PULMONARY HYPERTENSION

Mariposa Journal

SUMMER 2024 • PHA EUROPE'S OFFICIAL JOURNAL • N. 32

World PH Day Edition

BELAIR CENTER
early diagnosis • best treatment • better quality of life • finding a cure
PHA EUROPE
PULMONARY HYPERTENSION ASSOCIATION
for the patients

Wilhelmstraße 21 • A-1120 Vienna • AUSTRIA • info@phaeurope.org • www.phaeurope.org

Editor's memo

SUMMER EDITION • 2024

Dear Friends, Colleagues, and Supporters,
Welcome to the summer edition of our magazine, Mariposa! This issue is dedicated to World PH Day and the incredible events organized by our members and other associations globally. This event, started by our Spanish association ANHP twelve years ago and since 2013 carried on by PHA Europe, emphasizes the urgency of raising awareness about pulmonary hypertension. Held annually around May 5th, it unites organizations, healthcare professionals, patients, and their families worldwide to spotlight the challenges faced by the PH community.

Our World PH Day project continues to serve three main objectives. First, raising awareness about pulmonary hypertension through various campaigns, educational events, and media coverage helps dispel misconceptions and encourages early diagnosis. Second, building a global support network by bringing together patients, caregivers, healthcare professionals, and advocacy groups fosters a sense of community and empowers those affected by PH to share their stories and find support. Third, advocating for improved care by leveraging the visibility of World PH Day to push for better healthcare policies, increased research funding, and improved access to treatments.

Once again, our members have impressed us with their creativity. They arranged the illumination of buildings in blue to raise awareness, organized numerous sports events showcasing our WPHD logo, and held activities that allowed healthy individuals to experience the challenges of living with PH. Please take the time to read about all the events that took place, even in countries facing difficult times.

Additionally, WPHD was successfully promoted on all our social media channels. By using professional visuals shared globally, we reached a vast audience. We collaborated closely with the American Pulmonary Hypertension Association (PHA) to develop a campaign that could reach a global audience. Please check the section dedicated to social media to learn more about our successful digital campaign.

World PH Day was also marked by associations worldwide, not just those related to PHA Europe. The USA, Canada, Nigeria and Peru accepted our invitation to submit articles about their celebrations. Additionally, it is particularly heartening to read the reports from our new associated members in Argentina, who contributed significantly to the global awareness efforts.

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

A big thank you to all members, patients, family members, carers, and friends who contributed to making this WPHD a great success. Special thanks go out to our industry partners who continue to support our work. Our mission remains clear: to raise as much awareness as possible to ensure early diagnosis, improve quality of life, and extend the lifespan of those with pulmonary hypertension.

Hall Skaara
Project Manager

CONTENTS

BEL AIR CENTER

Bel Air Center has been a success since its grand opening, featuring a webinar by Prof. Marc Humbert and Prof. David Montani in connection with World PH Day on May 5th.

For those of you who are not familiar with our Bel Air Center, let me explain what it is:

Bel Air Center is a unique virtual PH conference center that employs the latest cutting-edge technology. It's open every day, year-round, catering to a global audience through our extensive translation features.

At its core, the platform offers engaging live presentations, along with a wide array of recorded presentations in multiple languages, accessible for viewing at any time.

Additionally, the center hosts a wealth of information and materials from PH associations worldwide and leading pharmaceutical companies.

For those who prefer auditory learning, we proudly feature the entire podcast series from PH Aware, including almost 500 episodes.

Moreover, you can browse our gallery showcasing artwork and contributions from PH patients, doctors, and various other stakeholders.

To foster connections, our social area allows you to chat and host video conferences with fellow members, creating a dynamic and interactive community.

Anyone can register to access the Bel Air Center. Simply go to the landing page: www.belaircenter.info and create a free account. Please provide as much information as possible during registration to help us tailor the platform and its content to your needs.

From our landing page, you can click on a link to access Bel Air Center. No password is required. You simply enter the email you provided during registration and request an access code. It will be sent to you within seconds, and you can then log in with your email address and the access code. (The use of an access code is only required occasionally for security reasons.)

The center currently offers more than forty presentations covering various aspects of PH. The latest presentation, given by HTA specialist Neil Bertelsen, provided an excellent introduction to the HTA process and how patient associations can get involved. This presentation is the first of a series of three. Make sure to create your Bel Air Center user account to be notified about this and other interesting upcoming webinars.

Another feature of the presentation room is that some webinars have been dubbed into several languages. Simply click on the blue filter icon in the right-hand corner and select the desired language. The webinars available in that language will then be displayed. We will increasingly utilize this feature to make our excellent material accessible to a wider audience worldwide.

Welcome to Bel Air Center! Make sure to create your free account and explore the center. It is open 24/7!

Hall Skaara
Project Manager

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

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

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

Find out more on

PHuman™

EM-102191 | June 2022

Hollie, 37
United Kingdom
Entrepreneur
Living with pulmonary arterial hypertension

Janssen Pharmaceutica NV © JP NV 2022.

We are MSD

For 130 years, we have tackled some of the world's biggest health challenges and provided hope in the fight against disease, for both people and animals. Today, we continue our commitment to be the premier research-intensive biopharmaceutical company in pursuit of medical breakthroughs that benefit patients and society for today, tomorrow and generations to come.

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PHA EUROPE – SOCIAL MEDIA ACTIVITIES

Translating the voices of PH patients into compelling social media campaigns is always challenging, but WPHD 2024 will be remembered as a truly groundbreaking global effort. Nearly all major global associations across continents joined PHA Europe in utilizing our customizable visuals, making the WPHD 2024 campaign the most successful to date. Divided into four parts, each dedicated to key aspects of the PH patient experience, the campaign united the global PH community in advocating for early diagnosis, access to care, patients themselves, and ultimately, finding a cure for PH.

With over 80 different visuals, infographics, and animated reels, PHA Europe's social media channels reached an impressive audience, totaling over 3.5 million users with a remarkable 4.2 million impressions on Facebook and Instagram combined. Additionally, LinkedIn and X contributed to reaching an extra 95,000 users, with nearly 45,000 reached organically.

This year's materials were not only translated into more than 15 languages but were also adapted by patient associations, who personalized the campaign, amplifying the voices of patients even further. The plethora of visuals also gave each association multiple options to choose from, making sure diversity was highlighted. Under the slogan „Let's Breathe in Unity for the Global PH Community," this year's WPHD campaign received notable support from the Pulmonary Hypertension Association in the USA, reinforcing our shared mission to empower PH patients globally.

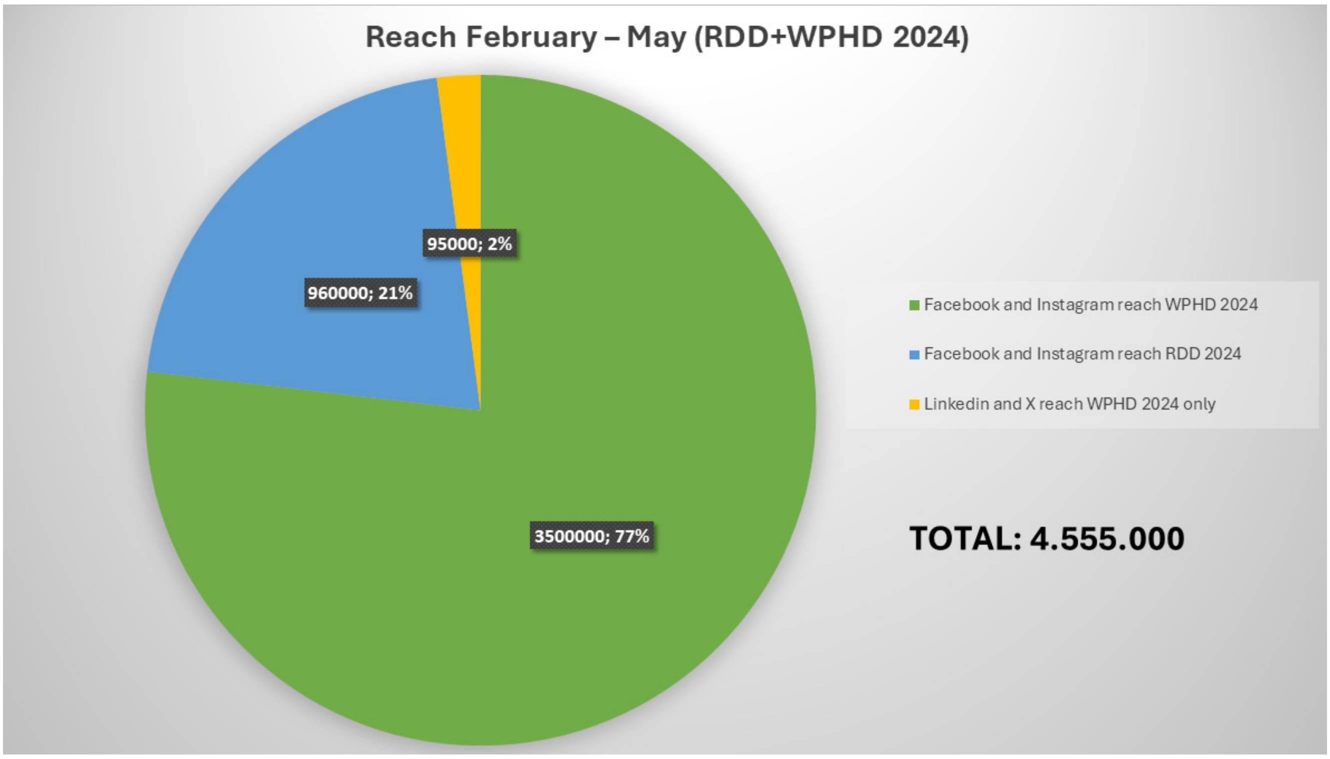
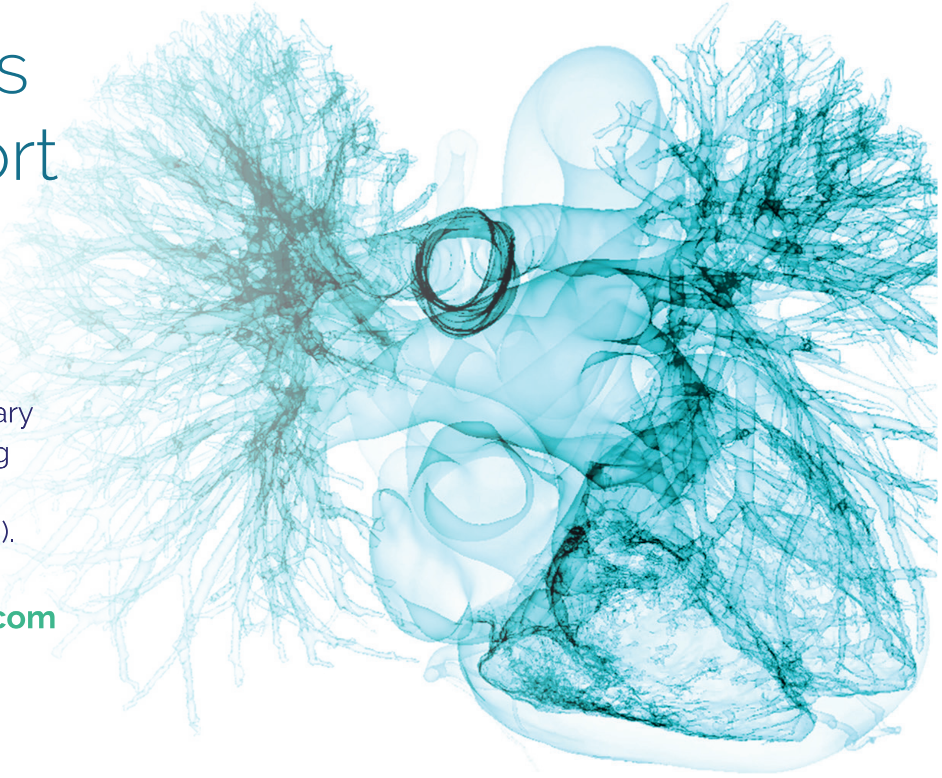


Figure 1Data from Meta Business Suite and SM Analytic tools

Our social media activities in May and June prominently featured a special webinar on non-PAH forms of pulmonary hypertension (WPHD webinar), showcasing Professor Dr. Ardeschir Ghofrani, a renowned expert in the field. This webinar was streamed through our advanced virtual conference platform, Bel Air Center, designed to facilitate the exchange of knowledge and connections among patients, experts, and pharmaceutical companies.

