: their drawings and poems were collected

in a booklet, they participated in running contests and they have just laughed, played and had very nice time in our colors, wearing our "Get Breathless for PH" T-shirts. In some countries sport events were supplemented with important meetings conferences.

This year we introduced new initiatives and fine-tuned what already worked in the past with great success.

Unfortunately we could not rely on Thunderclap, a tool which sent coordinated messages on different social media platforms, but managed to get the most from our social media platforms. Regular posts about member associations' activities, thematic educational articles about the disease, the treatment and classification, just to name a few, which helped us to get even more engagement than last years.

We composed two infographics: the first one is dealing with the facts and data of the condition. It contains



references to the underlying scientific literature and provides a short insight of the disease.

The second one is approaching the disease from a practical point of view: how the life can be managed with the disease and what type of assistance the patients can look for. We have included some of the key points and considerations from the result of the 'International Patient and Carer Survey'.

The infographics have reached more than 5.000 users and we are expecting more and more as we are progressing with the translations. Initially, they were drafted in English, but have been already translated into 10 more languages.

However, these infographics were published as part of the WPHD celebration, our plan is to use them later on as well, during discussions with other stakeholders. They are very colorful and eye-catching, easy to understand and may give a basic understanding of the disease, so they help

An educational part was integrated into this year's events. Scientific lectures have become integral parts of the WPHD celebrations. Many member associations held them as part of their event or separately as a standalone program. They managed to address passers-by and spread high level, reliable and up-to-date information about the disease with the help of local PH experts, who actively participate in these programs.

A webinar with special focus on CTEPH (chronic-thromboembolic pulmonary hypertension) and ERN-Lung (European Reference Network for rare respiratory diseases) was organized centrally and you can learn more about it from the present edition of the Mariposa.

The photo contest evolved to an unmissable part of

the World PH Day celebration, however, we made a twist this year and organized it on an online platform. Last year a jury of medical experts made the final decision, this year it was up to the wide community, everybody could vote. This move generated more noise around this initiative, more interaction and engagement and became a real awareness raising tool with more than 4.000 votes.

We had extended goals this year. On top of increasing the awareness of the disease, we aimed to ensure the engagement of relevant stakeholders and boost social media reach. I think the following numbers are self-explanatory and show we definitely exceeded our expectations: 50 events, more than 276,000 participants, 80 experts and celebrities, 291 pieces of media coverage and fabulous online numbers with more than 115,000 people reached and more than 12,000 likes solely on the Facebook page of PHA Europe.

Let me close this note with a very big thank you and applause to everybody, who contributed to the success of WPHD 2019 and made these series of events possible! Special thanks go to our industry partners, who let us dream big and make our plan come true. Their dedication and continuous support means us a lot and an important driver of WPHD celebration.

I am looking forward to next year's WPHD celebration. I think everybody is as excited as me, how it can be even bigger and more successful.

Gergely Meszaros
WPHD project manager
PHA Europe

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PHOTO CONTEST

PHA EUROPE 2019

Photos became integral part of our everyday life. We try to save the most valuable moments for the eternity, or at least for some years, as they help us relive those feelings and atmosphere.



Hundreds, if not thousands of photos, were taken worldwide on and around World PH Day. Unfortunately, there is no way to present all those photos in our Mariposa journal, so we asked our members to send us their best photos in order for us to organize a photo contest. As a result of their selection we originally received 27 photos, which later on participated in the contest.

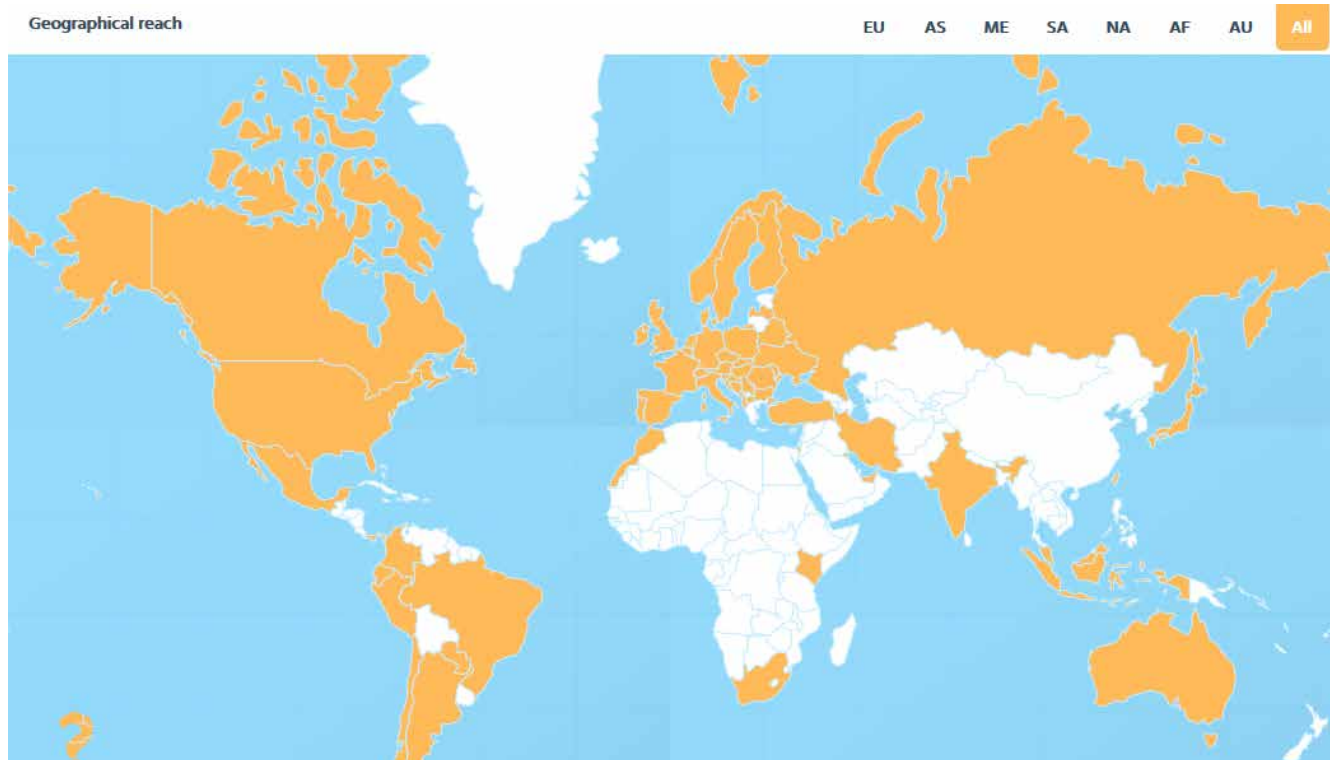
On top of some quality requirements, there were no further rules, but a maximum number of 3 photos per associations. Our main objectives with the photo contest have not changed to the previous year: to find the most meaningful pictures from each countries and to enhance the quality of the photos.

Last year we asked a jury consisting of well-known experts from the medical field to make the thought decision and choose the winner photo.

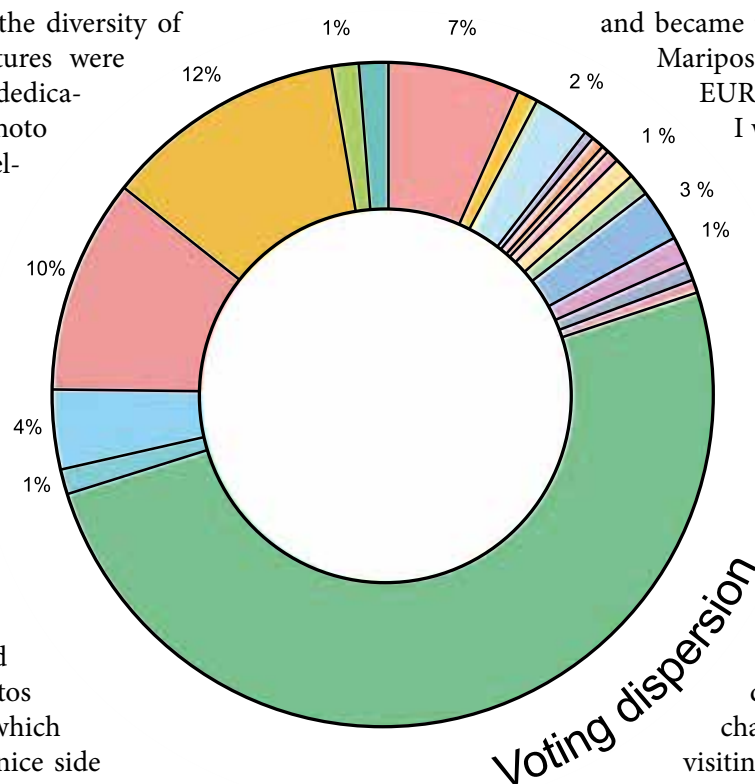
This year, to generate more visibility, we used a fully opened special voting platform. The numbers and the level of participation confirmed that we made a good decision: 3895 votes (many and more sharings on social media platforms), 61 countries and 624 cities reached.

We even managed to step out from the rare disease field: European Lung Foundation advertised our photo contest and the European Patient Forum made an article about it (<http://www.eu-patient.eu/News/News/world-pulmonary-hypertension-day--photo-contest/>) and our initiative was published in their July newsletter!

We can be very pleased with the geographical spread of the votes, but the white spots suggest that lot of work left in terms of raising awareness of PH.



It was very nice to see the diversity of photos: big crowd pictures were real testaments of the dedication towards PH. A photo with sharks and an excellent shot of a kingfisher on top of our logo were breathtaking. Pictures with children always bring smile and blue balloons became the non-official trademark of our World PH Day events. We must not forget about those, which were taken in beautiful natural scenes emanating relaxing and calm atmosphere. Photos were made, however, which not only presented the nice side of the life, but also gave insight into the difficulties PH patients need live with day by day. Let me congratulate Fundacion Contra la Hipertensión Pulmonar (FCHP) from Spain for the winning photo: their picture received the most votes



and became the cover photo of this Mariposa. In addition, they win EUR 1.000!

I would like to also thank for the member associations, who participated in the contest and made an excellent work of spreading the information about PH all over the world. It was a real fun and hope next year we can even manage to reach out to more countries.

You can learn more data, statistics and charts of the contest by visiting:

<https://www.surveylegend.com/s/114c>

Gergely Meszaros





WPHD 2019

CTEPH AND ERN-LUNG WEBINAR

Gergely Meszaros



Following the short introduction and some house-keeping Prof. Dr. Olivier Sitbon, from Université Paris-Sud Le Kremlin-Bicetre, France, chair of the Group 13.01 (pulmonary hypertension) of ERS Assembly 13 (Pulmonary Vascular Diseases) kicked-off this year's webinar. Our concept was to divide the webinar into three main parts: the first was dedicated to a lecture about CTEPH.

In the recent years lots of progress happened on this field, so it is worth to look back and get acquainted with the different treatment and medical intervention options. A new definition of CTEPH was introduced as a result of the World Symposium on PH in 2018: it is a symptomatic PH (mPAP, mean pulmonary arterial pressure >20 mmHg – previously it was ≥ 25 mmHg) with persistent perfusion defects after 3-6 months of adequate anticoagulation. Prof. Sitbon drew our attention to the clear distinction between pulmonary embolism (PE) and CTEPH: while clots are removed in case of PE, fibrotic material can be found in the vessels in CTEPH.

We learned, however, that due to unknown reasons 1-3% of acute PE patients turn into CTEPH. Possible reasons can be shear stress, vascular stenosis/occlusion. Data show that CTEPH is rare, but underdiagnosed. According to the estimation 13 per

new CTEPH patient per million inhabitants/year is expected, however registry data show only 5-6 per million observed incidence, which means that CTEPH is still underdiagnosed.

Prof. Sitbon gave insight into the diagnostic algorithm of CTEPH (underlining that V/Q scan is the key tool for detection, but also mentioning cone beam-CT as a new technique) and outlined the signs and symptoms of CTEPH. It was interesting to learn that it can be even months to years between the initiating event (possibly undetected by the patient) and the symptoms of CTEPH.

It was underlined that all CTEPH patients should be assessed by a multidisciplinary team.

This team should make a decision, whether the patient is operable or not, which indicates the possible treatment options. If, based on a risk/benefit ration assessment, the patient is operable, pulmonary end-arterectomy (PEA) is made, if not, targeted medical therapy is applied with or without balloon pulmonary angioplasty (BPA). The later approach applicable to those patients, who have persistent/recurrent symptoms despite the operation. Naturally, the surgery is not without risks: the more common complications are infection, persistent PH and neurological ones.

Seemingly an easy question...



Patients - not a homogenous group, but with different needs!



The role and impact of medical therapy – including the recommendations – as well as five medical trials regarding CTEPH were introduced.

We could learn more about PEA and BPA: different pictures were presented about the interventions and a table about the efficacy of BPA.

From a treatment point of view, a single CTEPH patient is quite well positioned, because multimodality approach can be followed. The ultimate goal is to normalize the pressure.

In his summary Prof. Sitbon touched on the definition of CTEPH, the importance of V/Q scan is setting up the diagnosis, the role of and treatment decision of the multidisciplinary team as a rare complication of acute PE.

In the second part Alexander Milanovich, an ex-CTEPH patient from Serbia shared his patient journey, which started in 2016 with a severe PE. He visited couple of physicians to find out the conditions he is suffering from. It took a while, but luckily he met a specialist in Belgrade and he underwent a BPA intervention. Nevertheless, his condition had not stabilized, so he visited a specialist after 8 months in Germany for further treatments. Everybody told him that his condition is a result of his professional athlete history. Luckily, the second intervention went well and Alexander is in good condition.

It was interesting that last year and this year as well our patient speakers were professional athletes: Patrick from Ireland is an open water swimmer and Alexander is a rugby player. Is it possible that “pushing hard” might result in PE and ultimately in some cases CTEPH?

The webinar was closed by a presentation about ERNs: “CTEPH in focus: meeting our patients’ expectations”. In his presentation Gergely Meszaros explored the challenges and expectations rare disease patient might have and face in Europe and the possible ways of solutions how these challenges can

be addressed. The main points of interest were care (focusing on diagnosis and access to treatment) research and registries. Following the general introduction of the European Reference Network (ERN) concept, more specific areas of the work of ERN-Lung (Rare Respiratory Diseases) were presented:

1. ERN Lung RD Registry Data Warehouse – a system based on patient consent and consisting of three major part
2. Clinical Trial Network – learning from and adapting best practices with the objective of intensifying clinical research and bringing new medications to the patients as quickly as possible, but following the common, high level standards and protocols
3. CPMS (Clinical Patient Management System) – how it works in the practice and the added value it brings into the patient journey
4. EXABO (online EXpert Advisory BOard) – an easy to use platform where patients can seek for answers from European top-level experts in their native language

Gergely Meszaros, however, underlined that a lot of work is ahead of ERNs and the most urging one is to find the way in which they can be integrated into the local health care system.

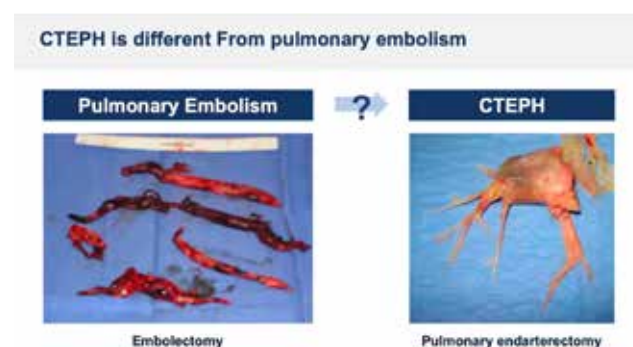
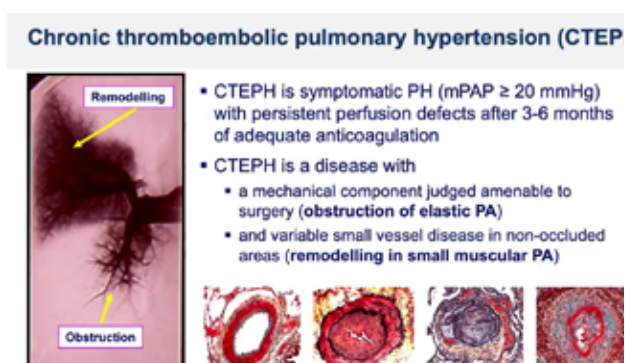
The presentation was closed by a final wish: patients and their interest always need to be in the center of all initiatives and changes.

The webinar lasted half an hour longer than scheduled, thus we did not have the chance to have a real Q&A session.

The webinar was well marketed on our social media channels and received valuable endorsements from European Lung Foundation (ELF), EURORDIS – Rare Diseases Europe and ERN-Lung.

The recording of the video was uploaded to our Facebook social media channel and available at:

<https://www.facebook.com/phaeurope/videos/326648404687733/>





WPHD 2019 - AUSTRIA

SILENT RUN AT THE VIENNA CENTRAL CEMETERY

Silent Run

The Central Cemetery is one of the largest cemeteries in the World. Many celebrities like Mozart, Beethoven, Schubert or Flaco are having their graves here.

The starting fees for the "Silent Run" at the Vienna Central Cemetery, which took place on May 25, 2019, were donated in their entirety to the association PH Austria. At bright sunshine and in a good mood, Mag. Renate Niklas, Managing Director of Friedhöfe Wien, handed over 3000 euros to PH Austria -Initiative Pulmonary Hypertension. "The run made me humble. It's a great event and has reminded me that we have to cherish life," said Alexander Bichl, winner of the 5km and 10km races.

First, the kids started their 1.25km long Kidsrun. Around 100 participants then took part in the 5km hobby run and more than 60 runners faced the 10km run at the Vienna Central Cemetery. The 5km-run was won with a time of 00: 18: 09.5 by Alexander Bichl. The first placed woman, Sylvia Walden, finished the 5km race with a time of 00: 24: 20.3. The winner of the 5km race also won the 10km race with a time of 00: 38: 23.3. Anja Jedynak was

the first woman to finish the 10km in 00: 48: 11.0. The musical framework was created by the Austropop trio "DIE3" with hits like "Es lebe der Zentralfriedhof", which were entertaining for free in the name of the good cause. At the award ceremony and the handing over of the donation check Mag. Renate Niklas emphasized: "I am pleased about the numerous participations in our Silent Run and especially about the fact that we could raise 3.000 Euro for children with PH. Our event was well attended. It is nice to see how the runners successfully completed this run with so much respect for the scenery and the occasion. "

The Vienna cemeteries are not only a place of remembrance, but also a resort and green oasis in the middle of the city of Vienna. The Viennese use their cemeteries for relaxation and sports. Already many people used the oases of nature to go for a walk, nordic walking and running. An overview panel in the entrance area (Gate 2) of the Vienna Central Cemetery shows the route guidance and information about the respective running routes. The routes themselves are measured by GPS and the routes are signposted.



Diver

Wolfgang H., a diver in the House of the Sea in Vienna, wanted to draw attention to the world pulmonary hypertension day (5 May) and that there are many children and adults among us who also rely on additional oxygen at the water surface. In addition, he wore the white WorldPHDay T-shirt with the lungs, which made the sharks very curious.



Reinhold Messner

On April 29, 2019, we were able to achieve a very ambitious goal. For the World Pulmonary Hypertension Day, we were looking for a celebrity who would make a statement on pulmonary hypertension and who will be available for a photo with our t - shirt. Therefore, we thought about who could describe how life with oxygen deficiency in the blood could feel.

So, we came to the extreme mountaineer Reinhold Messner, who was the first human to climb Mount Everest and then all eight-thousands without artificial oxygen. Who, if not him, can describe exactly how exhausting even the smallest activities can be? So, we dare to ask. About a month later we received the happy news that we will be able to conduct an interview with Mr.

Messner in Bolzano on April 29 at the MMM Firmian Museum.

We prepared ourselves well and after Reinhold Messner was awarded the ROMY for his documentary 'the last step' on April 13, we were able to record and study this documentation. Many statements in this documentation by Reinhold Messner and



Peter Habeler could have come from our patients. The atmosphere of the MMM Firmian was impressive. We felt like in Tibet and enjoyed the power and tranquility of this unique place. Reinhold Messner came with Maleen's book under his arm and answered our questions with great empathy.

These were his most important statements in conversation with Maleen Fischer- "You have no strength at first and wonder why you cannot get any further, then it is possible only step wise. Then again a break with hyperventilating, of course, then again a step, but not only the physical strength decreases, the strength in the legs or in the arms, also the mental strength diminishes, because the brain is supplied with blood and needs oxygenated energy, and so I have no more will, much less will, much less judgment, I have less willpower to move my legs anyway and that's why there is a hopelessness. And since the hope to maintain and not to be surrounded by despair is perhaps the art of your life, getting up every day and feeling this burden, I am very tired, I am weak, I need a lot of will for every activity. It costs me so much more power than normal people to master the everyday life or work that you have set out to master. This is imaginable with my experience that I have made in very high altitude, Mount Everest, or generally the eight thousands. But we have proved that it is possible to survive even at 8850 meters above sea level without artificial oxygen and still bring a bit of power, but it is an agony. With this agony, unfortunately, you have to live, but if you are now being able to use medicines that prolong one's life, you have at least the hope that there may be more research, more medicines, more help that even people with your difficulty, I do not want to say disability, more and more, maybe worldwide have hope they can live their lives with positive feelings, with hope for the future. "



After this interview there was a very interesting discussion with Mr. Messner, Mrs. Prof. Löffler Ragg and our patients. Of course, a small photo shoot was not missing!

Gerald Fischer, PH Austria - Initiative
Lungenhochdruck

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



WPHD 2019 - BELARUS

LET'S COLOR SMILE ON EVERYONE'S FACE!

Annual World Day of Pulmonary Hypertension took place in the city of Zhodino, Belarus on May 18. The city recreation park hospitably opened its doors to everybody eager to take part in the celebration of goodness and cordiality. Favorable atmosphere of friendliness and sunshine, smiles and fun, perky laughter of tirelessly running and frolicking children filled this day with warmth in the soul and hope for mutual help. Volleyball started the holiday for a reason – it is an active game, with the help of which we expressed support and solidarity towards people with PH who are experiencing the strongest breathlessness without any active actions. Any healthy person involved in sports, playing outdoor games in these moments is confronted with feelings close to those, experienced by people with PH, for whom these symptoms have already become part of a difficult life.

The photo-zone with colors of Holi of symbolic blue color caused great interest and joy among our young viewers. The children shared their mad energy and mood with others, took pictures and ran merrily, showing blue smiles. Thanks to the joint work of children and adults, colorful drawings appeared on the asphalt, decorating the park and attracting the attention of passers-by.

It was possible to measure your strength by engaging in tug-of-war, and both adults and children took part willingly.

Volunteer activists informed people about the manifestations of this disease, the significance of this event, flyers were distributed to each visitor describing the possibility to help our patients.

Juniors from the Youth Center gave the audience a

bright, colorful performance, and in the evening the guests of our holiday were in for a major surprise – a concert of the Post MC and Fresh Band groups. All the activities caused storm of positive emotions and there was no an indifferent person this day: the passers-by danced merrily, sang along and applauded with gratitude. We received so many kind smiles and observed a number of eyes full of joy!

It is nice to realize that this day we, for a moment, forgot about the difficult and painful everyday life, everything bad seemed to evaporate or not to exist at all. The desire was to extend this moment and make it an eternity. An eternity in which there will be no pain and suffering, where each person is a friend and helper and no matter what happens, there are those who will surely give you a helping hand.

We are grateful to the “Formula Zdorovya” Youth Center for its help in organizing, to our volunteers, to the mass media, to the newspapers Zhodinskaya Navi and Zhodinskiye Vesti, as well as to the Sfera TV channel for covering such an important event, and also to all not indifferent people who shared this holiday with us!

If there is the slightest opportunity to help, do not miss it, because receiving a sea of thanks in return is much more pleasant! Together for good!

Aksana Sniazhko

Aid to Patients with Pulmonary Hypertension

www.phbelarus.by

www.facebook.com/groups/phaBelarus





WPHD 2019 - BOSNIA AND HERZEGOVINA

EXTENSIVE ACTIVITIES FOR PATIENTS WITH PH



all generations with our story, from the youngest to the oldest.

We started hard

This year's activities dedicated to celebrate the 5th May - World Day of pulmonary hypertension, we started with our dear rafters who are always ready for action and activities that ultimately have a humanitarian character. A day filled with adrenaline and positive energy. Weather and River Krivaja were perfect. A large number of rafters from the region, mostly from Serbia and Bosnia and Herzegovina, supported the activities of our association WPHD. All the participants of this rafting on 04.05.2019. were breathing for pulmonary hypertension.

Circle for PH

We organized city bicycle ride called the "Circle for PH". In a very good mood and a good company, a group of cyclists from Zavidovici, a town in Bosnia and Herzegovina, were riding for the support of patients with pulmonary hypertension. On the event also attended representatives of print and electronic media. This was also a chance for another activity of the Association "Breath" from Bosnia and Herzegovina. On the route of 2,000 km long we show out Ismet Skulj, a bicyclist, a recreator, a marathoner from Bosnia and Herzegovina. For three years, Ismet Skulj has been supporting PH patients, adding miles and miles of support. This time driving through seven countries of Europe, raising awareness of PH and pointing at the difficult position of people suffering from this disease in Bosnia and Herzegovina.,,

"Heart full of smiles" with "Breath"

Association of citizens suffering from pulmonary hypertension "Breath" - in Bosnia and Herzegovina, continues with successfully collaboration with Association „Heart full of smiles“ from Sarajevo. As always, this Association gives full support to the patients of this disease in our country. This year's activity was in „Mjedenica“ in Sarajevo, where volunteers of both associations spent unforgettable hours in socializing with children with developmental difficulties. The children enjoyed the sports, music and art workshops that this time were organized for the occasion of World Pulmonary Hypertension Day. The focus was the symbol of the heart. In a unique and unforgettable way, all the participants of these

Association of citizens suffering from pulmonary hypertension "Breath" - in Bosnia and Herzegovina, as in previous years, tried to implement as many of the events which marked the WPHD 2019 as possible. This was done with the aim to attract the media to speak more and write more about the difficult situation of patients who is suffering from pulmonary hypertension in our country. Besides, one of our goals was to reach out to



events inhaled for all PH patients around the world.

Much more cities become part of our activities

Another event of celebration of World Day of Pulmonary Hypertension was realized in Bosnia and Herzegovina, thanks to the hikers and walkers from Zenica, Kakanj, Zavidovići and Sarajevo. They gladly accepted a call to raise awareness of this disease with us. In spite of bad weather, fifty walkers of today's undemanding, social and educational tours on Zmajevac took about 10 km and get breathless for all PH patients. It was a chance to talk about our disease, but also to enjoy the beautiful view of Zenica. Followed by rain at the first half of the tour, 50 participants from these three cities have helped us in this way to talk about pulmonary hypertension at each step and to share information about disease and the bad position of the patients in Bosnia and Herzegovina.

Talk about pulmonary hypertension with different generations

Our endeavor to the activities dedicated WPHD 2019 include all generations we rounded up with visit to the First Elementary School in Zavidovici, Bosnia and Herzegovina. With the students and their professor of physical and health education, Amir Muminovic, we talked about pulmonary hypertension and symptoms with the warning that every sign of fatigue it's important and person should visit a doctor. After the educational part, the students actively participated in the sports and recreational part, as well as the mini photo shooting on the topic of pulmonary hypertension, which caused special attention.

Through seven countries for PH patients

Ismet Skulj, a cyclist, a recreator and a marathoner from Bosnia and Herzegovina, has been riding a bicycle tour for the past two weeks regarding WPHD

2019. This year's drive goes through seven countries of Europe: Bosnia and Herzegovina, Croatia, Hungary, Czech Republic, Slovakia, Austria and Slovenia. Its length is over 2000 kilometers, and it is for all patients who is suffering from pulmonary hypertension! Riding for respect!

Otherwise, this is already the third year and the third consecutive drive of Ismet Skulj as a support for PH. These days we are expecting his return to Bosnia and Herzegovina, which will collect a total of 5.500 km of driving during the last three years dedicated to raising awareness of pulmonary hypertension.

Signing donors cards

As a result of the cooperation that lasted for years between the Association of Dialysis and Transplantation of the Federation of Bosnia and Herzegovina, the Donor Network of BiH and the Association of citizens suffering from pulmonary hypertension "Breath" in Bosnia and Herzegovina in Zavidovici, a public signature of donor cards was organized. This event was realized on the occasion of WPHD 2019 and the promotion of the campaign "For Life - Talk, Support, Share" conducted by the DTBiH Association and Donors Network of BiH in cooperation with the Ministry of Health of FBiH.

To the great satisfaction of the organizers, a large number of citizens have responded to this activity of these two associations that have the same goal - life. This was an opportunity to talk about organ donation, its meaning, but also the need for patients with whom transplantation is the only chance of excision.

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



WPHD 2019 - BULGARIA BSPPH

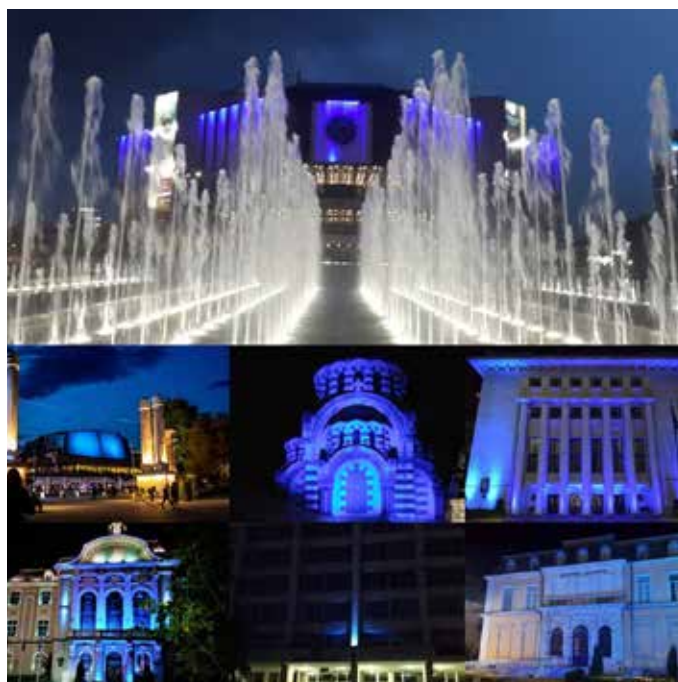
STAR TEAM GET BREATHLESS FOR PH

For the seventh consecutive year the Bulgarian Society of Patients with Pulmonary Hypertension (BSPPH) celebrated the World Pulmonary Hypertension Day. This year events are held with the support of the National Assembly of the Republic of Bulgaria – Healthcare committee, Ministry of Healthcare and the National Patient's Organization. In a special letter, Minister of Healthcare, Mr. Ananiev, states: "I highly appreciate the work of the Bulgarian

Society of Patients with Pulmonary Hypertension in support of the Bulgarian citizens affected by the disease. Our common goal - of the institutions and of NGO, is to provide each of these patients with the best diagnostic and treatment options."

Our team set the ambitious task of blue illumination of emblematic buildings in seven Bulgarian cities on the occasion of the World Pulmonary Hypertension Day. We are very proud because more than 1 million of population of Bulgaria learn about the problems of PH patients. An ambitious task that nevertheless became a reality. The BSPPH managed to reach a large number of people with excellent cooperation with seven municipalities and the local media. Six of the municipalities fully involved in the implementation of this year's initiative for free of charge and this is a very good example for successful campaign with a minimum budget that can reach a million audience. On 5th May the building of the National Palace of Culture (the biggest convention center in Bulgaria) was illuminated in blue as well as the municipality buildings of Plovdiv, Burgas, Stara Zagora and the Festival Complex in Varna, the Ecomuseum with aquarium in Ruse and the Chapel – Mausoleum St. George in Pleven. In our plans for the next year are to increase the number of municipalities that will support "Light in blue" initiative.