The impact of these campaigns was evident, as PHA Europe's pages gained over 330 new followers in May alone and 200 in the previous month. With the Rare Disease Campaign throughout February and a reach of more than 960,000 across all social media channels, PHA Europe managed to reach more than 4.5 million accounts in just 3 months, with more than 6 million impressions in total. With our content disseminated by an increasing number of patient associations and PHA Europe welcoming new members, the true extent of our reach is immeasurable. Yet, all indicators point to World Pulmonary Hypertension Day (WPHD) 2024 being the most impactful one yet. This underscores the power of unity in achieving meaningful change. We are proud of the global PH community, especially our European PH association and our PH family. Let this growing unity bring us closer to achieving better outcomes and a brighter future for all patients.



WORLD PH DAY WEBINAR

Understanding Non-PAH Pulmonary Hypertension: Key Insights and Treatment Recommendations

Prof. Dr. Ardeschir Ghofrani delivered an excellent presentation on World PH Day, focusing on the various types of Pulmonary Hypertension (PH) and their treatment recommendations. While Pulmonary Arterial Hypertension (PAH) often receives the most attention, Prof. Ghofrani chose to highlight the other types of PH in this webinar. Here is a short recap of his presentation:

Pulmonary Hypertension (PH) is a complex and varied group of diseases characterized by high blood pressure in the lungs. Unlike Pulmonary Arterial Hypertension (PAH), Non-PAH PH encompasses a broader spectrum of conditions, affecting a significant portion of the population, particularly those over the age of 65. PH is not a rare disease; it affects approximately 1% of the world's population, with prevalence increasing to 10% in individuals over 65.

The classification of PH is critical for diagnosis and treatment, as it encompasses a range of conditions beyond PAH. These include Group II PH associated with left heart disease, Group III PH associated with lung diseases and/or hypoxia, Group IV PH which is chronic thromboembolic pulmonary hypertension (CTEPH), and Group V PH, which involves unclear multifactorial mechanisms.

The treatment of PH varies significantly depending on the underlying cause. For Group II PH, which is due to left heart disease, the primary treatment goal remains the optimization of therapies for underlying heart conditions, with limited specific PH therapies available. In Group III PH, which is due to lung diseases and/or hypoxia, treatment focuses on optimizing therapy for the underlying lung condition. For instance, inhaled Treprostinil is currently the only approved therapy for ILD-PH, while phosphodiesterase-5 inhibitors (PDE-5i) may be considered in severe cases. Treatment decisions for COPD-PH are made on a case-by-case basis at expert centers.

Group IV PH, or chronic thromboembolic pulmonary hypertension (CTEPH), involves surgical options like pulmonary endarterectomy (PEA) for operable patients. For non-operable patients with distal obstructions, balloon pulmonary angioplasty (BPA) is used, and for those with microvasculopathy, medications like Riociguat are effective.

The landscape of PH treatment is continuously evolving with ongoing research and clinical trials. Notable studies include the INCREASE Study, which demonstrated the efficacy of inhaled Treprostinil in treating ILD-PH (currently only approved in the US), and the RACE Trial, which evaluated the safety and efficacy of Riociguat in combination with BPA, providing insights into multi-modal therapy approaches.

Non-PAH PH represents a diverse array of diseases, each requiring tailored treatment strategies. Advances in understanding and managing these conditions have led to more precise and effective therapies. Continued research and multidisciplinary collaboration remain essential for improving outcomes for PH patients worldwide.

Hall Skaara
Project Manager

OrphaCare

FOCUS ON PERSONALISED MEDICINE

Orpha*Care* is an international, up-and-coming company with a special focus on medical devices. The company organizes a comprehensive and competent patient support as well as distribution.

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

At OrphaCare, we don't just talk about personalised medicine,
WE LIVE IT!

For further information visit us at:
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*) EU Medical Device Regulation (MDR) 2017/745

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AOP HEALTH

AOP Health is the European pioneer for integrated therapies for rare diseases and in critical care.

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At Ferrer we want to make a positive impact in society and we do so by reinvesting a significant part of our profits in initiatives with social and environmental impact, as well as in our people.

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

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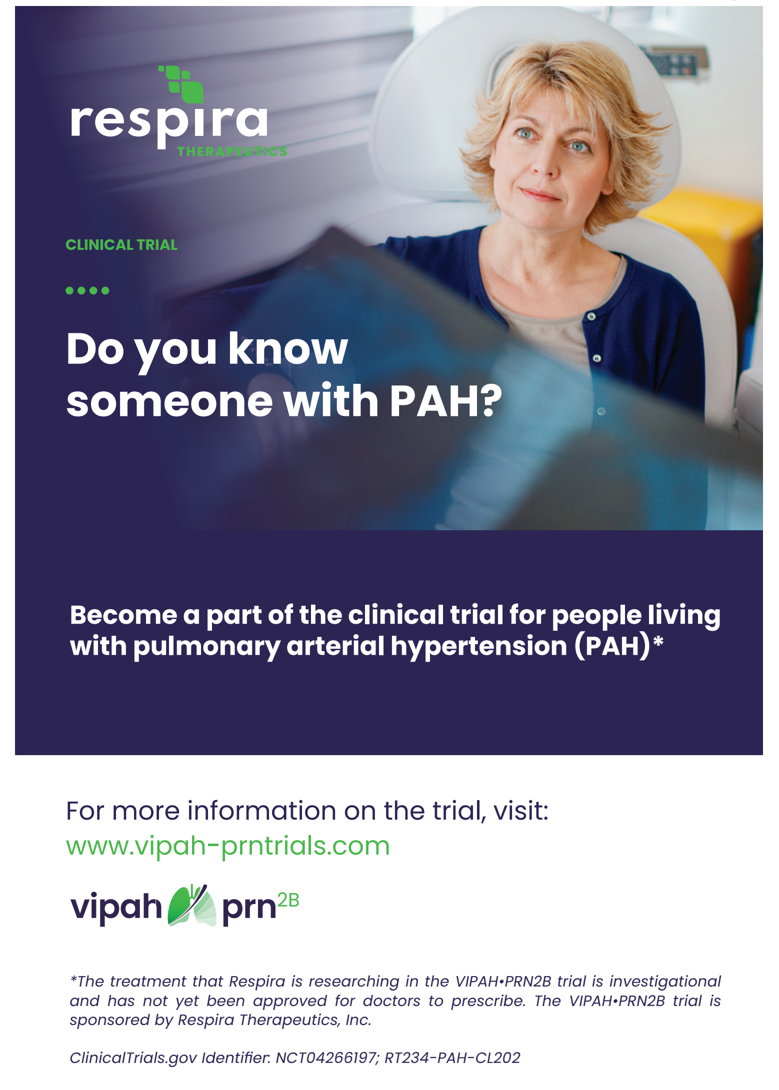


respira THERAPEUTICS

CLINICAL TRIAL

●●●●

Do you know someone with PAH?

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

For more information on the trial, visit:
www.vipah-prntrials.com

vipah prn 2B

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

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

ARGENTINA

WORLD PULMONARY HYPERTENSION DAY 2024

As part of the new commemoration of World PH Day, HIPUA - Pulmonary Hypertension Argentina organized the 3rd National Meeting on Pulmonary Hypertension, aimed at patients and their families. This event took place from April 30th to May 5th, and featured various types of activities.

On April 30th at 6:00 PM, the first of the activities began with the following invited experts in Pulmonary Hypertension: Dr. Liliana Favaloro, Dr. Clara María Huerta, Dr. Patricia Avellana, Dr. Nicolás Atamañuk, Dr. Eduardo Perna, Dr. Martín Bosio, and Dr. Cristian Botta.

It was a panel discussion held via the Zoom platform, centered around the latest updates in Pulmonary Hypertension.

The format of the meeting involved answering a series of questions that both patients and their families/caregivers had submitted upon registering for the event. After the Q&A session, a general discussion was held with all the invited professionals, where each speaker reinforced some concepts and provided additional information not covered during the initial rounds of questions.

The turnout exceeded our expectations with more than 80 people joining the Zoom session. Both patients and families were very active and eager to listen to the specialist doctors.

On May 2nd at 6:00 PM, another activity was held via Zoom. Its objective was to present to the patients and their families/caregivers three of the five working areas that make up HIPUA: the Legal Area led by Dr. Geraldine Alali, the Social Area led by Lic. Emma Ledesma, and the Psychology Area led by Lic. Jennifer Selles.

This time, the format of the meeting involved a brief presentation by each of the professionals.

Dr. Geraldine Alali spoke about the deregulation of social health insurance and prepaid medical plans, non-compliance in access to treatments, and the correct prescription of medications (generic drugs or brand name ones).

Lic. Emma Ledesma discussed the Unique Disability Certificate (CUD), explaining under what circumstances it should be processed, debunking the myth that „without a disability certificate, one cannot access medication."

Finally, Lic. Jennifer Selles addressed the uncertainty generated by the diagnosis, suggesting some tips to focus on the present and reduce anxiety.

All patients and families who attended this second meeting were very engaged, asking each of the participating professionals numerous questions.

On May 3rd at 10:00 AM, the 3rd Cardiopulmonary Rehabilitation Day for patients with Pulmonary Hypertension took place, organized by the Interdisciplinary Group of Hospital Fernández. It was the first in-person event post-pandemic with our patients and families, held in the Aula Magna of the hospital.

The day began with a few words from the hospital's director, Dr. Carlos Damin, followed by presentations from the interdisciplinary group members: Dr. Nicolás Atamañuk (cardiologist), Dr. Diego Litewca (pulmonologist), Dr. Eliana Calegari (pulmonologist), Dr. Luis Gómez (cardiologist), and Lic. Julieta Lardies (physiotherapist).

Patients with Pulmonary Hypertension and their families joined the event with excellent participation, filling the Aula Magna.


3° Encuentro Nacional de Hipertensión Pulmonar para pacientes y familiares

#SoloSeTrataDeRespirar

AGENDA DE ACTIVIDADES

Martes 30 de Abril 18:00 hs. zoom

Actualizaciones en Hipertensión Pulmonar. Consultando a nuestros referentes a nivel nacional.

REQUIERE INSCRIPCIÓN PREVIA

Viernes 3 de Mayo - 10:00 hs.

3° Jornada de Rehabilitación Cardiorrespiratoria para pacientes con Hipertensión Pulmonar.
Junto al Equipo Interdisciplinario del Hospital "J. A. Fernández"

EVENTO PRESENCIAL

REQUIERE INSCRIPCIÓN PREVIA

Jueves 2 de Mayo 18:00 hs. zoom

Consultas abiertas al Equipo Multidisciplinario de HIPUA (Áreas Legal, Social, y Psicología) desde dónde se darán tips para resolver diferentes problemáticas.

REQUIERE INSCRIPCIÓN PREVIA

Domingo 5 de Mayo

Conmemoración del **Día Mundial de la Hipertensión Pulmonar**


3° Encuentro Nacional de Hipertensión Pulmonar para pacientes y familiares

#SoloSeTrataDeRespirar

ACTUALIZACIONES EN HIPERTENSIÓN PULMONAR

Martes 30 de Abril

18:00 hs.

POR PLATAFORMA zoom

REQUIERE INSCRIPCIÓN PREVIA

Dra. Liliana Favaloro
Cardióloga - División de Insuficiencia Cardíaca, Trasplante Intratorácico e Hipertensión Pulmonar del Hospital Universitario Fundación Favaloro

Dr. Nicolás Atamañuk
Cardiólogo - Jefe del Equipo interdisciplinario de Hipertensión Pulmonar del Hospital "J.A.Fernández"

Dr. Eduardo Perna
Cardiólogo - División de Insuficiencia Cardíaca e Hipertensión Pulmonar Instituto de Cardiología de Corrientes "Juana Francisca Cabral"


3° Encuentro Nacional de Hipertensión Pulmonar para pacientes y familiares

#SoloSeTrataDeRespirar

ACTUALIZACIONES EN HIPERTENSIÓN PULMONAR

Dr. Martín Bosio
Neumonólogo - Jefe del Servicio de Hipertensión Pulmonar - Htal. Británico

Dr. Cristian Botta
Cardiólogo - Área de Insuficiencia Cardíaca e Hipertensión Pulmonar Hospital Cullen (Pcia. Santa Fe)

Dra. Clara Huerta
Cardióloga - Integrante del Programa de Insuficiencia Cardíaca, Hipertensión Pulmonar y Trasplante del Instituto Cardiovascular de Bs. As. (ICBA)

Dra. Patricia Avellana
Cardióloga - Integrante del Grupo de trabajo Interdisciplinario de HAP del Hospital Argerich

Martes 30 de Abril

18:00 hs.