On the 11th of May this year in fitness center "Spartak" in Sofia City, the coach Stefan Terziyski conducted in-



tensive one-hour workout where popular TV and movie actors, athletes, musicians, bloggers and friends were part of this year campaign „Get breathless for PH". In attendance were: Mr. Luchezar Ivanov - Deputy Chairperson of the National Assembly, the chair of the National Patient's Organization Dr. Stanimir Hasardzhiev and Dr. Lyubomir Dimitrov, deputy chair of BSPPH Kuzman Iliev, one of the well-known faces of NOVA TV leading the Plus-Minus show, said: "I'm join-

ing the team because I can help with that, and society needs to be committed to people who need support". Alexander Alexiev, famous actor said: "I lived in the States for a very long time. Going to supermarkets I was very often in a surrealistic film, in which dozens of elderly people walked with a portable oxygen concentrators Very few people talk about pulmonary hypertension in Bulgaria, it seems that little is known about it. That's why I'll run until I'm breathless."

Within the sports event the participants had opportunity to perform activities with different complexity that accelerate breathing. From 5th to 11th May 2019 every person who attends the sport complex joined the initiative by donating his/her 5 km running and mark that at the dedicated place in the fitness hall. For each run kilometer, the BSPPH donated resources for buy-



ing portable oxygen concentrate, which will be provided to PH patients.

During the sport event the famous Bulgarian actor Assen Blatehki pointed out : “I believe that as people we should not turn our head off from suffering PH patients and be where our support is important”. On 16th May 2019 within the biggest specialized medical exhibition Bulmedica/Buldental in Bulgaria, awareness raising meeting had carried out about the challenges that patients with pulmonary hypertension face. Medical doctors, patients and journalists have discussed the aspects of this rare disease. It was counted as a positive result that Bulgarian patients it is important to get easier access to clinics which perform pulmonary endarterectomy and BPA in our country. Unfortunately to date Bulgaria does not have preparations for intravenous treatment of pulmonary

hypertension. For patients it is critically important to get easier access to European clinics which perform pulmonary endarterectomy, as well as lung transplants or combined heart and lung transplants. This would return them to normal life.

On the last day of the exhibition – 17 May 2019, the Bulgarian Society of Patient with Pulmonary Hypertension had carry out free tests for oxygen saturation and spirometry. The two events took place within the exhibition in the Inter Expo Centre – Sofia.

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





WPHD 2019 - PHA BULGARIA

MODERN PENTATHLON WORLD CUP

On 24th of July PHA Bulgaria together with Bulgarian Federation Modern Pentathlon organized information campaign about PH which took place during the world championship in Sofia, Bulgaria. The event was attended by athletes from 326 athletes from 39 nations and was widely covered by the media especially with the great result of Svetla Janeva and Lubomir Germanov. Bulgaria had also their first world champion Svetla Zagurova.

The participants were able to learn about the rare disease and to understand a little what is to live with PH. Bulgarian team was involved and support PHA Bulgaria volunteers to bring the message around. Strong relationship was build with Bulgarian Pentathlon Federation and many ideas for future projects.

Todor bike tour

Todor is an operated patient of Chronic thromboembolic pulmonary hypertension (CTEPH), which is the only kind of pulmonary hypertension, potentially curable, without needing to resort to a lung transplant. The intervention was made in 2011 by Prof. Walter Klepetko from University Hospital – Vienna.

The human spirit defines our entire lives. It is that part of us that keeps us in difficult moments that makes us more bold and decisive, that helps us to defend ourselves through. It is the driving force and helps us to survive in this great adventure called life.

The year of 2019 he again dedicated to 5-th of May and all the people living with PH. the challenge for him was 5700 kilometers starting from Bucharest ending in Novosibirsk.

The passion of Todor is bicycle and long-distance tours cycling. This is his way to inform and to bring hope people in Bulgaria and around the world about the pulmonary hypertension disease and show that there is treatment in early and timely diagnosis. The use of appropriate therapy will improve the quality of life and bring the patient back to the everyday life of a healthy person.

Todor Mangarov, PHA Bulgaria

www.phabulgaria.eu

www.facebook.com/aph.bulgaria





WPHD 2019 -CROATIA

RUNNING CONTEST IN THE RAIN



The Word PH Day this year was marked by the Taste & Run Race, which took place on Saturday, on the 4th of May 2019 in the City of Pag, entitled "Get Breathless for PH".

The main goals this year were

- to raise public awareness of the problems with pulmonary hypertension, which is increasingly taking a toll among the younger population, ages between the 20 and 40
- to get the runners out of breath, the way PH patients are left without, during minimal effort and even when they rest
- to raise awareness about this difficult and rare illness that is still too unknown about and which, if not treated, causes disability and mortality within a few years.

A hundred brave runners wore our shirts with the slogan “Get breathless for Pulmonary Hypertension”, and despite the cold and the rain, all have finished the race successfully, both big and small! The race was organized with the help of tourist board of the City of Pag, the Run Croatia club, the Croatian House of Breathing Foundation, the Croatian Torakal Society and the Blue Wing Association, which brings together people with pulmonary hypertension in Croatia.

According to prof. dr. sc. Marko Jakopović from Croatia's House of Breathing Foundation, medicine has made great progress in treating pulmonary hypertension.

“There are many therapeutic options available. Though it is an incurable disease, it is possible to suspend the illness with the quality and systemic treatment and to allow patients a longer and better life.”

Enjoy the pictures we've caught between raindrops!

Zdenka Bradač and Katica Mavračić

www.plavakrila.hr





WPHD 2019 - CZECH REPUBLIC

THE MYTHICAL HIKE



To celebrate this year's World Pulmonary Hypertension Day our association chose a hike to a mythical mountain called Říp. The Říp Mountain played a crucial role in the history of the Czech Republic and is also one of the symbols of the Czech nation. Therefore we decided to spread awareness for pulmonary hypertension from the most Czech place in the world. According to the legend, Říp is the place where the first Slavs led by forefather Čech (Czech) had settled down. Forefather Czech and his brother Lech lived by the Vltava River with their people. One day, after long and terrible fights between the tribes, Czech and his brother decided to leave their war-stricken homeland, thinking that they could find a more peaceful land in the middle of Europe. They traveled for many days when forefather Czech pointed to a hill and when they climbed up he was so fascinated by the wonderful view of the beautiful land surrounding him that he decided to settle there. He called it 'the land of milk and honey' or 'the promised land'. To honour their leader, the people of his tribe started to call themselves Czech. The climb itself took place on Sunday May 5 and almost 100 people

participated. This year we purposefully selected a place where whole families with even children in strollers or with their pets could take part. And we are especially proud of our patients who hiked with us all the way up to the memorable Romanesque rotunda of Saint Gorge which can be found on the summit of the mountain. The patients, whose condition did not allow them to climb Říp with us, were driven to the top of the mountain by car. All together we released 100 blue balloons to honour every single one of our patients with pulmonary hypertension. Before the climb itself, there was a very successful press conference with more than 60 people attending. One of the biggest thanks belongs to Doc. MUDr. Jansa who not only climbed up the mountain with all of us, but also presented a very interesting lecture about the history, up to date treatment and also about what is new in the world of pulmonary hypertension.

*Martina Adamová, Sdružení Pacientů s Plicní Hypertenzí www.plicni-hypertenze.cz
www.facebook.com/Sdružení-pacientů-s-plicní-hyper*



WPHD 2019 - HUNGARY

COUNTRY WIDE CELEBRATIONS OF SPORT AND LIFE

Country wide celebrations of sport and life. Our Hungarian PH Association -Tüdőér Egylet has celebrated World PH Day with a Running Race, the Lillafüred Trail on 28th April, 2019. The objective of this sport event was to raise awareness besides pulmonary hypertension to the importance of the health preserving regular sport activity and the loving of the nature.

The venue was in Lillafüred in the proximity of Miskolc (4th biggest city of Hungary situated in the North-Eastern region of Hungary), in a picturesque valley with a stream. Favourite destination for hiking lovers, be it a short romantic walk, or a longer more challenging tour.

The radio of Miskolc was giving live coverage of the event. Eszter Csabuda, President of our association has informed the crowd and the audience of the Radio before the start about the activities and goals of the Hungarian PH Association, Tüdőér Egylet and the specific symptoms of PH and the available treatments. She has asked those present to support the Association to achieve these goals by giving donations at the PH booth. Furthermore

we have also collected toys for children with PH. PH specialist Dr. Kristóf Karlócai has also addressed the participants about the symptoms of the illness and thanked those running and the volunteers as well for their dedication and effort to raise awareness and wished them a good race. Máté Brógli, Chairperson of the Foundation of for Healthy Young People of Miskolc, a patient himself has also welcomed everybody. Even the rain and mud could not stop the children from running 1.4 kms then the adults completed 8.4 and 16.8 kms. The runners were met with volunteers in the finishing line to check their saturation. Information leaflets were distributed and Lilla Csonka Zöldiné from Actelion has been talking about PH to all participants and the audience of the Miskolc Radio. She, herself has completed the 16.8 km race among other runners who has dedicated their run for PH patients and were wearing „Get breathless for PH” T-shirts. The run has started with a breathtaking ascent so they could experience the struggle for oxygen that PH patients „enjoy” every day.





On the same day Gergely Mészáros was „Getting Breathless for PH” in the South-Western region of Hungary and was dedicating his run for PH patients. This time he has completed a trail run in the Mecsek! He has achieved 15th place in a tough race (29,8 km,D+1050,3:00:02).

On 8th May 2019 a patient- doctor meeting was held in the Budapest PH Center. Besides lectures about PH and CTEPH and discussions about the treatment updates, medals were distributed to the patients. These medals were from the Lillafüred Trail Race where runners dedicated their achievement to the PH patients. As Dr. Zöldiné Csonka Lilla from Actelion who has completed 16.8 km confessed when her lungs were burning due to breathlessness she was thinking about how patients must feel day by day. Sport activities did not stop at the run. The President of the Hungarian PH association, Eszter Csabuda has organised a 4 days bicycle

tour to the South-Eastern region of Hungary round Szeged (third biggest city from Hungary). On this awareness raising tour 20 supporters in the T-shirts with the logo „Get breathless for PH” have distributed leaflets and have talked about the typical symptoms and answered questions. The tour went through Szeged, Algyő, Hódmezővásárhely and Mártély. The timing was good, after the voting for European elections we had opportunity to meet and have discussions with locals without organising in advance. We were getting attention due to our uniform T-shirts and many times the interest of the local people was quite intensive.

Eszter Csabuda, Tüdőér Egylet

www.tudoer.hu

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





WPHD 2019 - ISRAEL

YOGA SESSION TO RAISE AWARENESS OF PH

Israel was incredible! Imagine the ocean, imagine clear waters, imagine fresh and healthy food options, patients, carers and educators! The Israel Association for Pulmonary Hypertension held our event this year at a hotel in coastal city Ashkelon! Why Ashkelon-Ashkelon is considered part of the Southern area of Israel, along the coast and we felt it important to develop new relationships with members of the public, patients, businesses and doctors of the area who needed to be made aware of Pulmonary Hypertension! Ashkelon is currently in the process of developing a new treatment center for PH and what better way to garner support and awareness than to host our WPHD event here! The opening of this center has created a wave of awareness with doctors in many fields in the area. Several clinics and treatment centers have come to realize the value and importance of one intensive care center specifically focused on PH, with the ability to detect as early as possible and treat appropriately. Our day started off with some socializing and mingling-Patients, carers, doctors and medical teams got together to hear one another and share in each others day to day coping with and living with PH. Our first expert speaker was Dr Avital Avriel, Director of the Ashkelon center. Dr Avital expanded on the importance of early detection and the development of the new center - expanding on the value of such a center! We discussed healthy lifestyle, responsibility of treatment and patient doctor relationship.

Our next honored guest speaker was Dr David Langebaan from Canada. Dr Langebaan arrived especially for our event to speak about the developments in treatment of pulmonary hypertension and more specifically about the correct treatment of Cteph patients. Dr Langebaans commitment, dedication and positivity gave our patients great hope for the future of PH. After a delicious, healthy and nutritious lunch, our

next highlights of our WPHD 2019 was our Breathless for PH experience-CHAIR YOGA! We all know and understand the difficulties which patients of PH feel when trying to exercise and feel well. We understand how what seems so normal for healthy individuals can be completely debilitating for PH patients. Well, Ayo (our Yoga expert) introduced us to the most liberating experience-Chair Yoga where each of us was able to partake at a level that was within our comfort zone, expand our breathing, expand our lung capacity, stretch our muscles and joints and focus on creating greater positivity! We were given the opportunity to learn new moves and each and every one of us felt excited at the opportunity of incorporating this into our daily healthy lifestyle routine!

Our event this year was hosted on a very special date for the Jewish people-Holocaust Remembrance day -the day when we commemorate the memories of 6 million Jews who were killed in the concentration camps-the Holocaust. We enhanced our experience with a memorial to all those lost with candles and a moment of silence.

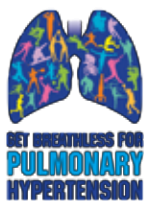
With a focus on creating awareness across the country, each participant at the conference left with a package of information flyers and brochures to leave at their schools, local grocery stores, community centers and medical care facilities. We each committed to sharing our information and doing our part in creating awareness.

Overall WPHD 2019 was a day filled with growth, awareness, inspiration, socializing, support, patients, carers and getting breathless for PH!

Maayan Steele

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





WPHD 2019 - ITALY

CONFERENCES

AND RUNNING COMPETITION FOR PH

As you know in the last six months in Italy there have been so many institutional changes for rare disease, than the AMIP – no profit organization had to do its utmost to represent the needs of the patients in the various institutional tables.

In April there was a general assembly, and Raffaele Della Volpe (Lello) resigned due to strictly private reasons and now the new President is Laura Gagliardini....over way we reorganized, as far as I understand we have new members who are actively involved in the AMIP activity.

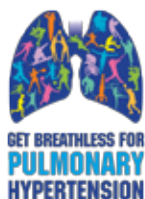
What have done in these six months? Well, we have collected in a book the poems and the drawings of children age of 3 and 5 from elementary school, where our testimonial (Eleza Drozina volley player, who is part of the Italian national team) and Lello have explained the pathology and the consequences on the quality of life in the children and adult with PH. We have participated in 3 national conferences (Rome, Palermo and Chieti) and in an important international one (Capri), or rather we have opened the works making the doctors understand the needs of the patients. We had the sol-

idarity of two theater companies that offered us their art. We also had the opportunity to present at running race and, as you can see, we were present at the day “HYMN TO LIFE – STOP THE SMOG” which took place in the central Via Caracciolo in Naples (9 June). In this occasion a volleyball team wore our t-shirts with the logo for the “WORLD PH DAY” made by Lello and Vittorio...and with idea to make it clear that for the patients it is definitely a world awareness day. Furthermore, considering that our scientific committee has created a network for PH (Italian Pulmonary Hypertensione network – IPHnet), to which about 30 hospitals have adhered until today on the national territory (from north to the islands). We have been called from various hospitals to help patients in care there. We are continuing to work with the patients on the “RESILIECE” projects.

A big hug to all

Vittorio Vivenzio AMIP- onlus





WPHD 2019 - LATVIA

OXYGEN FESTIVAL IN LATVIA



In Latvia World PH Day 2019 has celebrated on 7th May with Oxygen festival with Laughter yoga class, active dance and educational session at Pauls Stradins Clinical University Hospital in Riga. More than 80 participants spent wonderful and healthy time in friendly atmosphere. The event was opened by the speech of Chief Doctor of Clinical University Hospital Eva Strike and Head of Social and Welfare Committee of Parliament Dr.med. Andris Skride. Laughter yoga coach Arturs Laimigais demonstrated laughing healthy effects and realized laughter yoga practice with public. This part was very popular between PH patients and their carers. There were lectures of Dr.med. Anda Nodieva about oxygen therapy, physiotherapist Lina Butane about physical training for PH patients, and cardiologist Kristaps Sablinskis about latest PH and CTEPH therapy methods. In a break, our volunteer Sofia taught to public joyful dance.