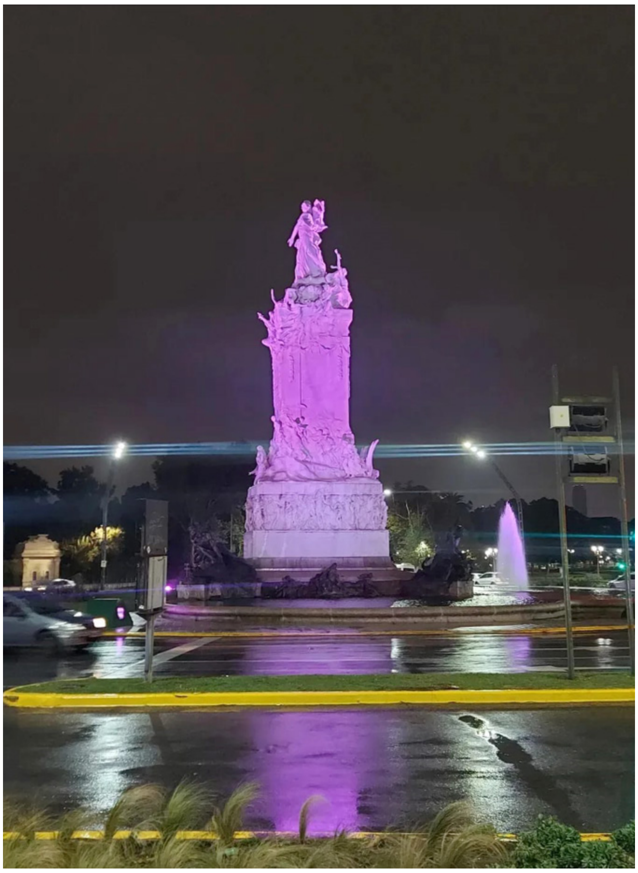
POR PLATAFORMA zoom

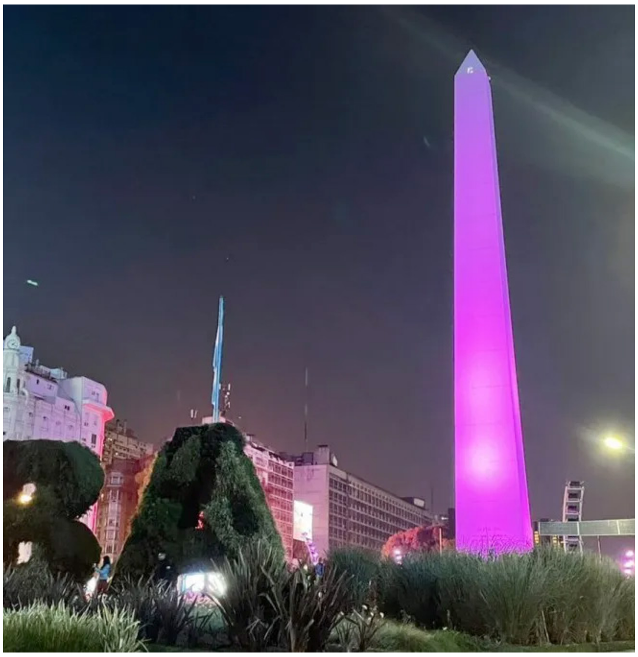
REQUIERE INSCRIPCIÓN PREVIA


3° Encuentro Nacional de Hipertensión Pulmonar para pacientes y familiares

#SoloSeTrataDeRespirar

CONSULTANDO AL EQUIPO MULTIDISCIPLINARIO DE HIPUA





As a conclusion, on May 5th, from 6:00 PM to midnight, various monuments in the Autonomous City of Buenos Aires were illuminated, including the Obelisk, the city's emblem, along with the planetarium, the Usina del Arte, the Lezama Palace, and the monument to the Spaniards.

The aim of these meetings is to guarantee access to excellent information provided by the top experts in Argentina, with the goal of fostering an active, empowered patient based on the premise that „INFORMING IS A WAY OF CARING" and that patients who takes care of themselves will undoubtedly achieve better treatment adherence and a better quality of life.

AUSTRIA

In time for World Pulmonary Hypertension Day, PH Austria - Initiative Lungenhochdruck aims to raise awareness of the often overlooked but serious condition. New stones symbolizing donations were installed at the Milestones Square in the Wiener Prater with prominent support on May 2nd. Dancer and „Fit mit den Stars" host Conny Kreuter and boxer Fadi Merza lent their support. The Ars Electronica Center in Linz supported us by illuminating the facade of the center in blue. Additionally, thanks to CEO Nora Lamac, the Wiener Riesenrad was also lit blue in solidarity on World PH Day.

With the „Milestones Square", there is a place of engagement and solidarity with those affected by the disease right in the heart of the Wiener Prater. The idea for the milestones came from the initiator of the Lungenkinder Research Association, Gerald Fischer, whose daughter is affected by Pulmonary Hypertension. With a donation of 29 euros, one can support PH Austria and immortalize themselves with a personal message on one of the stones. New stones were installed after the winter months.

„The milestones are an opportunity to make a visible statement with one's own donation. They stand as a symbol for the feeling shared by many PH sufferers of having a heavy stone on their chest that makes breathing difficult. The milestones are often given on special occasions - in the name of a birthday child or a mother for Mother's Day," says project initiator Gerald Fischer.

Conny Kreuter and Fadi Merza for the Lungenkinder

Host Conny Kreuter is currently busy in the studio and attending events. With the takeover of the TV format „Fit mit den Stars," the host has achieved record ratings at the beginning of the new show. Nevertheless, she consciously takes the time to support PH Austria in laying the stones. „Especially for rare diseases, about which little is known, it is all the more important to be seen and to draw attention to the affected individuals, as well as research and the development of treatment methods. This is a personal concern for me, and I am happy to help where I can," says the host.

Boxer Fadi Merza is also on board. For him, it was never a question: „The fights a boxer faces are nothing compared to the often lifelong battles that those affected by a disease endure. No one is as strong as these children and adults. That's why they deserve our support and respect," believes Fadi Merza.

BELARUS

Pulmonary Hypertension (PH) Awareness Month is a time when patients actively use their social networks to inform their followers and communities about PH. Social media posts filled with useful information about symptoms, treatment, and support play a crucial role in raising awareness. PH groups also do valuable work in spreading information and creating a community where patients can share experiences and support each other.

This year, patients have organized small events, taking photos and sharing their stories on social media. These photos and stories serve as inspiration and motivation for others, showing that, despite the challenges, it is possible to live fully and actively.

Unity and support for each other are especially important in this process. We are a team, and together we are stronger. Together, we can not only raise awareness about PH but also create a strong community where everyone feels understood and supported.

BELGIUM

PULMONARY HYPERTENSION SPOTLIGHTED THANKS TO THE ‚MOVE FOR PULMONARY HYPERTENSION 2024' CAMPAIGN

In conjunction with World PH Day on May 5th, the second edition of the Belgian ‚Move for Pulmonary Hypertension' campaign took place this year. The campaign aimed to raise awareness and funds for research into and treatment of pulmonary hypertension (PH). This disease, which affects the blood vessels in the lungs and leads to high blood pressure in the pulmonary artery, continues to have a significant impact on the lives of many patients worldwide. This overview article highlights the Belgian actions and achieved results of the 2024 campaign.

ACTIONS

During the campaign, various activities were organized to encourage people to move and simultaneously raise funds. In total, an impressive 13,232 kilometers and 1,750 euros were raised through numerous activities:

1. VIRTUAL MARATHONS AND WALKS:

Participants could register on the Strava app, a fitness app where they could share their performances and distances with other members of the group ‚PH Belgium – Pulmonary Hypertension vzw'. In total, 13,232 kilometers were covered in May.

2. LOCAL SPORTS EVENTS:

Several cities and towns organized local sports events, such as running races, a great opportunity to gain awareness and sometimes funds. For example, ‚Dwars door Desselgem' organized a sporting activity that donated 750 euros to Pulmonary Hypertension vzw.

3. CORPORATE CHALLENGES:

Companies were encouraged to form teams and participate. This not only raised funds but also provided fun images, fostered team spirit, and raised awareness within organizations. For instance, MSD organized a 6MWD challenge among colleagues, GossamerBio had colleagues complete the 6MWD backward, and Janssen (Johnson & Johnson) highlighted WPHD. Local hospitals also contributed, such as the team of physiotherapists for PH at UZ Leuven, who organized an extra tough 6MWD by carrying colleagues on their backs.

4. PERSONAL CHALLENGES:

Many individual athletes and supporters set their own challenges, such as walking or cycling a certain distance daily for a month, or participating in a sport event such as the Gran Fondo Claudio Chiapucci in France. Through personal crowdfunding pages, they could collect donations.

COMMUNICATION

Together with our association's godmother, actress Hilde Heijnen, we made a spot to draw attention to pulmonary hypertension and call for people to join the action. This spot was distributed through our social media channels.

RESULTS

The results of the ‚Move for Pulmonary Hypertension 2024' campaign were impressive and demonstrated the power of community involvement:

1. FUNDRAISING:

A total of 1,750 euros was raised. This money will be used for research into new treatments and patient support.

2. PARTICIPATION:

Many people participated in the various activities. The virtual events made participation more accessible, leading to a broader participant base.

3. AWARENESS:

The campaign reached a larger audience thanks to social media.

4. COMMUNITY SPIRIT:

The campaign brought communities together, from local sports clubs to multinational companies. This strengthened solidarity and support for PH patients and their families.

The ‚Move for Pulmonary Hypertension 2024' campaign was a great success thanks to its diverse and inclusive approach to fundraising and awareness. Through innovative actions and effective communication, not only was a substantial amount of money raised, but knowledge and understanding of PH were also increased. The dedication and involvement of participants and organizations worldwide show what is possible when people unite for a good cause.

BOSNIA AND HERZEGOVINA

WPHD 2024 – Bosnia and Herzegovina

UNITED IN THE FIGHT FOR A MEDICINE FOR ALL PH PATIENTS

This year, the Association of Citizens with Pulmonary Hypertension „Dah" - in Bosnia and Herzegovina marked WPHD 2024 for the tenth time in our country. With the great help of our long-time friends, as in previous years, we tried to include all generations with our celebration, as well as to organize educational and sports activities.

BLUE LIPS IN SCHOOLS

We started the celebration of WPHD 2024 in Bosnia and Herzegovina with a public announcement about this special day on the video banners of the company General Pro-Mark, with which we already traditionally cooperate, and we continued with our youngest support from the First Primary School in Zavidovići, who, together with their teacher Samira Isić and Emira Skejić showed that they are not only good artists, but that they already know something about certain symptoms of pulmonary hypertension. Thanks to them, blue lips appeared at school. When you have primary school children as your support, who have been participating in the celebration of World Pulmonary Hypertension Day for several years, then it's an indescribable feeling! They always surprise and delight us with their creativity and serious approach to the task they come up with on this occasion. These little ones already have big personas! Their commitment to the task and beautiful smiles leave us breathless! All over the world, only PH patients have this kind of support!

EDUCATION ABOUT PULMONARY HYPERTENSION ON THE STREETS

We continued our activities dedicated to WPHD 2024 on the streets of Zavidovići, a city located in the heart of Bosnia and Herzegovina. Considering that the week of the Red Cross and the Red Crescent was in progress, our activity gained even more importance.

The wonderful and hardworking volunteers of the Red Cross organization Zavidovići, Lamija, Sara and Mejra, and members of the Association of Citizens Suffering from Pulmonary Hypertension „Dah" - in Bosnia and Herzegovina had the opportunity to talk with many residents of this city about pulmonary hypertension and the problems faced by patients in our country.

On this occasion, we distributed a lot of PH promotional materials for adults and children: t-shirts, flyers, picture books, badges, pens, flags, which caused great interest of the citizens, and enabled us to introduce them all to the important facts related to the disease and the difficult situation of the patients in our country. First of all, we pointed out the fact that we all live in the same country, but that we do not all have the same position, that is, that all PH patients in Bosnia and Herzegovina do not have access to medicine.

During this activity, our stand was visited by some doctors, as well as current politicians from the Federation of Bosnia and Herzegovina. There is interest in helping us achieve our most important goal - a cure for all PH patients in Bosnia and Herzegovina.

AND WITH SPORT, WE RAISE AWARENESS ABOUT OUR DISEASE

Apart from Zavidovići, we also raised awareness about pulmonary hypertension in the capital of Bosnia and Herzegovina, Sarajevo, but also outside the borders of our country, in Germany, in Ahrensburg and Hamburg. On May 12th 2024 in Sarajevo, the 5th Sarajevo Marathon was held, which is the largest sports and running event in Bosnia and Herzegovina, in which 1,999 runners from 44 countries participated this year. Among such a group of running enthusiasts and sports professionals was our team - the team of PH BIH runners from SD Ultra Bihać, who, with their participation in this marathon, contributed to our celebration of WPHD 2024 again this year. Emina Čehajić Gradinović and Asmir Islamović ran a half marathon - 21 km, and Amar Čehajić and Enes Ibrahimagić ran a marathon - 42 km with the markings of the European PH community. They dedicated their participation in these races to patients with pulmonary hypertension. And this time, they lost their breath for all those who suffer from this rare and serious disease, and have once again earned the respect of the entire PH community of Europe and the world. We no longer count their kilometers because they are unstoppable!

In addition to runners, our faithful collaborator in marking the WPHD is the recreational cyclist from Bosnia and Herzegovina, Ismet Škulj, who does not forget us on his regular cycling tours. Together with us, he marked WPHD 2024 and this time driving on the roads of Europe. We record new kilometers of his ride in the north of Germany, where together with his host Stefan, he rode a bicycle for all those suffering from pulmonary hypertension on the sections around Arhensburg and Hamburg. Respect for more than 12,000 kilometers traveled for PH patients all over the world! Every year, Ismet is part of our team in charge of marking WPHD, and wherever he is, he dedicates his May rides to raising awareness about our disease.

CONTINUED SUPPORT OF OUR MEDIA

This year, like all the previous ones, there was no lack of support from the media. Our press release on the occasion of the celebration of WPHD 2024 was reported by many electronic media and portals. Due to their interest and willingness to help us achieve our primary goal - a cure for all PH patients in BiH, we must mention them: N1 info, TRN info, Bosna vijesti, Centralna, Magazin Plus, Zenit, Dnevni avaz, Raport, Bosna info, Anadolija BiH, BHRT, Preporod Info, and Mostarski. With the great help of our friends, we rated this year's celebration of WPHD 2024 in Bosnia and Herzegovina as very successful because we felt an extremely positive reaction at every step.Together to the goal!

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

BULGARIA PHA

NINTH NATIONAL CONFERENCE ON PULMONARY ARTERIAL HYPERTENSION: A BEACON OF HOPE AND KNOWLEDGE

On May 11th, 2024, the Hotel „Vereya" in Stara Zagora was abuzz with the energy and optimism of patients, healthcare professionals, and advocates gathered for the Ninth National Conference on Pulmonary Arterial Hypertension (PAH). Organized by the Association for Pulmonary Hypertension, this annual event has become a cornerstone for raising awareness, sharing cutting-edge medical knowledge, and fostering a supportive community for those affected by this challenging condition.

The conference opened with welcoming remarks from Todor Mangarov, Chairman of the Association, setting an enthusiastic tone for the day. Esteemed speakers delivered a series of insightful presentations covering various aspects of PAH. Dr. Simona Markova from the Hospital „Sv. Anna" provided a detailed overview of PAH classifications, diagnosis, and modern treatment options, emphasizing the importance of early and accurate diagnosis for effective management.

Dr. Diana Lekova-Nikova from the Hospital „Tokuda" shed light on the intersection of PAH and interstitial lung diseases, highlighting the complexities of managing these overlapping conditions. Radostina Getova discussed the critical topics of organ donation and transplantation in Bulgaria, offering hope and vital information to those in need of these life-saving procedures.

The afternoon sessions brought a more personal touch to the conference. Teodor Oprenov's heartfelt talk, „God, Why Me?" resonated deeply with the audience, sharing his personal journey and coping strategies. Stanislava Sabeva, a psychologist and therapist, explored the psychological dimensions of living with PAH, advocating for a holistic approach to patient care that includes mental and emotional well-being.

Pavlina Grigorova of the Association „Dignity" addressed the practical challenges related to disability assessments (TELK), offering solutions and support to navigate this often cumbersome process. Monika Marinova, from the Association of Tarlov Patients in Bulgaria, highlighted the struggles of those with perineural Tarlov cysts, a rare and frequently misunderstood condition, drawing attention to the need for greater awareness and research.

The conference concluded with a poignant presentation by Todor Mangarov, sharing his personal story of overcoming a thrombendarterectomy. His journey of resilience and recovery served as an inspiring testament to the strength and determination of PAH patients.

The event culminated in a lively discussion session and a communal dinner, where attendees had the opportunity to connect, share experiences, and build lasting relationships. The conference not only provided a wealth of information but also reinforced a strong sense of community and support among participants.

Overall, the Ninth National Conference on Pulmonary Arterial Hypertension was a resounding success, significantly contributing to the awareness and understanding of PAH. It highlighted the critical need for comprehensive care, encompassing both medical and emotional support, and underscored the importance of unity and advocacy in improving the lives of those affected by PAH.

EMPOWERING HEALTH AWARENESS: PHA BULGARIA PARTNERS WITH KICKBOX TEAM FOR IMPACTFUL EVENT

PHA Bulgaria is excited to announce a dynamic collaboration with a kickbox team to promote health awareness and physical well-being. This unique partnership, aimed at raising awareness about critical health issues, seamlessly blends the influence of sports with the mission of disseminating essential health information to communities across Bulgaria.

Location: Sport Club Masary, Sofia

EVENT OVERVIEW:

On May 5th, 2024, the sport club Masary in Sofia hosted „Strike for Health," an event designed to empower communities through a combination of health education and engaging physical activities. The day offered a variety of enriching experiences for all attendees.

HIGHLIGHTS OF THE EVENT:

- *Interactive workshops:*

Health professionals and experts lead engaging workshops covering vital topics, such as nutrition, exercise, stress management, and disease prevention. Participants gained practical knowledge and skills to enhance their health and well-being.

- *Demonstrations by Kickbox Team:*

The kickbox team performed dynamic demonstrations, showcasing their skills and techniques. These performances highlighted the importance of physical activity and inspired attendees to incorporate regular exercise into their daily lives.

- *Educational Booths:*

Informational booths offered a wealth of resources and materials on various health issues. Attendees learned about preventive measures, available healthcare services, and how to access support networks, empowering them with the knowledge to make informed health decisions.

- *Community Engagement Activities:*

These activities provided opportunities to connect with like-minded individuals and exchange ideas on promoting health and well-being within their communities.

- *Networking Opportunities:*

This event also served as a networking platform, allowing attendees to connect with representatives from PHA Bulgaria, the kickbox team, and other organizations dedicated to health promotion. This aspect of the event facilitated collaboration and the sharing of best practices in public health advocacy.

By combining the excitement of kickboxing with crucial health education, PHA Bulgaria and their kickbox team partners created a memorable and impactful event. „Strike for Health" hopes to empower communities, promote healthier lifestyles, and foster a collaborative spirit in the fight against health issues.

BULGARIA BSPPH

SPORTS ENTHUSIASTS JOINED THE INITIATIVE GET BREATHLESS FOR PH

On May 10th, 2024 at 15:00 there was a one-hour intensive sports event under the slogan “Get breathless for PH”. Twenty active young athletes played pickleball under the guidance of the conditioning coach Rositsa Petrova in Sports Olympic, and the Chairman of the Bulgarian Pickleball Federation Gergin Angelov hosted the event.

“Being active and brave and putting in the effort to exercise despite being in poor health and physical disadvantage is commendable. Therefore, the Bulgarian Pickleball Federation would like to provide incentive to all affected by pulmonary hypertension, to keep enjoying being out of breath because they feel the power of movement and sport,” said Gergin Angelov.

For the 11th time, Bulgaria is part of the global campaign “Get Breathless for PH” to celebrate the World Pulmonary Hypertension Day. All the initiatives organized in May by the Bulgarian Society of Patients with Pulmonary Hypertension are under the auspices of the Ministry of Health and the institutional support of the Executive Agency Medical Supervision.

“Pulmonary hypertension is the invisible disease that leaves you out of breath. There are many heroes struggling with this rare condition – patients and their families, as well as doctors who often have to work miracles in order to contain a crisis. When the disease progresses, patients depend on oxygen concentrators and expensive treatments. The only chance once they reach the terminal stage is a bilateral lung transplant. This rare disease takes away the ability of people in their active age to run, do sports, have fun - every step leaves them breathless," commented Natalia Maeva, chairperson of the Bulgarian Society of Patients with Pulmonary Hypertension.

After almost five years of efforts by BSPPH and other patient organizations, in April 2024, the National Health Insurance Fund accepted the requirements for issuing treatment protocols for patients with chronic hypoxemic respiratory failure, who need oxygen therapy at home. This is a huge step forward, as patients with pulmonary arterial hypertension will be able to receive oxygen concentrators and pay only for the supplies they need. "It remains to be seen when the first patient will actually receive their stationary concentrator," added Natalia Maeva.

For more info , please visit: *www.bspph.net* | Video: *https://www.youtube.com/watch?v=1TN_YGLK6l0*

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

Teams from 33 countries participated in the international pétanque tournament, held from May 22nd to May 29th at the Mesongi Beach resort on the island of Corfu, Greece. For the second year in a row, the representatives of the „Karo" dedicated their participation in this prestigious international competition to people living with pulmonary hypertension.

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

Among the participants in the doublets and triplets was Natalia Maeva, president of the Bulgarian society of patients with pulmonary hypertension, who, for the first time, took part in the authoritative international tournament.

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

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

WHY MENTAL HEALTH IS IMPORTANT FOR PH PATIENTS?

As part of the World Pulmonary Hypertension Day campaign, a patient webinar „Pulmonary hypertension: Mental health matters" was held on 21.05.2023. Dr. Lyubomir Dimitrov, an invasive cardiologist, head of the Department of Paediatric Cardiology at the National Hospital of Cardiology and deputy chairperson of the Bulgarian Society of Patients with Pulmonary Hypertension, spoke about the challenged that doctors and patients with PH face in order to make the correct diagnosis and how this affects mental health.

„All these patients should receive adequate medical care. We, I am talking about the doctors, the society, the state, should provide them adequate treatment", the expert said.

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

CANADA

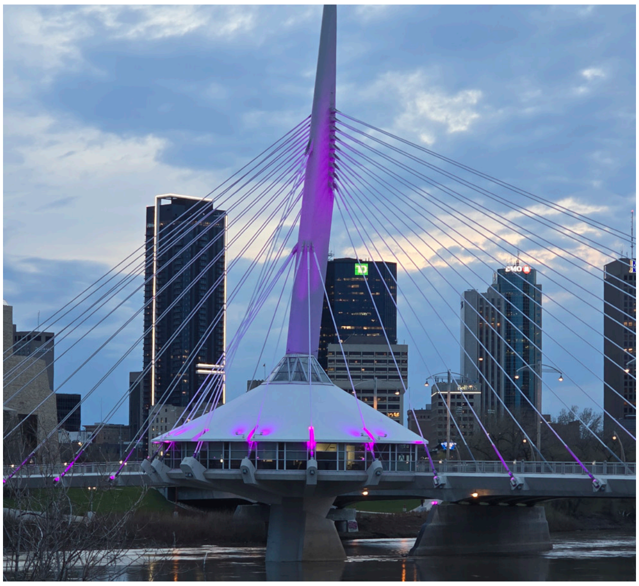
WORLD PH DAY 2024:

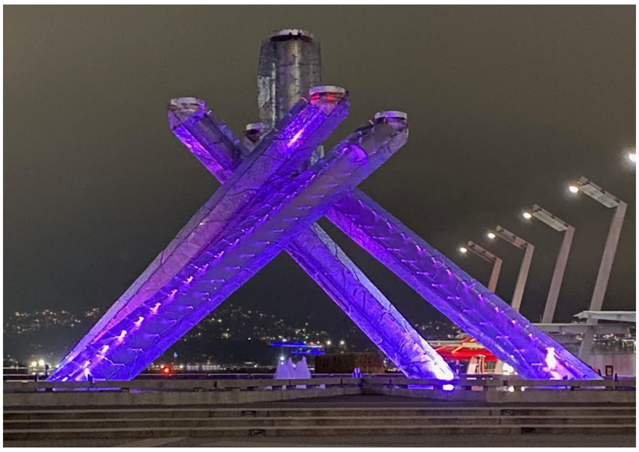
Advocacy and Awareness by PHA Canada and the Canadian PH Community

World PH Day 2024 marked an extraordinary effort by PHA Canada and the Canadian pulmonary hypertension (PH) community to raise awareness, advocate for better care, and celebrate the resilience of those affected by PH. This year's initiatives showcased a combination of public engagement, research dissemination, direct advocacy, and strategic media outreach, all aimed at making a significant impact on the lives of Canadians living with PH.