Public and PH patients attended an oxygen and blood

pressure monitoring point, consultations of nutrition specialist, exhibition of oxygen equipment, and oxygen cocktail bar.

LTV7 evening news told story of young patient Ariana with interviews of her mother Sofia and Arina. Journalist was interested in symptoms and possible cure of PH and actual problems with oxygen support therapy in Latvia. Dr.med. Anda Nodieva, pulmonologist, gave short review about oxygen therapy for PH patients. Pulmonary Hypertension Society President of PHA Latvia, Ieva Plume underlined the necessity of compensation system for patients with PH whose need oxygen therapy and made short review about full reimbursement of medications for patients with PH.

Ieva Plume

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





WPHD 2019 - LITHUANIA

COSY CONCERT TO RAISE AWARENESS OF PH



On the 5th of May PHA Lithuania invited everyone to the cosy yard of “Balti drambliai” coffee, where the concert took place as gift to the citizens. Between the songs PH was presented. Every guest could treat oneself with the oxygen cocktail, that has become a tradition of PH day in Lithuania. Everyone who came to the event was given a leaflet with main facts about the disease.

Before and after the concert, volunteers (mostly PH patients) chattered with the guest and the passers, who walked by the cafe. They were told about PH day, its prominence, the PH itself and a life with the diagnose.

Famous Lithuanian band „Arbata“ created a wonderful atmosphere and made everyone smile. If the weather outside was at least a few degrees warmer, more people would have joined the concert and could have heard our message. Despite this, those who came had a great afternoon and left with a good mood.

*Anastija Kovaliova,
Žmonių Sergančių Plautinė Hipertenzija Asociacija
www.phalithuania.eu*





WPHD 2019 - NORWAY

BACKWARD GAMES WITH BLUE LIPS



PH Awareness day, 5th. of May 2019, Jessheim Norway. The day started with a gathering at the LHL Hospital at Jessheim. 20 patients with their relatives attended. After some refreshments and some words from leader of the Norwegian association, Sølvi Molnes, the programme started.

Physiotherapist, Dag Helge Iversen, a specialist in the rehabilitation of heart- and heartfailure-patients, was the first on the list with his lecture about stress; "Lopsided considerations around stress". Here he highlighted how to cope with stress in life in general as well and related it to coping with the many challenges a PH diagnoses can mean. The lecture was good, meaningful and engaging.

After the theoretical session we went to UllKisa Athletics Arena to "get breathless for PH".

We wanted to maintain the brilliant idea of arranging the "Backward games" as a part of the WPHD and the games were officially opened by the local gymnastics and cheerleader group. The girls had been practicing for months and came with a wonderful show. The squad even had the purple color as their main color and every single one of them had blue lips as a gesture to the WPHD. As a part of the opening we got the opportunity to inform the many relatives of the girls who attended the games of disease. We didn't count but a place between 50-100 relatives were seated under the opening and the show.

As earlier there were 5 different challenges at the Backward games. 60 meter backward running, 3





steps backward jumping, throwing a ball backward, “The reading colours challenge” and the eggthrowing challenge. There were a lot of laughter and big smiles during the sessions. Both patients, their relatives and even some of the young cheerleaders participated. The relatives were superior in the competitions and will have to have some kind of handicap next year. This goes specially to the Molnes-family who appeared really strong. However it was a cold day so nobody said no to warm food and cold drinks in between. A PH-patients Band were ment to play for us this day as entertainment, but the vocalist became ill the night before so that had to be cancelled.

After several hours at the arena we went back to the hospital for the final part. There were a short but fun award ceremony before Sølvi led the group through “news on PH”, concerning both the disease, medications and the national and international organization. The participants were pleased about the day but there were a consensus about that next year there have to be a “real” patient meeting again.

The executive committee thanks the attendees and the attendees thanked the executive committee for their efforts arranging this event.

*Sølvi Molnes
Odd Erling Børstad*

www.pha-no.com - <http://on.fb.me/TDzyKI>





WPHD 2019 - POLAND

BOTH SPORT PROFESSIONALS AND AMATEURS GET BREATHLESS FOR POLISH PH PATIENTS

The women's volleyball team of AMW GAS Gdynia wore "Get breathless for PH" T-shirts during the training before an important game. They dedicated their training for all PH patients in Poland. On the same day the team was promoted to the 2nd division in women's volleyball.

On World PH Day, Tomasz Galbarczyk, whose brother has PH, took part in 2 BNI LELIWA RUN. Tomasz runs with his wife, children and friends. All of them dedicated their run both for Tomasz's brother and all PH patients.

Agnieszka Bartosiewicz

www.phapolska.org - on.fb.me/IORE2WJ





WPHD 2019 - PORTUGAL

SPORT AND EDUCATIONAL EVENT FOR PH



Sport event "Get Breathless For PH" Campaign - May 19th

In Portugal, the event took place in one of the most famous Portuguese forests - Bussaco National Forest - on May 19. The event was composed by a 30 km trail and 15 km walking.

Approximately 2000 people came from north to south of the country and also from Spain! To all participants was distributed a t-shirt allusive to World PH Day, as well as an informative leaflet on which the disease, symptoms, treatments were explained.

Several people raised questions about the disease and they said they felt proud to run/walk with our t-shirt!

Educational event "Open Day for PH" May 31st

To conclude the month of commemorations of World Pulmonary Hypertension Day, PH Portugal and the Unit of Pulmonary Vascular Disease of the University Hospital Center of Porto promoted an Open Day that included several activities. The event had about 60 attendees (patients, their friends and family, PH specialists, nurses, medical students, etc).

During the morning, several training actions took place, where PH was approached from several points of view:



- The importance of a tertiary and university hospital in the provision of health care in rare diseases; (speaker: clinical director of the University Hospital Center of Porto, Dr Jose Barros)
- History, competences and obligations of a European Reference Center for Pulmonary Hypertension; (speaker: Dr Abilio Reis, PH specialist of ERN-Lung and coordinator of the Unit of Pulmonary Vascular Disease of the University Hospital Center of Porto)
- The role of the Patients' Association in shaping health policies for PH; (speaker: Maria Joao Saraiwa, president of PH Portugal)
- The perspective of a patient with pulmonary hypertension. (speaker: Angela Leao, PH patient)

The World PH Day celebrations was also a time for intervention and a call for reflection by health authorities on some issues that are of concern to the scientific community and patients with PH. sThese issues are changes in the network of Treatment Centers with the creation of new Centers and new facilities, which have been criticized and challenged by PH Portugal and health professionals dedicated to PH at Portuguese Parliament. In this regard, after the morning sessions, speakers were invited to discuss with the audience the issues outlined above. Throughout the day, there was also educational sessions for patients with pulmonary hypertension, such as cardiorespiratory rehabilitation workshops and nutritional counselling.

In the workshop on cardiorespiratory rehabilitation, the physical activity appropriate to a PH patient and techniques they can adopt to save energy were some

of the topics covered. The workshop was provided by a team composed by physiatrists and physiotherapists trained by Dr Grünig, specialist in exercise rehabilitation programmes for pulmonary hypertension in Heidelberg, Germany. Several patients became interested in going under rehab!

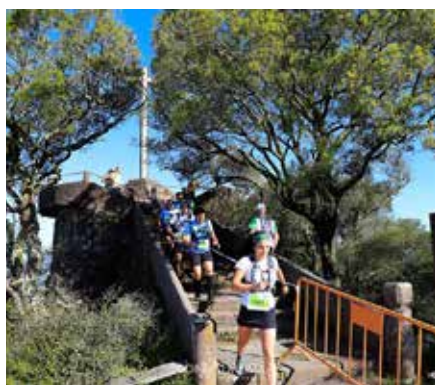
The workshop on nutrition raised several questions about what PH patients should eat or not, and several recipes were shared with each other. They became happy to be informed of the several solutions they have to their daily routine.

Teresa Carvalho

Associação Portuguesa de Hipertensão Pulmonar

www.aphp.pt - [www.facebook.com/](https://www.facebook.com/associacaoportuguesa-sahipertensaopulmonar)

[associacaoportuguesa-sahipertensaopulmonar](https://www.facebook.com/associacaoportuguesa-sahipertensaopulmonar)





WPHD 2019 - RUSSIA

CHILDREN TO RAISE AWARENESS OF PH

World Pulmonary Hypertension Day was held in the Champ de Mars, St. Petersburg, Russia, 1st of June. WPHD in Russia attended people from different Russian cities: PH patients, their friends and colleagues, doctors and other not indifferent people. There were 12 children, two of them are PH patients. All guests and people, who join the event from the street received a gifts - balloons with Association Logo and t-shirts with WPHD logo - to remember that are people around who can't run and jump and do sports like a healthy person because of their condition. Children held a gymnastic class for adults, after class they dance all together and did a lot of activities. Of course, there are people who can't join some activities because of condition, but they were happy to see their children and other guests dancing and playing, and they were proud and supported for all participants. WPHD event took 2,5 hours and attracted St. Petersburg citizens and tourists attention.

We choose St. Petersburg because this time of year a lot of tourists from Russia and other countries come to visit this beautiful and magic city. That helped us to join more people with different nations, speaking different languages to show that is a one big and terrible disease and WPHD united patients around the World.

The next day all event's participants were invited to an excursion to the Peterhof State Museum Reserve, which is located on the southern shore of the Gulf of Finland. It was a big pleasure to see sparkles in the children's eyes and to spend couple of days all together! We forgot about our problems, breathless and didn't see blue color on our lips and nails - we enjoyed time with our best friends, relatives and all guests spending these days in the wonderful St. Petersburg.

Lilya Yarullina, PHA Russia "Help and Save"

lilya-belle@yandex.ru





WPHD 2019 - SERBIA

RUNNING COMPETITIONS FOR PH



Association of Patients Pulmonary hypertension Serbia has marked World Pulmonary hypertension day with a series of events aiming to additionally, aiming to further raise the awareness of PH.

Our first completed project was organized participation of our team and association at Belgrade marathon, most significant and largest sport manifestation in the whole region, with more than 20.000 participants. Our Inspired by Hope team, gathered the greatest number of participants assembled in a team at the whole marathon, and therefore it was also the most noticeable team at the race. Almost 200 racers were running in special shirts honoring all suffering from PH. We have also organized a fundraiser during this event and managed to collect around 250.000 dinars (2.200 euros). Our second completed project was our participation at the half marathon in Dubrovnik, in Croatia, one of the most

beautiful races in Europe, where only 1000 racers can participate. Our team was consisted out of 10 racers, all dressed in our WPHD shirts. At that race, president of association PH Serbia, thanks to excellent therapies that she has received in the past two years, made an astonishing feat and all alone crossed the whole racing track, which was captured on amazing film.

Our third completed project was great scale expert seminary dedicated to PH. The first lady of Serbia Tamara Vučić, spouse to the president of Serbia recognized our great effort and tremendous work on all levels, honoring us by her presence. We presented her with a special plaque for extraordinary contribution and involvement field of PH. The seminary was also attended by Dr. Sanja Radojević-Škodrić, director of National Fund for Health Insurance of Serbia (RFZO).

More than 100 participants attended the event – PH patients, their families, friends of our association and ten most prominent experts in the field of PAH in Serbia, who prepared excellent lectures and presentations. In an attempt to raise awareness of PH among the general public, we have organized charity race of Hope under the title Race of Hope – We are PH Family – We Run Together, gathering more than 600 of the participants out of which 110 were children under the age of 12. We have organized three separate races, for families, for competitors and for kids, all symbolic in their unique way. We were also in charge of the organization of lectures on the topic of ecology. Children were presented with a book that we have developed, in an attempt to raise awareness of PH and other rare diseases among the youngest ones. All race participants were dressed in WPHD shirts during the whole event. Everyone was enjoying this amazing whole day event. Thousands of photos have been shared these past few days, together with hundreds of very positive comments of a participant. Our largest TV station prepared a special TV program covering this event, and that certainly says a lot about our success. This was also a charity event; we were gathering fundraisers for association PH Serbia and managed to collect more than 320.000 dinars (around 3000 euros) during the event.

During May, our exceptional Inspired by Hope team

has participated in 5 most important races in Serbia and across the region constantly trying to raise awareness of PH, dedicating their feats to all suffering from PH.

Inspired by Hope team is now definitely the most famous and most popular team in the region and all race organizers proudly call us to be a part of their races to additionally raise awareness of PH.

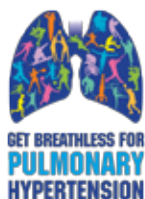
A month behind us was more than successful. It was perhaps the most successful month since the foundation of our association. We have managed to collect more than 5.000 euros through various fundraisers. In addition to that, we have become part of Philanthropic Association of Serbia that has granted us a space on their web platform, the largest platform in Serbia, to present and publish our projects in order to collect money for their subsequent realization, all in an attempt to be more active and visible. We have become partners of Belgrade marathon, largest and most significant sport manifestation in the whole region. We plan to participate in every event they organize as their partner.

Danijela and Mirko

PH Serbia

www.phserbia.rs





WPHD 2019 - SLOVAKIA

CLIMBING THE GREEN LAKE – WPHD GET BREATHLESS ACTIVITY



For the fifth time in the Get breathless for PH campaign, we have organized a symbolic climbing for PH patients on the peaks of the Slovak mountains under the motto “I will climb for you”.

This year, despite the unfavorable weather forecast, 139 participants met in the beautiful High Tatras. The event called „Gift your Breath for PH“ lasted for three days.

On the evening before the climbing, in the SOREA Hutník II Hotel in Tatranské Matliare we have hosted an information seminar on PH, where we explained the attendees the significance of the campaign and patients presented their life stories. The scientific part was led by Dr. Milan Luknár, Cardiologist from the Center for PAH.

On Saturday, the 4th May, the actual climb to Zelená pleso (1550 m asl) took place. There were 139 patient participants. Their families, friends, doctors, health and rehabilitation nurses, industry partners, took their photographs to the Green Lake on behalf of patients. Other participants from various parts of Slovakia and Czech Republic also came to support us.

The 17.2 km route was especially challenging for families with children. Journey was accompanied by rain and snow and the end of the journey it seemed we are in the middle of winter. Even though they all returned tired, they were smiling. Besides the good feeling, they were rewarded with small prizes during the evening's raffle.



Meanwhile patients took a walk to Strbske Pleso Lake and informed passers-by about the disease, handing out leaflets and brochures about PH.

“Plant your lungs” was the motto of the final activity. For PH patients we symbolically planted pine tree (Pinus cembra) in the Botanical Garden in Tatranska Lomnica on Sunday, May 5th. The whole activity was carried out in cooperation with the State Forest authorities of the High Tatras National Park. The tree is not only a symbol of health, fresh air, but especially lungs. The strength of this tree symbolizes the power of PAH patients.

The whole event was broadcasted on the Slovak Television.

Iveta Makovníková

Zdruzenie pacientov s pľúcnou hypertenziou

<https://www.facebook.com/Zdru%C5%BEenie-pacientov-s-p%C4%BE%C3%BAcnou-hypertenziou-oz-236811429798179/>





WPHD 2019 - SLOVENIA

ENLISTING ORGAN DONORS AT TRADITIONAL RUNNING EVENT



Our WPHD event took place in nature resort Mostec, on a Sunday afternoon, 19th of May. Around 200 runners gathered and »got breathless« by running 5 km for all PH patients. We are proud to say that many other attendees joined us too. Family members, medical doctors, nurses, pharmacists, and others came to watch and support the runners. Our event was a great occasion for patients to talk freely about their disease and exchange different experiences about life in general.

The representative of the Slovenija-Transplant institution joined us this year and was available to provide information about organ donation. The representative also made it possible for our par-

ticipants to enlist as an organ donor. Thanks to our event Slovenia now has 6 additional organ donors. To make the atmosphere relaxed and fun, we invited a DJ who was present till the end of our event. We had a zebra mascot who entertained the children and kept them occupied. Children also participated in raising awareness about PH by running 1 km. Despite the rainy afternoon, we are proud to say that our event turned out as a success.