THE PAINT CANADA PURPLE CAMPAIGN

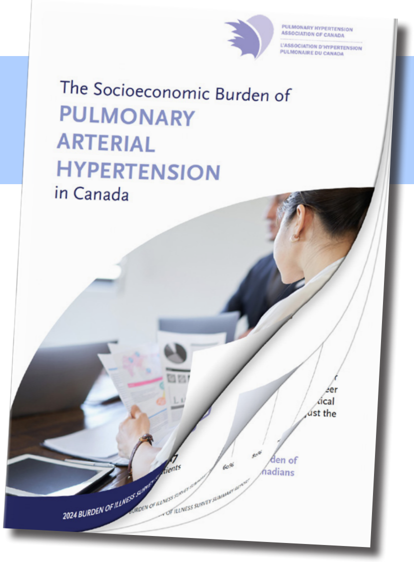
One of the standout features of World PH Day in Canada is the „Paint Canada Purple" campaign. Each year, this initiative encourages local community leaders to illuminate monuments in periwinkle purple on May 5th to honor those living with PH. This year, the campaign achieved remarkable success, with 23 landmarks across the country bathed in purple light and seven official proclamations recognizing May 5th as World PH Day. From coast to coast, the color purple became a beacon of hope and solidarity, bringing much-needed attention to this critical cause.





THE SOCIO-ECONOMIC BURDEN OF PULMONARY ARTERIAL HYPERTENSION (PAH)

PHA Canada, in collaboration with the Canadian VIGOUR Centre, conducted an in-depth survey to understand the socio-economic burden of pulmonary arterial hypertension (PAH). The findings revealed significant disruptions to the quality of life and major medical and socioeconomic impacts on patients. PHA Canada published a report aiming to raise awareness about the profound effects of PAH and advocating for better support and treatment options. The report can be found on PHA Canada's website: *www.phacanada.ca*



PULMONARY HYPERTENSION ASSOCIATION OF CANADA
L'ASSOCIATION D'HYPERTENSION PULMONAIRE DU CANADA

The Socioeconomic Burden of
PULMONARY
ARTERIAL
HYPERTENSION
in Canada

2024 BURDEN OF ILLNESS SURVEY SUMMARY REPORT

AWARENESS DAYS ON PARLIAMENT HILL

On May 6th and 7th, representatives of PHA Canada took their advocacy efforts to Parliament Hill in Ottawa. Their goal was to raise awareness among officials and parliamentarians about the challenges faced by Canadians with PAH and to urge prompt allocation of new funding for rare disease medicines through the National Strategy for Rare Disease Drugs.

The event included powerful speeches and personal stories from PAH ambassadors Jane and Jennifer, who shared their experiences and called for urgent action from federal and provincial governments to improve care for PAH patients. The efforts of PHA Canada were also recognized during Question Period in the House of Commons by Marie-France Lalonde, further elevating the awareness of PAH.

MEDIA OUTREACH

Effective media outreach played a pivotal role in amplifying the message of World PH Day 2024. PHA Canada engaged various media platforms to increase public understanding and support for PH initiatives. Highlights of this outreach included an op-ed by PHA Canada Board Member Dr. Sanjay Mehta in The Hill Times, a press release issued on May 6, 2024, and articles in Healthing and Benefits and Pensions Monitor discussing the severe impact of PAH and urging new funding for its treatment.

CONCLUSION

World PH Day 2024 was a testament to the dedication and resilience of the PH community in Canada. Through vibrant public displays, crucial research dissemination, direct advocacy, and strategic media engagement, PHA Canada successfully highlighted the needs and challenges of those living with PH. These efforts not only raised awareness but also fostered a stronger community and advocated for better healthcare policies. As we move forward, let's continue to build on this momentum and strive for a brighter future for all those affected by pulmonary hypertension.

CROATIA

A month of excitement is behind us, but the impressions are still settling. Since founding the Blue Wings Association, we have been actively trying to mark the International Day of Pulmonary Hypertension through various activities throughout May, like all other associations in the world. This year, we were everywhere, from the beginning of the month onwards. On May 11th, the Sava Marathon was held in Zagreb, raising awareness of our disease for the third year in a row. The excellent cooperation with selected runners always delights us. On May 27th, we held a press conference at the Croatian House of Breathing Foundation. The speakers were Fedža Džubur, a specialist internist of the Institute for Respiratory Insufficiency, Pulmonary Circulation Diseases and Lung Transplantation of the KBC Zagreb, doctor of family medicine Nataša Ban Toskić, Dr. president of KoHom- a (coordination of family medicine), and Zdenka Bradač, president of the Blue Wings association. During a press conference, we gave special importance to the fastest possible diagnosis, so that patients would lose as little time as possible until the correct diagnosis was discovered, because unfortunately, even today the numbers are devastating and people lose up to 3 years from the first symptom to establishing a diagnosis. Since therapies are available in Croatia, the key problem is how to reach patients as soon as possible. It was also mentioned that the prognosis for pulmonary hypertension is worse than for certain types of cancer.

The announcement aroused great public interest, and the news was reported by numerous portals, TV houses, and radio stations. After the announcement, Dr. Fedža Džubur received an invitation to be a guest on Z1 television in the 45-minute program “Hour of health,” where he had the opportunity to talk about the disease itself, available therapies, and the lung transplant program. in Croatia and other issues related to PH. Our dear friends from SU Argo contributed in their own way to the celebration of WPHD in Croatia, traveling 670 km in boats along the Mura, Drava, and Danube, proudly wearing our shirts. Breathe for PH! They covered the distance in just a few days! The same t-shirts marked our last activity of the year, the Plitvice Marathon, which left both runners and visitors breathless. For the first time, we collaborated with AK Plitvice on the only marathon run in the National Park. The media-covered this event and the popular marathon gathered over 1,500 runners in three days—one day specifically was dedicated to raising awareness about PH. The marathon brought together runners from 47 countries, and on this occasion, we share with you pictures from the beautiful Plitvice lakes!

Plućna hipertenzija, rijetka i teška bolest

BORNA ĆORIĆ 73. NA NAJNOVIJOJ ATP LJESTVICI

PANONSKA PUSTOLOVINA NERETVANSKOM LAĐOM

Glavni cilj i misija Panonske pustolovine je kontinuirano ukazivati na važnost očuvanja prirode i čovjekova okoliša.

CZECH REPUBLIC

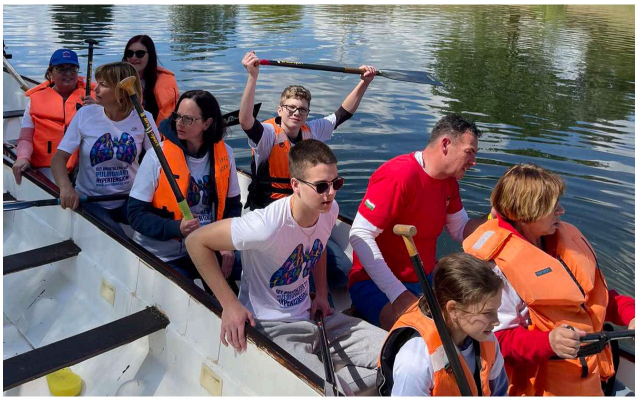
World Pulmonary Hypertension Day, which is observed annually on May 5th, has been commemorated in the Czech Republic since 2012 with the mission of increasing public awareness about this mysterious disease. This day is dedicated to raising awareness about pulmonary hypertension, a serious and often life-threatening condition that affects the pulmonary arteries and causes high blood pressure in the lungs. World Pulmonary Hypertension Day is traditionally highlighted by lighting significant buildings in Prague, Brno, and Olomouc in blue. The blue color is chosen because patients often experience blue lips due to the disease. Additionally, numerous articles in the media and TV appearances by Professor Jansa contribute to raising awareness. We also commemorated this important day together with our family members, friends, and companions. We celebrated World Pulmonary Hypertension Day by sharing, enjoying good company, and climbing Vyšehrad. Vyšehrad is one of the most famous and significant historical sites in Prague. It is not only a place of historical and cultural importance but also an oasis of tranquility in the midst of a bustling metropolis. Our visit to Vyšehrad provided us with a profound experience of Czech history, culture, and nature. Located on the right bank of the Vltava River and surrounded by beautiful parks and gardens, Vyšehrad is renowned not only for its history but also for its stunning views of Prague. This place is associated with the legendary Libuše and her faithful horse Šemík. We came together to climb this national cultural monument and experienced unforgettable views of Prague.

HUNGARY

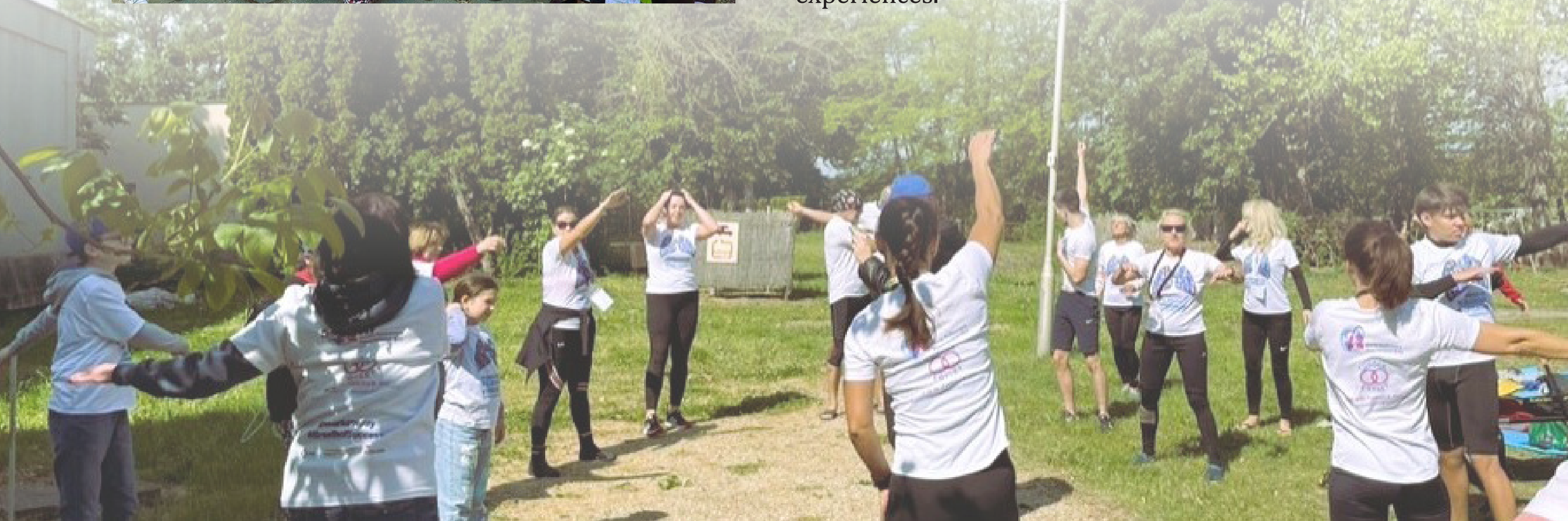
„GET BREATHLESS FOR PH" AT THE HUNGARIAN DRAGONBOAT CHAMPIONSHIP

Luckily, our sports ambassadors did not let us down this year either. Last year, a team ran for us around Lake Balaton. This year, on April 20, 2024, the 'Dunai Sárkányok' (Danube Dragons) competed for us on the Danube at the 13th Long-distance Hungarian Dragonboat Championship. The president and members of the Hungarian Dragon Boat Association supported our initiative to draw attention to our rare disease on the site of the race. At the all-day event, the Dunai Sárkányok entered in 3 races, with about 20 people, a mix of women and men, rowing distances of 8 and 4 kilometers.

We had the opportunity to set up our stand in a wonderful environment, on the Petőfi island in Baja, on the banks of the Danube. Our colorful t-shirts quickly attracted attention. In addition to handing out leaflets and information materials, interested people blew up balloons, and we checked their blood oxygen level and pulse before and after to see how they reacted. The approximately 1,000 competitors and fans present listened with interest to our stories about what a PH patient experiences everyday and what exertion means to them. Many people took our information materials with them. After the competition, they came back to our stand and told us that they now became aware of the feeling of heavy breathing, as they too had pushed themselves almost to the point of total breathlessness while finishing the race. We discussed that, although they regenerate quickly, unfortunately, this feeling is constant for those living with PH. We saw the smile of sympathy on their faces and answered their many questions tirelessly.



This event was also a pleasant break from the everyday environment for the members of the association. In the evening, we headed home recharged by the nice experiences.



RAISING AWARENESS TO PH IN CAMPAIGNS

At the end of April, we launched 2 campaigns. We sent press releases to the media, as a result of which several online platforms reported on World PH Day and our association. In the meantime, we also joined the PHA Europe campaign. We posted the visual elements translated into Hungarian about PH, the symptoms, the challenges of people living with PH, etc.


2024. MÁJUS 05.

Gyakori betegség ritka szövődménye - célzott vizsgálattal lerövidíthető a betegút

HUNGARIAN

SAJTÓKÖZLEMÉNY eLitMed

JOGKÉRÉS | MEGOSZTÁS

A tüdőben jelentkező tromboembólia után megmaradó tünetek ritka betegségre, kisvérköri magas vérnyomásra, pulmonális hipertóniára (PH) utalhatnak. A pontos diagnózis felállítása akár évekbe is telhet, célzott szívultrahang vizsgálattal azonban lerövidíthető ez az időszak, a kezelés pedig sokkal jobb életminőséget biztosíthat az érintetteknek.