Tadeja Ravnik

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





WPHD 2019 - SPAIN ANHP

CELEBRATION OF WORLD PH DAY

The National Association of Pulmonary Hypertension of Spain run different activities with the aim of raising awareness and to funds.

The last 4th of May we attended the football match of La Liga 1/2/3 (Spanish second division) Gimnàstic de Tarragona- Extremadura giving information before the match and increasing the awareness of in pulmonary hypertension through a video during the break. This was possible thanks to the project “BBVA CX Juntos Crecemos”. José María Andreu Solé, responsible for marketing and RSC of Nàstic and Julio Esporrín, representative of BBVA (Spanish bank who is the sponsor of the football league) gave 15 free tickets for our members.

For us, this activity was very special because we were able to do it thanks to Mariona, our member who passed away last year and put us in contact with the club. So we would like to dedicate this activity to remember her one more day because a special person is never forgotten. Thank you Mariona!

On May 6th into Doce de Octubre University Hospital on Madrid, we gave information to the people who participated in the “Feel the PH room” about the hypertension pulmonary, their symptoms, consequences and treatment. People could do activities such as making the bed, ironing, sweeping or riding a bike with a 25kg vest, breathing in a straw with the stuffy nose. This is what a person with pulmonary Hypertension feels usually every day. Doctors like Dra. Escribano (cardiologist) or Dra. Ayán (rehabilitator) Pulmonary Hypertension specialist took part in the activity.



We were also interviewed for the National Radio of Spain and Telemadrid (regional Tv Channel). The last 17th of May, thanks to the municipal sports center of Arganzuela in Madrid we run a solidarity sport event where the participants pedaled on spinning bikes in favor of pulmonary hypertension patients. With this activity we started a project which with we will do the kilometers of Spanish Cycling Tour (3.272 km) in different gyms. This event will end next year.

Finally last June 1st and thanks to the participation of the FitBox Club of Humanes gymnasium in Madrid, the city council and the Bizzis store, we held a solidarity sports event where more than 100 people cycled for 4 hours on spinning bicycles until they were able to travel the distance of the Camino de Santiago (775km) with the slogan “Suma Km, Suma vida, sigue el camino hasta conseguirlo” (add km, add life, follow the path until you get it). This activity is also part of the proj-

ect mentioned above. The activity was published in the newspaper Humanes de Madrid.

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 to spread the information about our disease, because having 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 2019 - SPAIN FCHP

CELEBRATION OF WORLD PH DAY

II PULMONARY HYPERTENSION FORUM

Held on February 15 at the Virgen del Rocío University Hospital (Seville).

The inauguration was in charge of Dr. Emilio García, HUVR Medical Assistant Director, Dr. Francisco García Hernández, of the Internal Medicine Unit of the Multidisciplinary University of HP. Dr. Remedios Otero, an expert pulmonologist at HP, and Mr. Enrique Carazo, President of the Pulmonary Hypertension Foundation. The presentations that were presented at the forum were of special interest among the more than 100 attendees in Aula Magna of the General Hospital of the HUVR. Among them were doctors specialized in pulmonology, cardiology, internists, pediatric cardiology and nursing DUE, as well as hospital pharmacy. One of the most emotional moments was the patient's voice, where Jessica Pinto, a young woman affected since 20 months of HP, told us that "your best ally to carry the disease, is to have a balanced body and mind. Be happy and develop as a person." The event has been carried out by Salvador Calderón, Vice President of the Foundation against Pulmonary Hypertension and affected by HP and with a daughter with the same medical condition, along with Dr. Remedios Otero, pulmonologist of the Multidisciplinary Unit of HP at the HUVR.

Dr. Remedios Otero, new Patron of Honor of the FCHP

For this involvement and dedication in the field of Pulmonary Hypertension, for the creation of the Multidisciplinary Unit and the constant support for the Foundation against Pulmonary Hypertension, it has been decided to appoint Dr. Remedios Otero, Patron of Honor of the FCHP.

A title that the doctor has taken with special joy and enthusiasm. Thank you for being part of our team. It has been a success because of the involvement and participation of those affected, with representation of patients and professionals from different Andalusian provinces. With the commitment to continue growing in agreements, knowledge and commitments, the HUVR has once again achieved a resounding success in the forum.

Dr. Barberá, leader of the EMPATHY PROJECT

Dr. Barberá, leader of the EMPATHY Project, wanted

to send us a very important message: to record the importance of providing blood samples to the BIOBANK of patients with Pulmonary Hypertension.

The objectives of this bank are to facilitate the analysis of the genetic and molecular changes involved in the progression of diseases, the evaluation of the efficacy of new drugs and the application of specific therapeutic methods for specific population groups. These tasks will contribute to the consolidation of a personalized medicine.

Special mentions for speakers

The Foundation against Pulmonary Hypertension, wanted to give special mention to the speakers who have participated in the forum. A job that has created commitments since the beginning of the organization. We continue working to train, inform, cooperate, create collaborations, with the patient and the professional.

SCIENTIFIC RECOGNITION

On March 1 we were in the Official Act for World Rare Disease Day. This year has been a very special year for the Scientific Recognition Award. A recognition of good work, perseverance, struggle, courage, perseverance, represented by Enrique Carazo, but of which you are part of each one of you, the people affected, the families, the Friends, people who help us selflessly, doctors, researchers, institutions ...

From the hands of SM Queen Leticia, it has been held at the Duque de Pastrana Complex, a site belonging to the ONCE Social Group. In the final stretch of this event, the associative fabric has also had María Luisa Carcedo as Minister of Health, Consumption and Social Welfare.

His Majesty recalled that the movement "deserves our active commitment" and that "they also deserve results" alluding to the importance of research, but also to improve diagnostic times, access to treatments and coverage of benefits.

His words also coincide with the motto of the campaign 'Rare diseases, an integral challenge, a global challenge' to which ERDF today puts the finishing touch.

Empathy project

In addition to social recognition and socio-health professionals, the organization also wanted to recognize the work of two other agents in a clear example of co-

ordination: associative fabric and researchers. Enrique Carazo, president of the Foundation against Pulmonary Hypertension, has received this recognition. With it, FEDER seeks to enhance the synergy between Dr. Joan Albert Barberá, researcher and leader of the Empathy Project, as well as Dr. Miguel Ángel Gómez, researchers with more than 40 years of experience in Pulmonary Hypertension, and other recognized professionals doctors, with the group of families that has managed to allocate more than 290,000 euros to it. In addition, the Empathy Project stands out for being a pioneering initiative, which has the support of more than 20 collaborating centers, in which Spanish centers and universities participate in order to facilitate the diagnosis of this rare disease and find new ways of treatment.

Conference „Parlando on Health 2019”

From March 17 to April 12, 2019. The cycle of talks on healthy habits held by professionals and socio-health experts in the four health centers of Parla (Madrid) took place: San Blas, Painters, Las Américas and Isabel II. Topics such as endometriosis, neuromuscular diseases, rare diseases such as Pulmonary Hypertension, alcohol use problems, drug-related problems, pain management, sexually transmitted infections or cardiopulmonary resuscitation, among many others, will be those treated in a simple but rigorous way in „Talking about health” in this cycle of talks. Aimed at the general population.

The Foundation against Pulmonary Hypertension, collaborated with the Workshop „Breathing sometimes ... costs”, a way of talking about habits when it comes to breathing in day to day, anxiety, when we are diagnosed with a rare lung disease. Our psychologist Mamen Almazán, along with Laura Ranz, were in charge of directing the Foundation's workshop against Pulmonary Hypertension.

Some innovative workshops

The very important collaboration of the Primary Care Assistance Management, the Infanta Cristina Univer-

sity Hospital and the Parla City Council. It has been vital for the good results obtained in terms of participation and dissemination.

It was held in the San Blas, Los Pintores, Las Américas and Isabel II centers, in Municipal Centers (House of Culture, Youth House) and at the Infanta Cristina University Hospital. It was the first health cycle, which has been carried out for a whole month in the health centers of the town of Parleña.

With these cycles, we try to raise awareness and bring the population closer to the problem of health in different areas, and with this, it is intended to be the precursors of this type of workshops in the other populations of the Community of Madrid.

The Foundation against Pulmonary Hypertension (FCHP) has presented the dissemination campaign of the disease in Metro de Madrid, thanks to the “100 Solidarity Days” program. This great event was attended by Emilio Butragueño, Director of Institutional Relations of Real Madrid, CF, and Patron of Honor of the FCHP. María Pedroviejo, actress of numerous series such as „Tell Me”, TV host Carlos García Hirschfeld, also Patron of the FCHP and Enrique Carazo, President of the FCHP. Campaign framed on World Pulmonary Hypertension Day. The informative campaign in Metro Madrid is framed in the “100 Solidarity Days of Metro”. It will be between April 30 and May 7, making it coincide with the World Day of Pulmonary Hypertension. It will be seen by some 2,300,000 travelers a day. A great disclosure to publicize Pulmonary Hypertension. On May 5, World Pulmonary Hypertension Day is celebrated. During the month of May, numerous informative acts will be made all over the world.

Enrique Carazo Minguez

FCHP Fundación Contra la Hipertensión Pulmonar

www.fchp.es/es

www.facebook.com/fundacionhp





WPHD 2019 - SPAIN HPE ORG

MULTIPLE EVENTS TO MARK WORD PH DAY



One more year at HPE-ORG we have joined the World Day campaign in several cities of the Spanish territory such as: Valencia, Granada, Tarragona, Sant Feliu de Llobregat and Barcelona, with good results, generating contacts with both the public administration and related new work projects with our organization.

The Word PH Day, we have reached about 15,300 people approximately, counting the reach in our social networks and website, because the press, digital news and others cannot measure. This year we have organized six social awareness and outreach activities of PH. Two of them already consolidated in time as they have a continuity,



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bregat gives visibility to minority diseases with the booth “Health and Minority Diseases” at the 40th FIRA COMERCIAL I INDUSTRIAL DEL BAIX LLOBREGAT. For three days more than 30,000 people visit the fair, going through our stall, politicians from different parties and Juan Carlos Navarro, ex Barça and NBA basketball player.

For the second consecutive year we were invited by the Tarragona City Council to participate in the 29th edition of the Popular Bicycle of Tarragona and a group of our delegation participated in it for Pulmonary Hypertension. Finally, on May 30, we organized an informative and dissemination

day on PH at La Fe Hospital in Valencia where we were accompanied by a group of patients and Dr. Raquel López Reyes from the Pulmonology Service of the University and Polytechnic Hospital of La Fe, Valencia. We are very proud with our growing participation in the WORLD PH DAY and we are pleased to motivate the attendance participation in their activities and events. On the other hand, we also want to mention a relevant activity since each year we participate in the “National Organ and Tissue Donor Day” celebrated in Spain. It is a date of homage to all the people, institutions, organizations and associations that are committed to the donation of organs and tissues, commemorating this day with various activities.

María Rodríguez, Hipertensión Pulmonar España

www.hipertension-pulmonar.com

www.facebook.com/pg/HPSpain.org





WPHD 2019 - UKRAINE PHA CENTAURS FOR PH



On the 21st of April, 2019, Ukrainian patients with pulmonary hypertension from different cities of Ukraine gathered in Kyiv.

In the Kyivan Rus Park they were waiting for a real holiday - patients joined the dramatized opening of the horse-trick festival "Centaurs". Together with the country's best stunts, they went to the arena and greeted the festival participants and spectators. Flags of the Association and of the World PH Day were raised just next to the Flag of Ukraine.

Later on the patients conference took place, during which the presentation was published by the Association with the support of Bayer's Patient Guide PH "Patient's Rights. Legislative base", where issues of providing medicines were discussed.

Patients were greeted by representatives of the Public Association "Rare diseases of Ukraine Tatijana" – Tetiana Kulesha and Larysa Voloshyna. The level of awareness about Pulmonary Hypertension was discussed during a quiz prepared by our patient Iryna Sydorchuk, conducted with Iryna Zhyvylo and Dmitriy Serdtsev, PH doctors.

We were glad to hand over to our patients the "No-LAG" - the first Ukrainian medicine of Sildenafil

for treatment of Pulmonary Hypertension, which Microchim Company provided as a charity to our patients. This is an additional month of therapy, which is extremely appropriate in conditions of untimely provision under the state program!

Also patients participated in cheerleading master class conducted by us for the choreographers of the Red Foxes studio, takes care of the Children's Heart Foundation, which operates at the Institute of Pediatric Cardiology.

Patients also rode on horses and descended on the false wires. And the most long-awaited and excited was the launch of a balloon that dipped in the sky with our patients on board: Victoria Burbura, Grigory Kozik and Yulia Berebenets. This amazing surprise was arranged by the team of Air Kulya.

We are extremely grateful to everyone who has helped to fulfill this day with happiness and joy to all our patients.

Oksana Aleksandrova
Ukraine Association of Patients with Pulmonary Hypertension
www.pha.org.ua - info@pha.org.ua



WPHD 2019 - UKRAINE PHURDA

IN THE RHYTHM OF PULMONARY HYPERTENSION



This year, the World Pulmonary Hypertension Day was particularly intensive.

We organized and held several activities in various directions: sports, awareness, charity and rehabilitation. Representatives of the CF “Sister Dalila” and PHURDA became members of expert groups at the Ministry of Health of Ukraine on Issues of support in the procurement of medicines and medical products in the areas of “Pulmonary arterial hypertension” and

“Before and after transplantation surgery”. At the end of April, the first meetings were held already. We launched flesh mob in FB social media in support of PH community. With the aim of involving as much participants as possible, with the help of volunteers we made video-instruction both in Ukrainian and English languages. We sincerely thank everyone whose participation helped us to break information barrier. Among those who joined the flesh mob were First lady of Lviv, wife of the Head of Regional State Adminis-



tration, Deputy Mayor, deputies of Local Council and Parliament, Head of Health Department and also the president of PHA Europe Hall Skaara and Chair of British Lung Support Foundation Tessa Jelen. Important thing is that very different and famous people from around the world, such as Canadian virtuoso violinist Vasily Popadiuk, as well as our friends from Great Britain, Canada and France, decided to participate in the fleshmob. Totally 30 videos were taken in support of WPHD and patients with PH. We are proud of the result, because all these videos were viewed 10,758 times. And that's only for a few days !!! We also selected 4 videos that scored the largest number of "likes", "hearts", "views" and creativity. The winners received special gifts. Therefore, we can say that the flash mob turned out to be an excellent tool in overcoming the information barrier towards PH !!!

All videos you may see here:

<https://www.facebook.com/groups/332834927436294/>

On the eve of the WPHD and within the frames of the Lviv City Day celebration, a solemn theatrical procession went through the city center and the pulmonary hypertension team accompanied by The First Lady of Lviv participated in it. The procession has given us a great informative and awareness effect. Only broadcast in FB got more than 800 views. And the information about PHURDA, WPHD and PH patients sounded all over the city. Participation in procession has first results already. The talks on finding options for providing city residents with drugs from PH have started. The city of Lviv has supported a rehabilitation program for PH patients.

Link for video:

<https://www.youtube.com/watch?v=CmP9l0IK-UA>

On May 5, on the main square of Lviv, a happy morning exercise was held in order to attract pub-

lic attention to the problems of PH. The event was supported by well-known people, volunteers, partners and all sympathetic people. The weather has become another test for us. The whole day it was raining. But it did not scare and did not become a barrier for those who came to support us. Also there was a charity fair, which was mostly organized by PH patients. You could make a donation and taste charity coffee, and purchase a butterfly ticket to participate in a charity lottery. There were three winners, who received precious gifts from a lottery partner – Omron company. The guests of the event enjoyed the children's dance band and the music band, who came specially to our event from other cities of Ukraine. The event was attended by about 200 people. Also, in the facilities of the Lviv City Council we had a meeting with patients and volunteers with the special participation of the mayor's counselor. In addition to a pleasant talk, we conducted a short questioner on generic drugs and transplants. We received an important feedbacks from patients, their families, and volunteers who were unaware PH. This helped us better understand and analyze the attitude, vision and perception of the PH situation through the prism of the role of a patient, a doctor, an official. Also, Omron spoke about the importance of choosing the right portable nebulizer that does not limit the lives of patients who require frequent inhalations. So, we managed to hold an educational and fundraising campaign and collect about 180 euros.