Magyarországon a tüdőembólia gyakori, nagyjából évente mintegy tízezer embert érintő súlyos betegség. Megfelelő, időbeni kezeléssel az esetek többségében teljes lehet a gyógyulás, ha viszont a tüdőembólia után 3-6 hónappal is tüneteket észlel magán az érintett, mindenképpen javasolt kardiológus szakorvoshoz fordulni.

Ritkán, de előfordul, hogy krónikus szövődményként pulmonális hipertónia alakul ki, mely az általános tünetek, mint a légszomj, fáradékonyság, csökkent terhelhetőség, mellkasi fájdalom, krónikus köhögés miatt nehezen diagnosztizálható. Az esetek többségében túl sok idő, akár 1-2 év is eltelik, mire pontos diagnózis után megfelelő kezelést kaphat a beteg.

12TH NATIONAL MEETING FOR PH PATIENTS

On May 25, 2024, we managed to hold our National PH Patient meeting for the 12th time. All PH patients in the country were invited to the meeting. Our fellow patients could gain new knowledge by listening to the educational lectures of PH specialists. Such empowered patient programs help fellow patients to cooperate better with the treating physicians and to consent to medical reccomendations more willingly. Education promotes positive thinking and thus contributes to the development of a healthy lifestyle. About 60 people participated in the event.

The doctor-patient meetings are the best forums for pulmonary hypertension patients to meet fellow patients and exchange experiences. Within an organized framework, they can tell how the symptoms of the disease and the various treatments affected them. Fellow patients can learn a lot from these and draw strength from the spiritual support.

The meeting is also a good opportunity for doctors working in the field of PH to meet patients informally. In the framework of this, lectures are held on topics affecting the patients' everyday life. There is opportunity to ask questions and share concerns that affect the entire PH community.

Once again, we heard interesting and useful information on many topics.

We talked about blood thinners as an introduction. This was followed by useful diet tips. Once again, we distributed the Nutrition booklet that was supported by OrphaCare and PHA Europe.

Then a difficult topic followed: how to live with the medicine pump. A fellow patient told us about the difficulties of this through her personal experiences, and our treating doctor summarized the knowledge about the different devices and substances.
5 years after her previous presentation, the representative of NEAK (Hungarian National Health Fund) was able to come to present for us again and assured us that they will continue to strive for good cooperation despite the stressful circumstances.
To end the event, we had the opportunity to do breathing exercises led by our physiotherapist, exercises that are recommended for every day.

Recordings of the lectures will be uploaded to YouTube, so everyone can recall/watch them.

We really hope we can meet again next year!

Eszter Csabuda,
Tüdőér Egylet

www.tudoer.hu
https://www.facebook.com/tudoer.egylet

ISRAEL

PH Ambassador program

This past Sunday night, after many months of planning, the Israel Pulmonary Hypertension association was excited to launch the first of its PH Ambassador training sessions. The goal of this program is to create an extended team of people, ranging across the demographic of Israeli society and eventually also including professionals in the healthcare industry, who can serve as ambassadors for Pulmonary Hypertension. The role of these ambassadors, who were selected from among the members of the association and volunteered for this purpose, is to increase awareness of pulmonary hypertension among the general public and to bring patients awareness of all their rights on one hand, and on the other hand, to take care of all their needs—whether it is understanding the various medications and research that exist, or whether it is a deep understanding of how to properly manage this disease in order not to complicate their lives.

Our first session welcomed 10 participants - parents of children with PH and patients (newly diagnosed and older). The group came from great distances, even from the north and east of the country, traveling long hours just to arrive and build a new set of ambassadors for the diagnosed patients, and those who are not yet diagnosed.

PH Israel's CEO welcomed the group and explained the program goals, the potential, and the vision. After brief introductions, which became individual moments of inspiration, the group delved into some extensive learning. The introduction included discussions of the following: how the disease affects the blood vessels in different ways, its effect on the heart and lungs, the different symptoms, the target population, the great difficulty in diagnosis, especially when it comes to young women, the different drugs, the new studies to treat the disease, and the side effects as well as dealing with them. Additionally, it was discussed how we explain PH, how we address the concerns of new patients, what our roles are, how do they differ from medical teams, and the advice that can or can't be shared.

The conscious decision to limit the group size and ensure that each participant was able to ask questions, contribute their opinions, and be an active partner in the discussion, proved to be a huge success.

The evening raised a lot of thought-provoking ideas, patients new and old felt that they had learned so much and were excited and encouraged by the potential. The current group will continue with several meetings during which project goals will be defined and implemented. Some ideas, which came from our first meeting, and we hope to see implemented by our Ambassadors are: Ph Chat groups - Social get togethers for small groups of PH Patients, who live near each other, are of similar age or life stages, and who can support one another - the idea was to have a cup of coffee with someone who doesn't need an explanation as to why I have a an oxygen concentrator with me, why I can't walk too far to a restaurant, and what I have to deal with on a daily basis to manage; information packages for individual medical facilities - each ambassador would be able to distribute an information-about-PH package to their family health care provider and staff, that way enabling the reach to extend and be strengthened by the personal relationship with the patient and their family. We were very excited by the many ideas which came about. The participants felt empowered by the information shared with them, and we look forward to our next meeting and the impact we hope to have.

Another meeting held as part of our WPHD Ambassador program launch was a patient and medical team collaboration. Patient representatives accompanied CEO Aryeh Copperman to a meeting with representatives of the MSD medical company. The meeting created a space for the medical professionals to hear about the experience, challenges, and opinions of the patients and their families. The dialogue generated new understandings. Patients and their families felt that their opinions and experiences were heard, and the medical teams received answers to their questions and a deeper understanding. The association was able to advocate for PH Israel and strengthen the voice of the patients.

LATVIA

LATVIA CELEBRATES WORLD PULMONARY HYPERTENSION DAY WITH OXYGEN FESTIVAL

The main event of World Pulmonary Hypertension Day 2024 in Latvia was the Oxygen Festival on the 10th of May at the Main Building of Pauls Stradins University Hospital in Riga, the capital of Latvia. The festival's opening speeches were given by the Chair of Pauls Stradins Clinical University Hospital, Lauris Vidzis and Dr. med. professor Andris Skride, a popular cardiologist in Latvia and a main specialist in PH.

There were consultations for the event's participants about lung and heart health, which were given by well qualified physicians – pneumologists Dr.med. Dace Zentina, Dr. Zaiga Kravale, Dr. Rudolfs Vilde, cardiologist Dr. Santa Strazdina. Nurses performed express examinations for 104 on-site participants: measurements of glucose, cholesterol, hemoglobin, blood pressure, pulse oximeter, as well as with bioimpedance scales (to determine muscle, fat, body fluid, bones mass and their percentage distribution, which allows to calculate biological age and metabolic rate). PHA Latvia distributed information on PAH, clinical research, and exercise programs that can be done at home for PAH patients. Interviews were done with patients Ieva Araja and Linda Romanovska about everyday life, and travel experience with the illness. Physiotherapist Lina Puga led a 30-minute workout session for a more active part of participants. The partners of PHA Latvia provided oxygen cocktails in an Oxygen booth, and partners from "Meness aptieka", the biggest pharmacy retailer, distributed a healthy chocolate bar for every participant, and additionally, "Skriveru Partikas kombinats" distributed dairy candies. The moderator of the Oxygen festival was Ieva Plume, PHA Latvia's President. This time, we attracted five volunteers to help with the event - PHA Latvia members and medicine students. The Oxygen festival was organized by PHA Latvia in collaboration with Pauls Stradins Clinical University Hospital, where there is also a residence of the PH center of Latvia.

The event participants mainly were seniors, with the youngest participant being 23 years old and the oldest 87 years old. Participants came from the capital of Riga and areas near the capital, as well as from regions of Zemgale and Vidzeme.

The Oxygen festival gave PHA Latvia more visibility via mass media and stakeholders. As introduction to the event, PHA Latvia realized a social media campaign titled “Breathe together” from April on the society’s home page and Facebook account. The campaign started with a personal story of Ieva Plume on national TV broadcasting “Life hasn’t draft”. We achieved excellent media reaching results: two national radio stations announced the Oxygen festival on the morning news the 10th of May and LTV1, and the national TV channel put the event on the morning news headline. Ieva Plume gave an interview about the festival results to the national press agency LETA, and there was also an article regarding the festival. The total reach of the event on a mass media level was 95 000 by media monitoring data. We are proud of our motivated team, which performed such an eye-catching event.

Ieva Plume,
PHA Latvia President

http://www.phlatvia.lv
https://www.facebook.com/phlatvia/

NIGERIA

PHA Europe is always filled with immense pride and joy when we see our vibrant colors, lung symbols, and graphics making a real difference—helping patients and associations raise awareness and empower one another in the ongoing fight against pulmonary hypertension.

One standout moment comes from Nigeria, where the @walk4ph association project of the Cardiac Community used the WPHD visuals to create a powerful impact, adding another unforgettable memory to our collective album of success. These past victories pave the way for new triumphs, reminding us of the strength in our unity.

NORTH MACEDONIA

World Pulmonary Hypertension Day is becoming more and more famous in our country. With each event and with each celebration, we reach a new number of audiences and a growing awareness for PH. Not only for the patients and the team of our association, but also for all the people in our country, this now becomes a greater reality, and greater awareness of the presence of this disease in the world grows.

This year, for the third time, we organized a big event accompanied by a 5 km run for support and awareness for people with PH and in honor of all our lost PH fighters. We had a large audience, and despite the bad and hot weather conditions, the square of our city was full. All came to support the patients and to let them know that they are not alone, but that people are behind them.

The event was held for the second time in the city Gevgelija, the city of one of our fallen PH fighters, founders and president of our association, Gjurgica Kjaeva. She is well known in our region, and in a large part of our country, and one of the biggest reasons why people know about this disease, why they support us, why they are here with us, and why the patients have medicine.

Music groups, a folklore ensemble, and a hip hop dance group participated in the event. We conveyed the message through music and dance, to fight for a better future for the patients. And like every year, the runners did their job tirelessly and ran in honor of the PH patients and were got breathless.

This event will be continued every year, and it will grow every year in numbers to spread more awareness for PH.

PERU

We are „Llapan Kallpa," an Organization of Patients with Pulmonary Hypertension in Peru. We work to raise awareness, educate, and conduct workshops and talks about this rare disease that affects more than 1,000 Peruvians.

This year, as every year, we commemorate WORLD PULMONARY HYPERTENSION DAY with the theme "MULTIDISCIPLINARY CARE IN PULMONARY HYPERTENSION," addressing this disease comprehensively with the assistance of more than 50 doctors from various specialties. This important event was held at the Guillermo Almenara Irigoyen Hospital and was coordinated by the Pulmonary Hypertension Unit led by Dr. Fernando Villanueva Pérez. We welcomed some new patients, who participated for the first time.

ATENCIÓN MULTIDISCIPLINARIA EN HIPERTENSIÓN PULMONAR

HOSPITAL NACIONAL GUILLERMO ALMENARA IRIGOYEN

AUDITORIO DE NEFROLOGÍA

29 MAYO

09:30 A.M.

*DIRIGIDO A PROFESIONALES DE LA SALUD

ORGANIZAN:

Unidad de Hipertensión Pulmonar del Servicio de Cardiología del Hospital Nacional Guillermo Almenara Irigoyen

PORTUGAL

MEDIA BLITZ

Our commitment to raising awareness about Pulmonary Hypertension began on April 30th, marking the start of a multifaceted campaign aimed at shining a spotlight on the importance of **early diagnosis**. To reach audiences far and wide, we launched an intensive media blitz, using the power of television to amplify our message.

In addition to personal narratives, our media coverage included news clippings and feature segments dedicated to raising awareness about pulmonary hypertension. From morning shows to primetime news programs, we seized every opportunity to educate the public about the signs, symptoms, and risk factors associated with this often misunderstood condition. Through compelling storytelling and expert insights, we endeavored to dismantle misconceptions and empower viewers to take charge of their health.

MAY 1ST - MAKING A DIFFERENCE

On the 1st of May, the "Associação 20kms de Almeirim – Petanque section", organized a friendly match, uniting 36 participants from different clubs. By wearing our "Get Breathless For Pulmonary Hypertension" t-shirts, not only did they demonstrate their dedication to our cause, but also served as ambassadors for awareness within our community. Their efforts are a reminder that advocacy knows no bounds – the opportunities to spread awareness and make a difference are endless.