Links for video:

<https://www.youtube.com/watch?v=B-eUjdGmVRY>

https://www.youtube.com/watch?v=8V_BDOyvVGs

Except public events we also held a family weekend with a rehab program for PH patients and their families. It took place in the facilities of St. Joseph House on May 10-12. Within the framework of the weekend there were held a session of group psychotherapy, a session of dance-moving therapy,





relay race, a “Hat Party” and a barbecue. It was a time when patients and their families, without being loaded with home affairs, received high-quality psychological support and physical rehab. Thematic party added its mood. Such kind of family therapy event is to improve the psychological climate in families of PH patients, to withdraw family members from the state of stress, to provide with social and medical care and to help restoration of dignity. We spent time with use, relax and fun :) “After participation in the rehabilitation program in Norway, which was held within the framework of the memorandum between PHURDA and PHA Norway. At that time I thought it would be good to have such rehab in Ukraine. Now already we have rehab program in Ukraine. It’s nice that it starts from Lviv.” - Victoria, a PH patient.

Link for video:

<https://www.youtube.com/watch?v=t0ygCPYToGU>

“Music for life” is an initiative that has grown into a grand musical performance. On May 25, musicians and performers: beginners and lovers, well known and not very: Sofia Nakhryiko, Katherine Fitch - Peace Corps Volunteer, Dzvinka Bendyk, Аня Рига, Julfy Patlatus, Ivan Znabar and Vitalik, Max Ptashnyk, Marian Romanchuk - vocalist from DiZeX band and Tornadobrandz gathered together and presented their music to passers-by and

guests, created an incredible atmosphere of rhythm and kindness. They presented not only music but also their time to support the CF “Sister Dalila”, PHURDA and PH patients . During the event, visitors made their donations into special boxes. So, we managed to raise 1831 UAH. But what is more important, we broke the information barrier in the direction of PH, met new friends and a patient with symptoms similar to PH, negotiated with the charity organization which deals with orphan nosology, and all that began just with a simple talk.

At the invitation of Member of Parliament Iryna Sysoienko representatives of the CF “Sister Dalila” and PHURDA participated in the meeting of the Subcommittee on Monitoring the Implementation of Medical Reform of the Parliament Committee on Healthcare Issues. We talked about the problems and needs of citizens suffering from rare (orphan) diseases. During the meeting, the positions of all present NGOs, representatives of orphan patients were heard, the opportunities and needs were clarified, as well as the pros and cons. It was a constructive discussion of the participants interested in improving the condition of orphan patients. As a result, an action plan has been developed.

Oksana Kulish, Sister Dalila-PHURDA-Ukraine

<http://poryatunok.info/uk/>





WPHD 2019 - ALL OVER THE WORD: AUSTRALIA

WE MAY ALL HAVE THE SAME DISEASE, BUT WE ALL HAVE OUR OWN STORIES

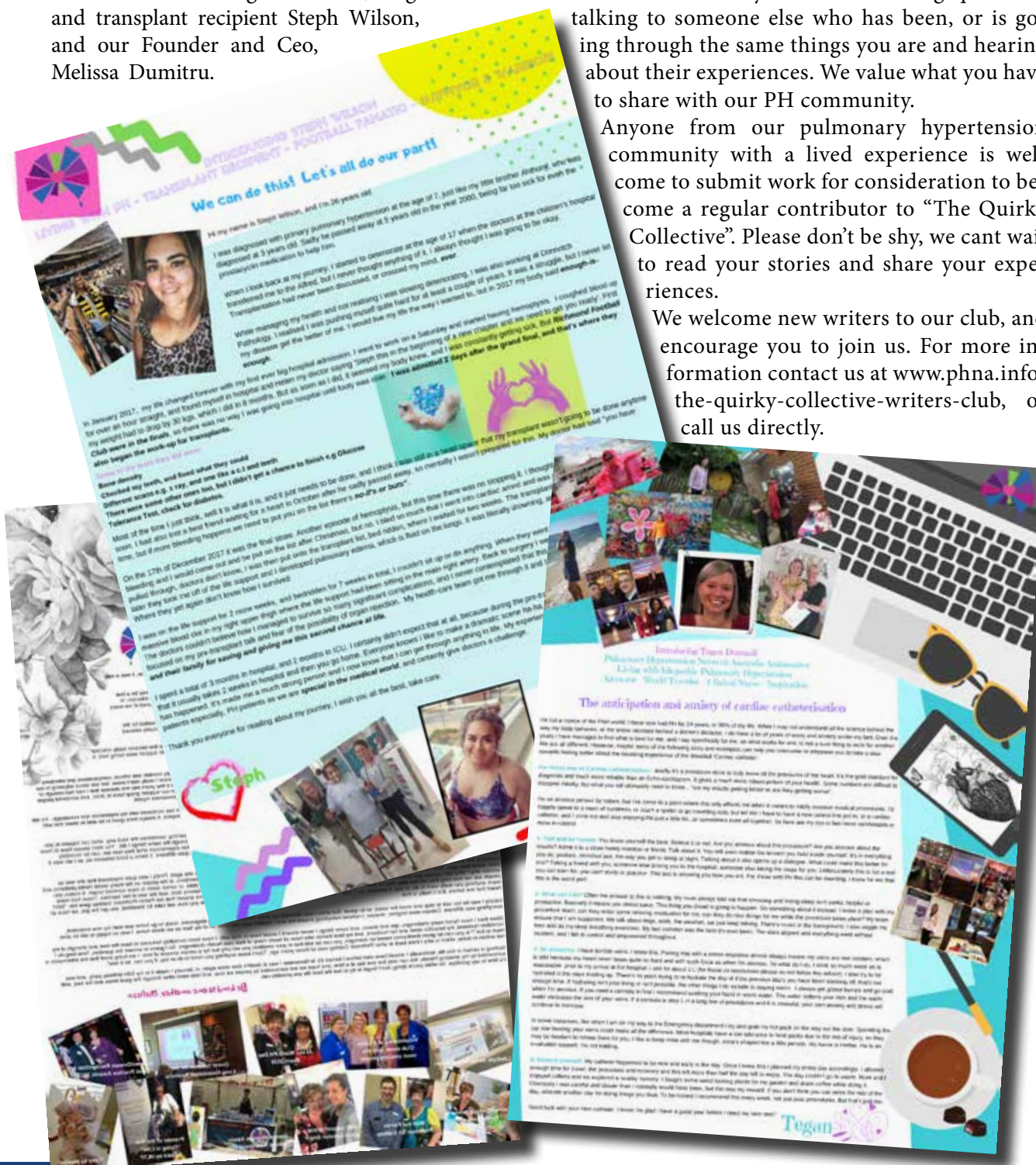
Welcome to the all new PHNA writers club. We are so pleased to be launching this new “Network” initiative in honour of World PH Day, 5th May 2019, and to kick off our 2019 theme, “Hope is where the Heart is”.

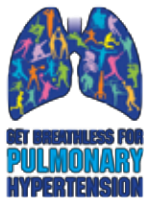
Our new initiative begins with the personal stories of our Ambassador Tegan Dunmall, her good friend and transplant recipient Steph Wilson, and our Founder and Ceo, Melissa Dumitru.

Three short stories for you to enjoy and share on various things they have experienced on their journeys. If you are someone living with pulmonary hypertension, a carer, a family member, or even a medical, health professional, or a community services sector worker, we would love to share your stories with our community. There is nothing quite like talking to someone else who has been, or is going through the same things you are and hearing about their experiences. We value what you have to share with our PH community.

Anyone from our pulmonary hypertension community with a lived experience is welcome to submit work for consideration to become a regular contributor to “The Quirky Collective”. Please don’t be shy, we can’t wait to read your stories and share your experiences.

We welcome new writers to our club, and encourage you to join us. For more information contact us at www.phna.info/the-quirky-collective-writers-club, or call us directly.





WPHD 2019 - ALL OVER THE WORD: USA PHA

GLOBAL PH MESSAGING SHARED AROUND THE WORLD

The Pulmonary Hypertension Association (PHA) in the United States joined with 80 other international pulmonary hypertension (PH) associations around the world to raise awareness of PH on World PH Day on May 5. PHA worked closely with partner organizations to develop the 2019 World PH Day logo, which featured a globe in a periwinkle heart.

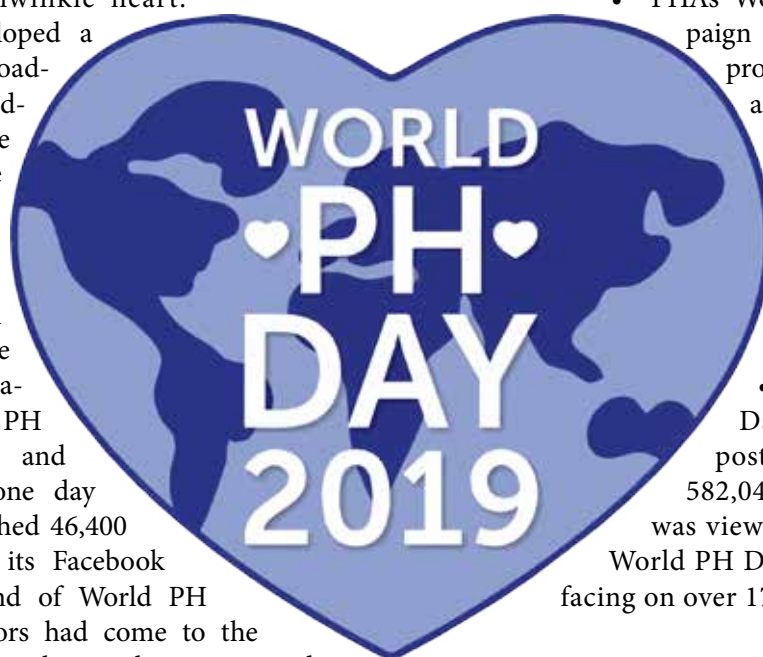
PHA also developed a shareable download-able kit that included a customizable press release and a series of social media graphics with information on PH around the globe, emphasizing the five PH groups, causes and symptoms. In one day alone, PHA reached 46,400 people through its Facebook page. By the end of World PH Day, 1,928 visitors had come to the WorldPHDay.org website to learn more and download graphics to share.

PHA continued its social media campaign for World PH Day throughout the month of May, sharing out graphics and information on Facebook, Twitter, Instagram and LinkedIn. During May, WorldPHDay.org received more than 2,400 visitors. Pages on the web-

site were viewed nearly 5,000 times with 85.4% of the traffic being new visitors. Social media accounted for 43.7% of the traffic to the site.

PHA's World PH Day campaign celebrated the following successes:

- PHA's World PH Day Facebook campaign reached over 66,700 people prompting over 7,300 likes, shares and comments. The top post for Facebook reached 14,300 people, which garnered over 1,200 likes, shares and comments. times with 85.4% of the traffic being new visitors.
- The hashtag, #WorldPH-Day2019 was used in over 290 posts on Twitter and seen by 582,048 users. Overall, the hashtag was viewed 750,900 times on Twitter. World PH Day tweets for the month surfacing on over 17,200 Twitter feeds.
- Content on Instagram was displayed over 8,800 impressions which led to over 6,100 viewing the content. Over 400 reposts, comments and likes resulted from Instagram posts.
- PHA's message on LinkedIn reached 2,500 professionals.



Media clippings

AUSTRIA

Wiens Zentralfriedhof hat nun zwei Laufstrecken
„Joggen erlaubt“

S eit Anfang März gibt es zwei mit GPS-Vermessung und beschaltete Routen für Jogger am Zentralfriedhof Wien. Eine Strecke dauert 10,3 Kilometer und eine Strecke zwei Kilometer lang. Gestartet wird jeweils beim Tor 2. Die kurze Route führt zuerst durch die breite Allee zur Pilsenerengasse, danach umrundet man entlang der Arkaden das Karl-Borromäus-Friedhofskirche und läuft dann zurück zum Tor 2. Die 5 Kilometer lange Route hingegen führt viel weiter in das Friedhofsviertel hinein. Auf dieser Laufstrecke wird unter anderem das älteste Grabmal des Zentralfriedhofs

Friedhöfe Wien meint: „Der Friedhof als Ort der Begegnung und als Lebensraum steht seinem Wertspruch: das ich Friedhof einen schönen Garten, unsere Vorfahren an unserem Leben teilhaben zu lassen.“ Natürlich möchte Niemand auf einen Friedhof, das so auch kleine Signale gesetzt wird, was die Friedhofsgemeinschaft gerne hätte, dass gelassen wird, beziehungsweise dass es in diesem Anfall sehr willkommen ist, auf anderen Teilen aber verbleibt nicht zu sein. Am 25. Mai 2020 findet von 10.30 bis 15.30 Uhr ein Öffnungsfest statt. Die erste Laufveranstaltung in der Geschichte des Wiener

Die Debatte um den Silent Run

Laufstrecken am Zentralfriedhof: Sind sie pietätlos oder nicht?

(Preis). Wie die bz berichtet, wurden Anfang März zwei Laufstrecken mit direkter Strecke durch den Zentralfriedhof eröffnet. Seither gilt die Frage: Ist das pietätlos? Darauf hat nun die Volksanwaltschaft eine klare Antwort: Ja. Erstens sei der Friedhof nicht als Sportanlage gewidmet und zusätzlich bilden Läufer eine Störung der Totenruhe. Darauf aufmerksam gemacht wurden sie durch die Beschwerde einer älteren Dame. Sie fühle sich von vorbeilaufenden Joggern in ihrem Bett-Ritual gestört, vor allem wenn diese auch noch lautstark Musik durch die Kopfhörer dröhnen lassen.



Die Drei! wurden am 25. Mai gerne die beiden Laufstrecken musikalisch eröffnen.

Volksanwältin Gertrude Briek äußerte schriftlich ihre Bedenken bezüglich der Laufstrecken am Zentralfriedhof. Darin ebenfalls enthalten sind starke Äußerungen gegen die am 25. Mai stattfindende Eröffnungsparty. Im Moment noch geplant ist der Auftritt der Austropop-Band „Die Drei“ direkt beim Tor zwei. Renate Niklas, Geschäftsführerin der Friedhöfe Wien kann die Aufforderung nicht verstehen. Sie gibt zu bedenken, dass schon in früheren Zeiten Friedhöfe als sozialer Treffpunkt in Verwendung waren. Doch auch Wiens Bewohner sehen die Laufstrecken als problematisch an. In einer bz-Umfrage hatten sich Hunderte Leser beteiligt. Das Ergebnis: 62 Prozent waren der Meinung, dass man am Friedhof nicht laufen sollte. Nur 38 Prozent hatten damit kein Problem.



Stille Läufe durch den Zentralfriedhof

Viele werden es wohl als pietätlos erachten, wenn sich schwitzende Jogger durch den Zentralfriedhof quälen. Doch die Geschäftsführung der Wiener Friedhöfe erwidert: „Die Laufstrecken zwischen den Grabsteinen. Stillschweigend wurden zwei Kilometer und „Silent Run“ (zwei Kilometer) gemaint.“

Neue Laufstrecken am Zentralfriedhof

(ae). Der Zentralfriedhof ist ein beliebtes Ziel für Läufer. Für Sportler wurden zwei Strecken ausgemessen, eine über zwei und eine über fünf Kilometer. Beide starten beim Haupttor. Die Laufstrecken heißen „Silent Run“. Am 25. Mai (10.30–15.30 Uhr) findet die erste Laufveranstaltung in der Geschichte des Friedhofs statt. Es gibt drei Bewerbe (1,25, 5 und 10 Kilometer).