4TH AND 5TH OF MAY - WPHD

This year, we decided to commemorate World Pulmonary Hypertension Day in the city of Viseu, which was declared the European city of sport 2024, with a vast program of activities.

An inaugural tailormade Neon 5km walk (by Catarina from Viriathus Runners) held on Saturday evening, marked a milestone in our quest to raise awareness and support for all affected by PH. More than 100 participants (friends, family, patients) filled the historical streets of Viseu, with a vibrant energy, illuminating every step taken with their glow sticks, symbolizing a "beacon of HOPE" for a rare, but not invisible condition.

Our morning began with a burst of youthful energy, with lively dancing performed by children aged 8 to 16 (from Street Gymn). Following their lead, participants of all ages joined in a series of fun and accessible dance routines, expertly organized by Sara, ensuring that everyone, including patients could comfortably take part. As the morning progressed, a Pilates session took place, offering all participants the opportunity to nurture both their body and mind.

Two workshops were held – Dr. Pedro Saraiva led an excellent session on how to manage energy/effort levels during activities, providing many practical and useful tips for patients and their families. Our second workshop was held by a team of dedicated nurses from Hospital Garcia de Orta with essential knowledge on Basic Life Support. Through various demonstrations, our participants felt better prepared to handle unexpected situations. A special thanks goes out to “Sociedade Portuguesa de Cardiologia” for the donation of their childrens book on Basic Life Support to hand out to all the little ones present.

Cátia Rodrigues, the President of the Patients organization expressed gratitude to sponsors and collaborators who have supported the association throughout its remarkable 20 year journey. A symbolic award was offered as a token of heartfelt appreciation.

To conclude the day, family and friends gathered to share a meal, meet fellow PHighters for the first time, share experiences, find comfort, strength, and hope.

CREATIVE FUND RAISING EVENTS

On May 25th, a fun and memorable boat trip organized by our dedicated sponsor Rui Alves took place in Lisbon. Among various projects presented, our Patient Organisation had the opportunity to talk about pulmonary hypertension, highlighting the impact of this condition, the importance of early diagnosis, and the role of the Association in patients lives. All aboard contributed generously towards our fund-raising efforts.

May the 30th, was the inauguration date of an art exhibition featuring 32 paintings, created by a pulmonary hypertension patient during her isolation period amid the COVID19 pandemic in 2020. With an excellent attendance, it was more than just an art display, it was a celebration of resilience, creativity, and the enduring human capacity to find beauty and meaning even in the most challenging circumstances, demonstrating how creative expression can be a vital outlet for coping and healing. The proceeds go directly towards supporting our association's mission, as well as others.

As our awareness campaign continues, we remain committed to shed light on Pulmonary Hypertension and ensure that no one faces this condition alone. Thank you to everyone who has been a part of this journey.

SLOVAKIA

In April, we started running a social media campaign, commemorating World Pulmonary Hypertension Day. In addition, we invited the public to activities that took place during May. MSD, a pharmaceutical research company, helped us in spreading awareness throughout the campaign. We sent a graphic to the Ministry of Health's internal network, and the Health Committee also commemorated World PH Day with us. On the 6th of May, an interview on the topic of PAH with cardiologist Milan Luknár M.D. was broadcasted by TV JOJ. During May, the same topic was also covered by several other media outlets.

The campaign was supported by athletes wearing "Get breathless for PH" t-shirts during the ČSOB marathon, Wings for Live World, Urban Challange running competitions, as well as the two-day Vltava Run relay race. They caught the public's attention with photos of patients on their backs and the message "I run for you".

On the third weekend of May, three activities took place in the Turiec region as part of our "Get Breathless for PH" project. The entire project was supported by Ján Danko, the mayor of Martin city.

A total of 129 participants gathered in Martinské Hole Hotel. On the evening of May 17th, a seminar on pediatric pulmonary hypertension was held there. Martin Záhorec, the head of the Children's Cardio Center (DKC) in Bratislava, was the main speaker. His very interesting lecture was complemented by Katka Galátová, who is a regular participant of our activities, with the professional point of view of a DKC nurse. The story of a child patient named Otto was presented. The program finished with a lecture on international cooperation in the field of PAH from cardiologist Milan Luknár. At the end, there was a free debate about these topics.

On the next morning, 111 participants climbed Minčol peak (1364 m above sea level). It was the eighth symbolic climb of this kind in a row with the „I'll climb for you" motto. Most of the participants consisted of family members, doctors, health and rehabilitation nurses, friends, and event partners from AOP Orphan and MSD. They were also joined by enthusiasts from the local region, who were attracted by the idea of the event. The route was 11 km long, and the participants managed to finish it in about 5 hours. The age range of the participants varied as well. Zuzka, a patient with PAH, came with her family and her son Oskar, whom she gave birth to less than 4 months ago. Together, they joined the climb, although they did not quite manage to reach the top. However, the oldest participant at the age of 80 did finish the entire ascent without any problems. Some of the participants carried the photos of patients to draw attention to their serious illness. On the way, they met with people who were curious about this expedition and the pictures of the patients. This was a perfect opportunity to pass on the information about PH. Some of these passers-by joined us and climbed to the top for a good cause. The view, in all directions, was wonderful and after catching breath, some people even sang a couple of joyful songs. The participants of the ascent could enjoy not only their performance, but also receiving an award in the form of a medal.

In order to leave behind a legacy in individual regions, we have been planting trees with the „Plant your lungs" motto for the past couple of years. After climbing Minčol, we planted a chestnut tree in the center of Martin with the support of the regional TV Turiec. The tree is a symbol of earth, healthy lungs, which everyone, especially patients with PH, need. Next to the tree, on a board, we have left a message referring to our patient organization, and we hope and believe it will be helpful for someone searching for their correct diagnosis

We finished the day in the form of an informal evaluation of the event. The participants had a chance to win in a rich raffle. Tatiana Kubišová, the president of the Rare Diseases Association, presented her first children's book on rare diseases, gifting 20 autographed copies to children.

Overall, the feedback for the event was excellent, especially from the first-time attendees. These activities still enjoy a very high popularity, and we are all looking forward to the next year, this time in another region.

Iveta Makovníková

Združenie pacientov s pľúcnou hypertenziou, o.z.

SLOVENIA

For this year, the members of the association wanted to be heard even more. We have chosen the two largest Slovenian cities, Ljubljana and Maribor, as the city of awareness. Together with specialist doctors, we shed light on the problem of identifying and diagnosing PH to passers-by and numerous media, and presented important progress in the field of treatment of the disease itself; both surgically and therapeutically with a new biologic drug for PAH coming at the end of the year.

We also received support for our work from the mayors of both cities and many well-known Slovenians, who invited their followers to both events via Instagram. For a country with 2 million people, we were extremely pleased with the number of speakers. 10% of citizens received invitations on social networks. We are happy that we had guest appearances in the most watched morning shows of two of the largest Slovenian TV networks.

SUPPORT FROM THE MAYOR OF LJUBLJANA, ZORAN JANKOVIĆ: WE STRONGLY SUPPORT SUCH EVENTS IN THE MUNICIPALITY

The event “Every Breath Counts” was also visited by the mayor of Ljubljana, Zoran Janković. „We strongly support everything that benefits health in the municipality, and we especially like to host awareness events like this on Prešeren Square. We discussed with the members of the association that all similar awareness campaigns, including those with other actors, would be combined one day here on Prešeren Square,” said Ljubljana mayor Zoran Janković when he visited the stand of the Association for Pulmonary Hypertension.

THE CAMPAIGN “LET’S RECOGNIZE PULMONARY HYPERTENSION”

WITH THE SLOGAN “EVERY BREATH COUNTS” IN LJUBLJANA AND MARIBOR

Passers-by talked to patients with pulmonary hypertension and asked for advice on how to deal with symptoms—specialists from UKC Ljubljana (Dr. Polono Mlakar, Dr. Barbara Salobir, leaders in the field of pulmonary hypertension treatment in Slovenia) and pulmonologist Dr. Iztoka Fošnarič, from UKC Maribor.

THE POPULAR 6-MINUTE WALKING TEST WITH STRAWS AND A NOSE CLIP

Half of the visitors also tested themselves in an adapted six-minute walking test for healthy people, which makes it easier for the individual to imagine what it's like to breathe with the lungs of a patient with PH. The breathing of the patient is almost the same as the breathing of a healthy person with a nose clip and two straws in the mouth.

Testimonials from individuals who have tried the adapted 6-minute walk test:

„A really interesting test. I had the biggest crisis at the beginning of my walk, because I was not used to the feeling that there was simply no air. It's like I'm panicking. Then I tried to breathe more slowly and take really deep breaths. During the entire walking test, I could not fully exhale the air from my lungs and was therefore more and more out of breath. It is hard for me to imagine that a person could be active in sports at a top level with such a disease," sums up the personal experience of the six-minute walk test, Lena Gabrščček, Paralympian and captain of the volleyball team at the upcoming Olympic Games in Paris.

„I am very grateful for my healthy lungs, which allow me to do the test without any major problems. But I believe that not everyone is so lucky. That's why I think it's really important to raise awareness about pulmonary hypertension," says stand-up comedian and host Ana Maria Mitič.

„My wife has been diagnosed with pulmonary hypertension, and sometimes it's really illogical to me that she has to rest after walking, say, five meters. It's hard to put yourself in someone else's shoes if you don't have any problems yourself. With this test, you really get at least a little insight into what it's like to actually breathe for patients. Just moving is difficult without doing anything," said a passing visitor to the event, Edi, after the six-minute walking test.

„It is really extremely difficult. I had the biggest challenges with breathing air into my lungs. And when I think that here at the training ground we walked on a flat surface for only a few minutes... how difficult it must be for patients to do some activities, walking up a hill... I completely lost the feeling of breathing properly after just these few minutes," describes the experience of a sports journalist on RTV Slovenia Anže Bašelj.

IF YOU STILL HAVE DIFFICULTY BREATHING FOR A FEW MONTHS AFTER A PULMONARY EMBOLISM, SEE YOUR DOCTOR

Chronic thromboembolic pulmonary hypertension, which is one of the five types of PH, usually occurs in individuals after a pulmonary embolism. About 4% of patients are those in whom anticoagulant drugs do not dissolve all blood clots after a pulmonary embolism.

“IF WE WANT TO TREAT PATIENTS CORRECTLY, WE MUST FIRST RECOGNIZE PH” URGE THE BIGGEST EXPERTS IN THE FIELD OF CTEPH”

The number is small, so it is also very difficult to recognize these patients,” warns Dr. Polona Mlakar. „We must be aware that it is not normal for someone months or years after a pulmonary embolism to be unable to do the same activities as before the disease, is still short of breath and constantly tired,” she adds.

A visitor from Hungary confided in us at the stand that after suffering a pulmonary embolism, she has been noticing reduced capacity and difficulty breathing for at least two years. We suggested that she consult a specialist again and encouraged her to draw attention to the possibility of PH, as she is currently being treated for asthma.

PULMONARY THROMBENDARTERECTOMY IS NOW ALSO PERFORMED IN SLOVENIA

An important achievement in the treatment of chronic thromboembolic pulmonary hypertension (CTPH) in Slovenia is the initiation of an extensive and very demanding operation - pulmonary thrombendarterectomy. „Slovenian patients who were suitable for this type of surgery were previously sent to Vienna, where three to five were operated on annually,” explains Dr. Polona Mlakar. After training and monitoring all interventions at the Royal Papworth Hospital in Cambridge - this is the second largest center for such interventions in the world after San Diego in the USA - the first operative interventions at UKC LJ were performed under the guidance of proctor surgeon Choo Yen Ng in November 2022. „So far, we have performed 10 operations with the help of the proctor, and in February this year, the team with cardiac surgeon prof. dr. Jušem Kšelo, the first operation of this kind was performed completely independently, without the presence of a proctor,” describes Dr. Polona Mlakar.

WE WELCOMED NEW MEMBERS TO THE ASSOCIATION

At both events and through social networks, we invited patients to our association. For this purpose, we even recorded some videos to tell our stories with this disease and thus encourage other patients to connect with us. The aim of the association is not only public awareness, but also support, optimism, education and advice on how to live with the disease as best as possible. To our delight, we received quite a few calls and took a step forward towards our goal. Our society is now bigger with quite a few new members.

Tadeja Ravnik

Society for Pulmonary Hypertension of Slovenia

www.pljucna-hipertenzija.si

SPAIN ANHP

From the National Association of Pulmonary Hypertension, we have launched the campaign “Hipersensibilizate… somos Hipertensión Pulmonar (“Raise Awareness… We are Pulmonary Hypertension”) in honor of World Pulmonary Hypertension Day. As part of this campaign, we have carried out several outreach activities about Pulmonary Hypertension with the primary goal of sensitizing and raising public awareness about the disease, and the invisible disability it causes in those who suffer from it.