Der Zentralfriedhof wird zur Bewegungsarena
„Stiller Lauf“ in Wien

Viele Wiener nutzen den Zentralfriedhof bereits fürs Walken oder Laufen. Jetzt entsprechen die Wiener Friedhöfe der Entwicklung und eröffnen auch ganz offiziell die ersten zwei Laufstrecken auf dem Zentralfriedhof. Eine Übersichtstafel im Eingangsbereich (Tor 2) zeigt die Routenführung und Infos. Passend dazu der Name „Silent Run“ („Stiller Lauf“). Am 25. Mai findet das Eröffnungsfest statt.



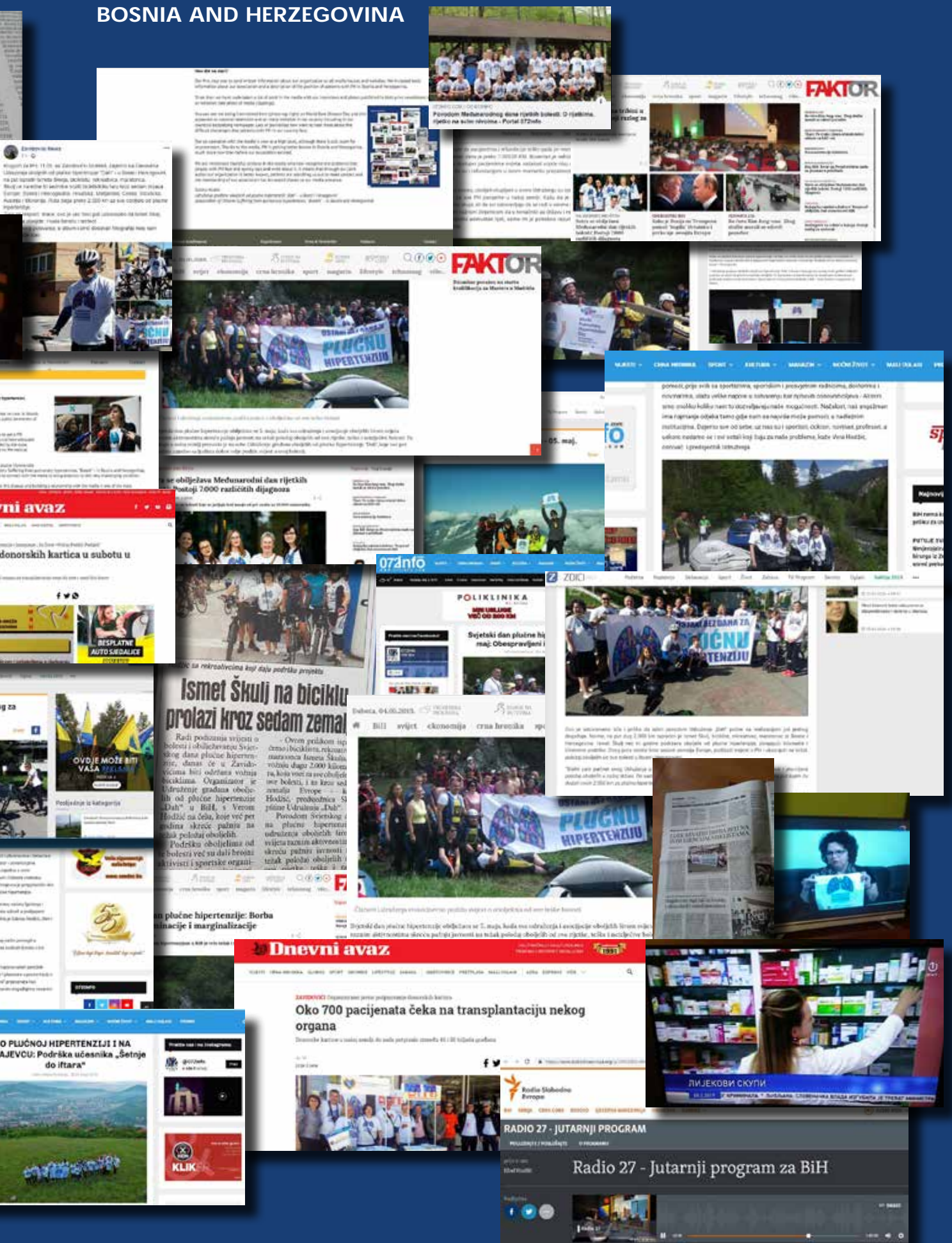
ZWEI LAUFSTRECKEN FÜR SPORTFANS UND EIN ERÖFFNUNGSFEST
Es lebe der Zentralfriedhof

Der Wiener Zentralfriedhof ist nicht nur ein Ort der Begegnung, sondern auch eine große Oase zur Erholung und zum Sport. Damit Lauf-Paare auf ihre Kosten kommen und dennoch den Verstorbenen die Ehre erweisen, haben die Friedhöfe Wien zwei Laufstrecken unter den Namen „Silent Run I & II“ eröffnet, die durch das Areal führen.

Das offizielle Opening dazu wird am 25. Mai gefeiert, der Eröffnungsveranstaltung kommt „PH Austria – Initiative Längenhochdruck“ und dem „Langerkis der Persönlichkeitsentwicklung“ zugute. Neben Läufern für Kinder und Erwachsene wird es dann auch musikalisch unterhalten: Das Austropop-Trio „DEB“ tritt auf. Infos auf www.friedhofwien.at



BOSNIA AND HERZEGOVINA



BULGARIA



Deliverables

World Fit Day 2020
Get Healthy! Get Fit!

- Coordination with third parties for T - shirts, print materials, photographer services, video services, fitness lesson;
- Coordination with medical services to support the normal event execution;
- Creating of Calendar with activities, photos, video and texts to promote the page;
- Coordinating with official Facebook representative in Bulgaria to create a paid campaign to boost the fan page and selected activities;





Conclusion:
The results and a good feedback presentation of the base to build on



Deliverables

- Communication of the idea of the events for WPHD 2019:
 - Light Burgundy Blue – 5th May
 - The main sport event “Hot breathers for PH” – 11 May 2019
 - One day seminar: 16 May 2019
 - Autism/Asperger 17 May 2019
- Preparation of list of media to be invited
- Coordination with all the institutions for preparation of all the news
- many documents
- Preparation of insulations, texts, materials and press information
- Dissemination of the press release




World Health Day 2019
Last Breathers for PH



Publicity

- New SOS clothing: from 10€ to 12.50€/2010
- 10 T-shirts (unisex) - 10 euros each (10€ - 10.50€ and 11.50€ each) - 10.50€ each
- 100 tea towels
- 100 T-shirts
- 100 Buttons

We can save a species in 10€ - 10.50€ - 11.50€

«Save our species, save our planet» (SOS) and the motto:
«Save our species, save our planet» (SOS) message.

More of SOS - Save our planet.


World PH Day 2019 - BSPPH
Event evaluation report

- Representatives of the Health Commission of National
- Mr. Karl Ananiev - Minister of Health, sent. used

» With the dissemination of informational materials we reached more than 2000 people during the event.

» More than 10 people took part in the sport event.

» We have distributed 100 T-shirts and 300 branded bags in the fitness center Sparrow, Sofia, Bulgaria.

» All of them were informed about the campaign.



45 journalists attended during the main event on 13 May.

Light in blue

Blue illuminates the occasion of the 50th anniversary of the 1968 invasion of Czechoslovakia by the Soviet-led Warsaw Pact forces. The event is part of the 50th anniversary of the 1968 invasion of Czechoslovakia by the Soviet-led Warsaw Pact forces. The event is part of the 50th anniversary of the 1968 invasion of Czechoslovakia by the Soviet-led Warsaw Pact forces.

A collage of various news and media content, including a person speaking, a news anchor, and a person in a green jacket.



Area of Improvements

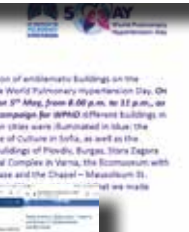
- The development of the event assessed that such events should be organized at a working level in close-knit after a call to assist to women after participation.
- The issue of sub-ventilation systems based on spring itself must be considered, performance is better than those implemented in the streets.
- Changes in the participants after events were made due to the lack of judgment of the event flow.
- Clear communication with the state service unit in order to avoid any misunderstandings.
- Detailed preliminary coordination with the clinic regarding communication protocol.



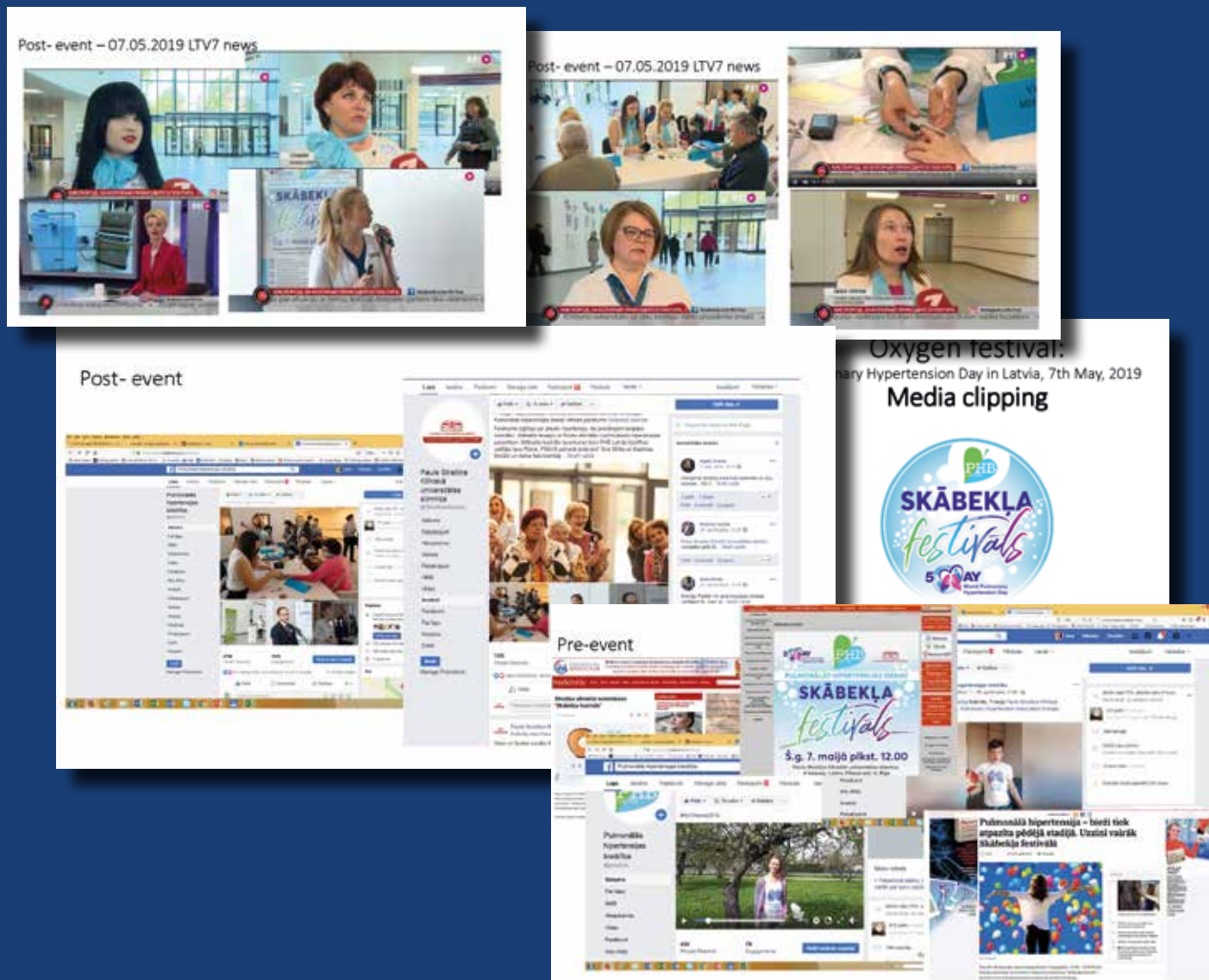

CROATIA

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CZECH REPUBLIC



LATVIA



PORTUGAL



HUNGARY



BORS EGÉSZSÉG

Beszélgünk a Min töbenünk növényekkel

pulmonális artériás hipertóniáról • ha elrontott a hangunk? • Gyógy- a szarkalábak élén • Horoszkóp

SÁRI ÉVI

GYAKORLOM A VISSZAUTASÍTÁST

Naarjegy egy 1000- es kiterjedt és egy 1000- es kiterjedt

LACTO SEVEN

100% természetes, 100% természetes, 100% természetes

Azt hitte, itt a vég

2. HETKÖZNAPI HÍRŐR

2018. március 23. péntek

Az elmúlt napok során a központi és a perifériás keringési rendszer...
Azt hitte, itt a vég...
Azt hitte, itt a vég...
Azt hitte, itt a vég...

Rettegett foggyókúra

2018. március 23. péntek

2018. március 23. péntek

Azt hitte, itt a vég...
Azt hitte, itt a vég...
Azt hitte, itt a vég...
Azt hitte, itt a vég...

SAÚDE+NUVE

Open Day com Workshops para os doentes, no

SAÚDE+NUVE

Open Day com Workshops para os doentes, no

Doentes raros querem papel mais ativo das autoridades de saúde

27 de julho de 2018

Doentes raros querem papel mais ativo das autoridades de saúde

NOVA EDIÇÃO ÍNDICE

ÍNDICE

NOVA EDIÇÃO ÍNDICE

hírd-ig

Pernas pesadas e cansadas

hírd-ig

SERBIA



Леа Милетић
ученица VI-2 ОШ „Кнегиња Милица“

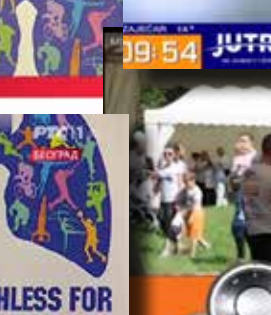
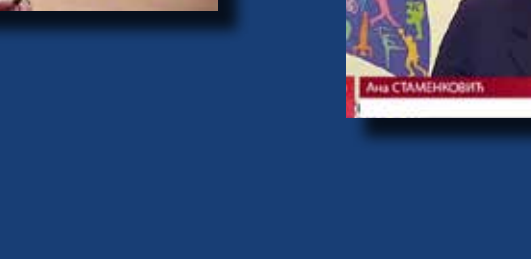
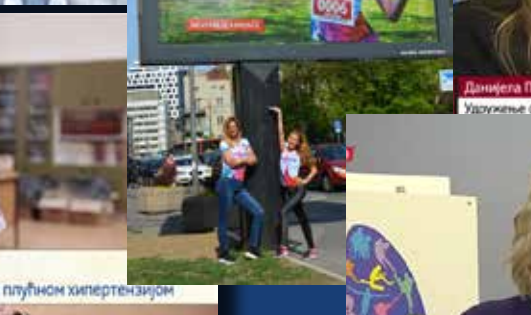
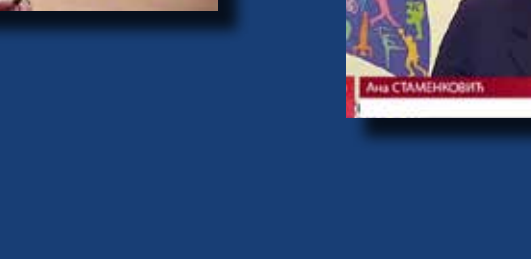
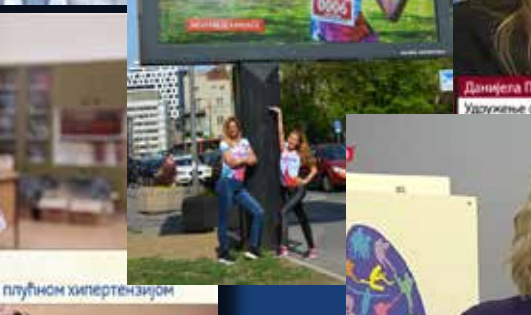
Međunarodni dan plućne arterijske hipertenzije, reke, teške kronične bolesti krvnih sudova pluća, obeležava se 5. maja. Ove godine su na skupu reč imali vodeći stručnjaci u ovoj oblasti, pacijenti, a prisutnima se obratio i sugrađanin predsednik Tamara Vučić. Danijela Pešić, predsednik PAH Srbije uručila je Tamari Vučić primanje za izuzetan doprinos unapređenju položaja osoba sa ... The post Tamara Vučić uručena primanje za izuzetan doprinos unapređenju položaja osoba sa PAH i nesebičnom zalaganju za spasavanje ljudskih

Brazil appeared first on Story

BOŠTNA HADON SHOD KALENDAR TBAČI: BERGOTATZ * BOSTANI CLAN

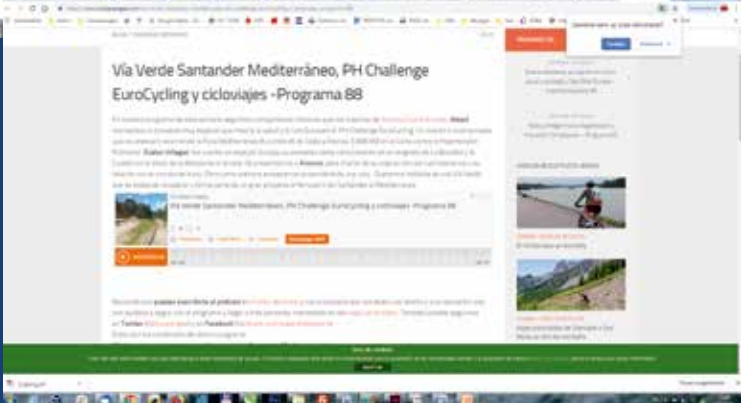
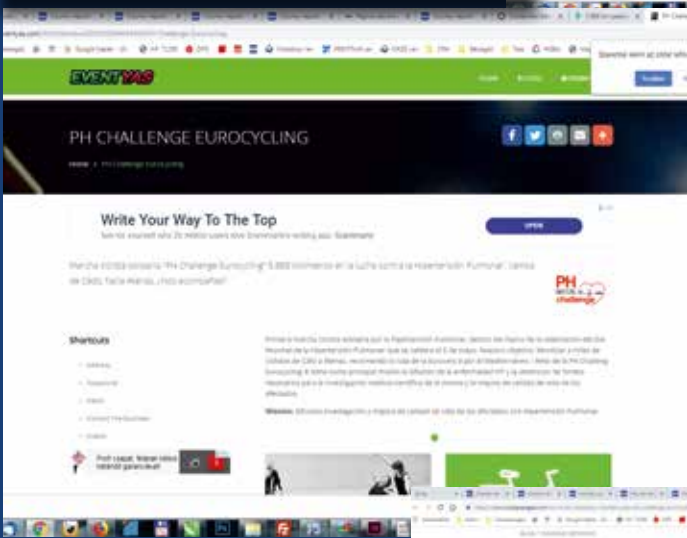
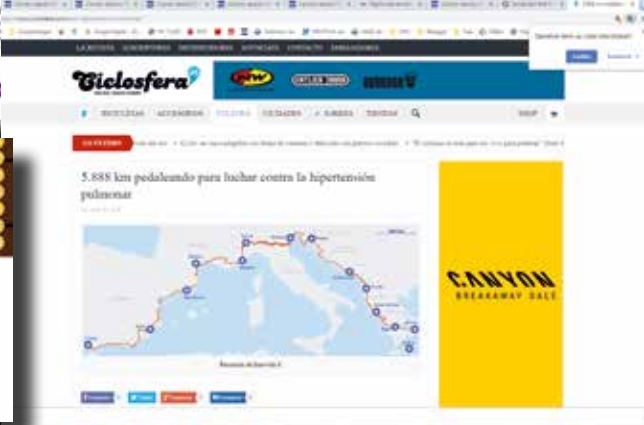


Tamara Vučić povodom Međunarodnog dana plućne arterijske hipertenzije: Empaciju smo negde usput zaboravili

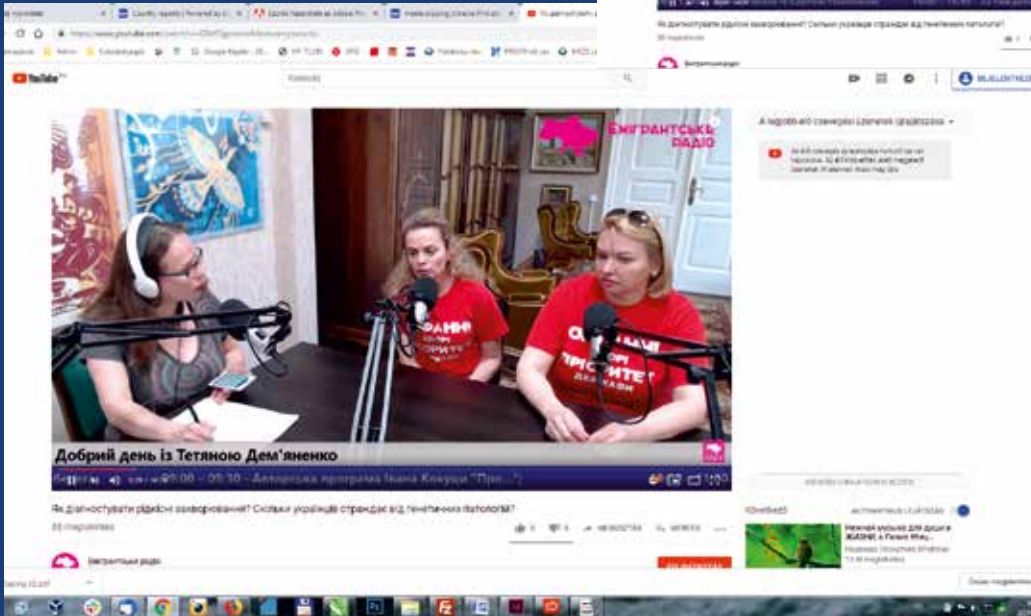
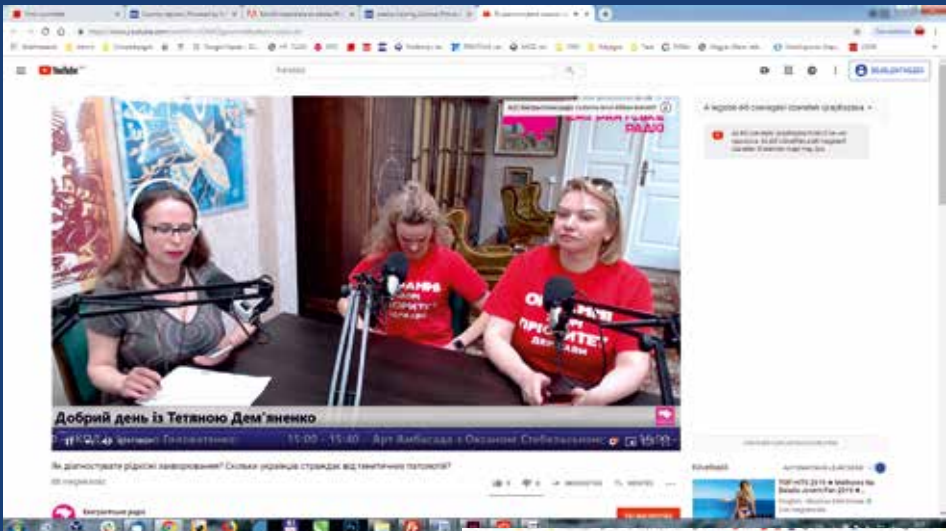


SLOVAKIA





UKRAINE PHA



Upcoming Events 2019

August 31- September 4, Paris, France

EUROPEAN SOCIETY OF CARDIOLOGY ANNUAL CONGRESS

This congress is the largest cardiovascular medicine meeting in the world and covers all disciplines from basic research to clinical practice.



September 15-18, Copenhagen, Denmark

EUROPEAN SOCIETY FOR ORGAN TRANSPLANTATION CONGRESS

Biennial congress, which gathers the European and international transplant scene.

September 28- October 2, Madrid, Spain

EUROPEAN RESPIRATORY SOCIETY ANNUAL CONGRESS

This congress involves not only leading experts in respiratory medicine, but also in the entire spectrum of research and practice.



November 12-14, Brussels, Belgium

EUROPEAN PATIENT'S FORUM

This event will provide an exceptional opportunity for dialogue, engagement with a wide.

2020 AT A GLANCE

- EURORDIS BALCK PEARL AWARDS, 18th February, Brussels, Belgium
- EUROPEAN CONFERENCE ON RARE DISEASES AND ORPHAN PRODUCTS (ECRD), 15-16th May, Stockholm, Sweden
- INTERNATIONAL PH CONFERENCE PHA USA, 12-14th June, Anaheim, California, USA
- EUROPEAN SOCIETY OF CARDIOLOGY (ESC) ANNUAL CONGRESS, 29th August - 2nd September, Amsterdam, The Netherlands
- EUROPEAN RESPIRATORY SOCIETY (ERS) ANNUAL CONGRESS, 5-9th September, Vienna, Austria

Next PHAE newsletter

The next Mariposa Journal will be issued in December 2018 (Winter edition). The main focus will be the reports from the national member associations about their activities in the course of the year. It will also feature any other inter-esting and relevant developments at European and international level. We would be very grateful if the members could send their contributions by the 30th of October at latest. These may be sent in the national language and we will provide for translation. Any photos should have a minimum resolution of 1 MB. The PDF will be posted on the PHA Europe website.

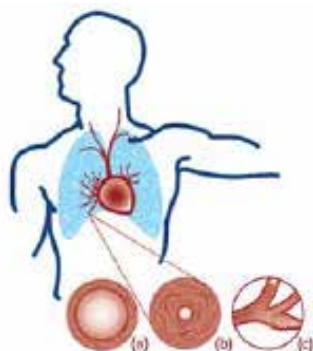
Many thanks in advance!

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

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.

Sponsors



(listed by alphabetical order)

Members of PHA Europe and contact details

AUSTRIA



PH Austria
Initiative Lungenhochdruck
Wilhelmstraße, 19 - 1120 Wien
www.phaustria.org
info@phaustria.org

FINLAND



Suomen PAH-potilasyhdistys ry. PHA Finland
c/o Tuulia Nikulainen
Kettutie 4 C, 00800 Helsinki, Finland
suomenpahry@gmail.com

BELARUS



Aid to Patients with Pulmonary Hypertension
Zapadnaya str.13 - 3, Minsk, 220036
www.phbelarus.by - phbelarus@yandex.ru

HUNGARY



Tüdőér Egylet
19, Cházár András Utca - 1146 Budapest
www.tudoer.hu - csabuda.eszter@t-online.hu

BOSNIA AND HERCEGOVINA



Udruženje građana oboljelih od plućne hipertenzije "DAH" - u Bosni i Hercegovini
Zlatnih ljiljana 33, 72220 Zavidovići, BiH
ugphbih@gmail.com

IRELAND



PHA Ireland
c/o Regina Prenderville
56 Eccles Street, Dublin 7, Ireland
<http://www.pulmonaryhypertension.ie/pha-ireland/pha@mater.ie>

BULGARIA



Pulmonary Hypertension Association
37 Hadji Dimitar str, ent. B, fl. 2, ap. 3
5800 Pleven
www.phabulgaria.eu - todormangarov@abv.bg
info@phabulgaria.eu

ISRAEL



PHA Israel
13 HaShoshan Street - Beit Shemesh 99590
Israel
<http://www.pulmonaryhypertension.ie/pha-ireland/pha@mater.ie>



The Bulgarian Society of Patients with
Pulmonary Hypertension - BSPPH
1 Geneva str. - 1142 Sofia
www.bspph.net - bgspph@gmail.com

ITALY



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

CROATIA



Plava krila - Udruga pacijenata oboljelih
od plućne hipertenzije
Gorica Jamnička 23 - 10451 Pisarovina
infoplavakrila@gmail.com - www.plavakrila.hr



Associazione Malati di Ipertensione
Polmonare Onlus
Via Ardea, 1/B - 00183 Roma
www.assoamip.net - info@assoamip.net
info@phaustria.org

CZECH REPUBLIC



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

LATVIA



PHA Latvia
Str. Celtnieku 6a - 35, Salaspils - LV - 2121
www.phlatvia.lv/en/ - info@phlatvia.lv

DENMARK



PAH Patientforeningen
c/o Bente Rasmussen
Ørbæksvej, 20
DK 2920 Hørsholm
<http://pah.dk> - pahforening@gmail.com

LITHUANIA



Žmonių Sergančių Plautinė Hipertenzija Asociacija
Energetikų 28-21 Visaginas, Lietuva
www.phalithuania.eu - kovaliova.nastya@gmail.com

NORWAY



PHA Norway
c/o Hall Skåra
Kantarellgrenda 6 - 1352 Kolsås
www.pha-no.com - hall@pha-no.com

SLOVENIA



Drus'tvo Za Pljuc'no Hipertenzijo Slovenije
Slovenska 29, 1000 Ljubljana
dbph.slovenije@gmail.com
www.facebook.com/PljucnaHipertenzija

POLAND



Polskie Stowarzyszenie Osób z Nadciśnieniem Płucnym i Ich Przyjaciół
Władysława IV 34a m.15, 81-084 Gdynia
www.phapolska.org - Alicja.morze@phapolska.org
Agnieszka.bartosiewicz@phapolska.org

SPAIN



ANHP Asociación Nacional de Hipertensión Pulmonar
Calle Villajimena nº 85, 1º 4 C.P.
28032 Madrid
www.hipertensionpulmonar.es informacion@hipertensionpulmonar.es

PORTUGAL



Associação Portuguesa de Hipertensão Pulmonar
Avenida Dr. Luis Navega, 38-42 - 3050 Mealhada
www.hp.sunlive.pt - mariajsaraiva@gmail.com



FCHP Fundación Contra la Hipertensión Pulmonar
c/o Enrique Carazo Minguez - Calle Pablo Neruda, 39 28980 Parla - Madrid
<http://www.fchp.es/es> - info@fchp.es
<https://www.facebook.com/fundacionhp>
<https://twitter.com/fundacionhp>

ROMANIA



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



Hipertensión Pulmonar España Organización de Pacientes (HPE-ORG)
Sant Feliu de Llobregat
c/o Anselm Clavé no 33 3o 3a - CP 08980 Barcelona
<http://www.hipertension-pulmonar.com/presidencia@hpe-org.com>

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

SWEDEN



Nätverket för PAH
c/o Patrik Hassel
Kärntorpsvägen, 37
121 55 Johanneshov
www.pah-sverige.se - patrik@pah-sverige.se

SWITZERLAND



Schweizer PH-Verein (SPHV) für Menschen mit pulmonaler Hypertonie
Strangenholzstrasse 5
8633 Wolfhausen
www.lungenhochdruck.ch - www.sphv.ch **President:** praesi@lungenhochdruck.ch **Webmaster:** bosshard@lungenhochdruck.ch

SERBIA



Plućna Hipertenzija Srbija
Str: Bulevar Crvene Armije 11b/3 11070
Beograd - Republika Srbija
daniijela@pesic.rs
info@plicni-hypertenze.cz

UKRAINE



Pulmonary Hypertension Ukrainian Rare Disease Association-PH URDA
Hlyboka street 12, Lviv 79013
kulish609@gmail.com - <http://poryatunok.info/uk/>

SLOVAKIA



Združenie pacientov s plúcnou hypertenziou, o.z.
Luc'enská, 31 - 990 01 Veľký Krtíš
www.phaslovakia.org - phaslovakia@gmail.com



Ukraine Association of Patients with Pulmonary Hypertension
Panasa Myrnoho str.,14 (litera A) 01011, Kiev
www.pha.org.ua - info@pha.org.ua





Editor & responsible for the content: PHAEUROPE
Mooslackengasse 17
A-1190 Vienna Austria
Austria

info@phaeurope.org - www.phaeurope.org