The campaign has had a significant impact, primarily on social media, reaching the widest possible audience. The dissemination was carried out in coordination with the PHA Europe (Pulmonary Hypertension Association of Europe), thus spreading knowledge about the disease, its main symptoms, the importance of treatment, and its impact on the daily lives of patients, their families, and/ or caregivers. Beyond scientific dissemination, we have undertaken various awareness-raising actions:

ON MAY THE 5TH, we illuminated several iconic landmarks in blue, the color associated with the disease, throughout Spain. We also shared a map with the locations of these landmarks: *https://www.google.com/maps/d/u/1/edit?mid=1gVxm7JZhwb7juwJ40cm-Q0oKW0VCj34&usp=sharing*

ON MAY THE 6TH, we carried out the awareness activity “Feel Pulmonary Hypertension.” In this activity, participants experience the reality of those with this condition by performing daily activities with added weight to feel the characteristic symptoms, such as shortness of breath, chest pressure, etc. This event was covered in the news by the Spanish public broadcaster, Radio Televisión Española (RTVE).

ON MAY THE 7TH, we organized the psycho-educational workshop “El peso de nuestra mochila: La HP” (“The weight of Our Backpack: HP”) aimed at pulmonary hypertension patients, conducted by Isabel Martínez, a psychologist from the organization.

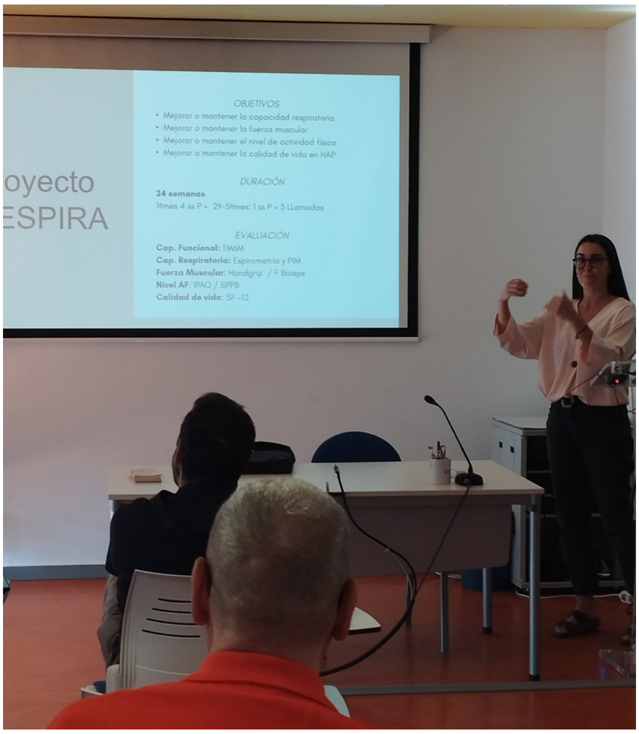
ALSO, ON MAY THE 7TH, Radio Jabato’s social action segment interviewed Eva García, a patient and president of ANHP Spain, Ricardo Cejudo, a caregiver of a pulmonary hypertension patient, Anahi Magali, a pulmonary hypertension patient, and Sara Heras, a social worker from ANHP. We raised awareness about the disease, symptoms, treatments, and its impact on the lives of those with PH and their caregivers.

ON MAY THE 16TH, we held an online workshop on the importance of breathing, meditation, and connecting with ourselves, titled “Los Secretos de la naturaleza”) (“The Secrets of Nature”).

ON MAY THE 24TH, we organized a talk on “The role of Nursing in Pulmonary Hypertension” with the nurse Inés Maria Castro Aramado from the specialized clinic for interstitial diseases and pulmonary hypertension at Regional Hospital of Málaga.

ON MAY THE 25TH AND THE 26TH, we held a gathering for pulmonary hypertension patients and caregivers in Málaga, where we enjoyed a recreational weekend promoting mutual aid, cohesion, and belonging to ANHP. We also took World PH Day to the streets of Málaga, (Andalusia, Spain).

ON MAY THE 27TH, we hosted “Let’s Talk about Pulmonary Hypertension,” organized in collaboration with the Heart Failure and Pulmonary Hypertension Unit at Puerta de Hierro University Hospital in Madrid, Spain. The event addressed the current situation of PH and its future perspective regarding challenges in diagnosis and new treatments, led by doctors Manuel Gómez bueno, head of the unit, and Dr. Cristina García Gallo, pulmonologist from the multidisciplinary unit. Isabel Martines and Carmen Crespo, psychologist and social worker from ANHP respectively, discussed the role of patient associations focusing on the importance of the multidisciplinary approach to the disease, the significance of mutual support among patients, and strategies for dealing with disability and work incapacity procedures. We also had Teresa García-Barredo, physiotherapist from our RESPIRA project, highlight the importance of respiratory exercises in PH patients, both theoretically and practically.



Throughout the campaign, we achieved disease awareness through digital written media as well as television and radio, contributing to a greater impact of our actions.

At ANHP, our objective is to raise awareness about the disease to educate and sensitize people about pulmonary hypertension, because only knowledge can lead to early diagnosis, preventing disease progression along with appropriate treatment, thus improving the prognosis of pulmonary hypertension. Raising awareness about pulmonary hypertension and its symptoms saves lives.

SPAIN FCHP

MAY 1

1st Day with Pulmonary Hypertension Patients at HU La Fe in Valencia!

We are grateful to Dr. Reyes, pulmonologist at the Pulmonary Hypertension Unit, the nursing team, and all the patients for sharing their knowledge and experiences. Together, we have created bonds of unity and solidarity with the foundation to address the needs of those living with PH! We continue to build this path of support and hope together.

MAY 4

1st Motorbike Rally LOS CARRASPERAS in Cantillana (Seville)

A massive motorbike rally in Cantillana (Seville), where over 1,000 people gathered to raise awareness of the disease and collect funds. We thank all the collaborators and the Cantillana city council for their participation.

MAY 3

Signing of the agreement "integral projects programs for the employment integration of pulmonary hypertension patients"

The Grafos Association and the Pulmonary Hypertension Foundation signed a collaboration agreement, starting an alliance aimed at providing job opportunities for people affected by this disease. This agreement opens the door for pulmonary hypertension patients to receive career guidance and training, allowing them to integrate into the labor market in high-demand sectors, thanks to the Integrales project.

MAY 3

Alexandra's Story on Canal Sur TV, the family of little Alexandra affected by Pulmonary Hypertension shares their story of overcoming challenges.

https://www.facebook.com/fundacionhp/videos/1111481256551952

MAY 4

Winners of the Inocente Inocente Award:

We won the Inocente Inocente Award with the help of Andrea Miguélez Ranz, Paratriathlete of the spanish team, two-time World Champion and European Champion, who will attend the Paris 2024 Paralympic Games. The monetary amount of this award is destined for a project at the Virgen del Rocío hospitals (Seville) and HU Ramón y Cajal (Madrid): „Virtual Reality in Cardiac Rehabilitation for Pediatric Patients with Pulmonary Hypertension."

MAY 5

Blue Illumination of the Most Iconic Buildings in Some Cities of Spain.

Here is the link to the map of these locations: *https://www.google.com/maps/d/u/0/edit?mid=1KlV0y3pGU4IP1HtnrwzEBYBdwaVUnlo&ll=39.867052645476%2C-4.539654999999997&z=6*

MAY 8

Our little Laia and Her Mom Are a True Example of Bravery and Struggle for Many Families Affected by #PulmonaryHypertension (#PH)!

They shared their story on @copealicante, spreading information about the disease and #WorldPHDay. What does Laia dream of doing if a cure is found? Don't miss the interview to find out. Here is the link: *https://www.facebook.com/fundacionhp/videos/1532243834300450*

MAY 9

Solidarity Race at Rafael Altamira Primary School in Alicante.

Spreading awareness about #PulmonaryHypertension is crucial, especially from a young age, so they know that there are people with serious health issues. That is what they do at Laia's school, raising awareness about the disease she has, and thus raising funds to find a cure.

MAY 9

Appearance on TV Andalucía Spreading Information About Salvador Calderón Barbero's Book „The Expert and Informed Patient."

He talks about the importance of the role of the expert patient. Salvador is affected by Pulmonary Hypertension, and the father of two girls with the disease. Here is the link: *https://www.facebook.com/fundacionhp/videos/1233958330924724*

MAY 10

Our President Enrique Carazo Shared Valuable Information About #PulmonaryHypertension on Hoy Por Hoy Cadena Ser Tenerife, in Honor of World Pulmonary Hypertension Day!

Don't miss this important interview! *https://www.facebook.com/fundacionhp/videos/1114043373047629*

MAY 10

We Held an Important Work Meeting with the Minister of Health of the Canary Islands Government, Ms. Esther Monzón.

Enrique Carazo Mínguez and Salvador Calderón participated in this meeting to alert about the problems of changes in our intravenous and subcutaneous medication. „What works for us and keeps us at low-risk profiles in our pathology, we DO NOT want changes," they emphasized during the meeting. They also pointed out that „behind a medication, there is a professional team providing support and coverage for patients with #PulmonaryHypertension."

MAY 11

What a Pleasure to Return to HU Doctor Negrín in Las Palmas de Gran Canaria With Pulmonary Hypertension Patients, Doctors, Nurses, and the Incredible Spanish Musical Group Efecto Pasillo!

We remain committed to educating, informing, and providing all possible support from the Pulmonary Hypertension Foundation. Thanks to everyone for making it possible!

MAY 19

When Sports and Solidarity Come Together, Incredible Moments Arise.

And that’s what happened last Sunday at the 1st Solidarity Skating Race for Pulmonary Hypertension. Organized by the Club Patín Parla with a great team like Ainara and Javi, it couldn’t have gone better. It was an impressive turnout, where unforgettable moments were created like the workshop „What does a child with Pulmonary Hypertension feel?” in which participants could experience and understand what patients with this disease experience. Besides fun skill and speed competitions, where we could see the level of all skaters, we saw their willingness to support Pulmonary Hypertension. We thank all the skaters and their families, the Parla City Council, the mayor Ramón Jurado Rodríguez, and the Casa del Deporte for their support and collaboration. All proceeds will go to Pulmonary Hypertension research. Thank you from the bottom of our hearts.

MAY 20

Training Days at Primary Health Care Centers Such as San Blas in Parla and San Hilario in Dos Hermanas (Seville), the latter was conducted by pulmonologist Remedios Otero Candelera, from the multidisciplinary team at Virgen del Rocío Hospital in Seville, along with expert patient Salvador Calderón. During the training, guidelines and tools were provided to primary care doctors to facilitate early diagnosis of pulmonary disease.

MAY 24

Webinar "The Transplant Process in Pulmonary Hypertension" Conducted by Dr. Pilar Escribano, Cardiologist at the #PH Unit of H.U. 12 de Octubre, Was a Great Success!

We had excellent participation, not only from patients and families, but also from numerous medical professionals. We are very proud of the work that was done.

Fundación Contra la
Hipertensión Pulmonar

"EL PROCESO DEL TRASPLANTE
EN LA
HIPERTENSIÓN PULMONAR"

Dra. Pilar Escribano
Cardióloga de la Unidad de Hipertensión
Pulmonar del HU 12 de Octubre

Día:
24 mayo 2024

Hora:
15:00- 16:00

Descubre el papel del trasplante en la lucha contra la hipertensión pulmonar! Únete a nuestra webinar para conocer los últimos avances y perspectivas en este campo vital de la medicina. . ¡No te lo pierdas!

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FORMATO ONLINE

SPAIN HPE-ORG

SOCIAL AWARENESS CAMPAIGN WORLD PH DAY 2024

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Hipertensión Pulmonar España ORG pacientes

MAY 5TH WORLD PH DAY 2024

In celebration of World Pulmonary Hypertension Day on May 5th, throughout the month of May, Hipertensión Pulmonar España Organización de Pacientes has joined the social media campaign launched by PHA Europe along with PHA and the entire global Pulmonary Hypertension community to raise awareness about this disease with the hashtags: *#WorldPHDay2024 #WeBreathUnited #WPHD #pulmonaryhypertension #UnitedForDiagnosis #awareness #patientcare #patientempowerment #UnitedForCures #PHAEurope #HipertensiónPulmonar*

Next to the international campaign, HPE-ORG has conducted its own campaign by replacing visual images with photographs of real patients and adding their own awareness and motivational phrases.

As usual, our organization has engaged our partners to take the lead in organizing activities to raise awareness of this disease in their respective cities. Thanks to this initiative, we have involved several city councils to illuminate buildings in blue across multiple locations in Spain, including: the Miner's Fountain in Guardo, the façade of the Municipal Palace in Tarragona, Torre dels vents and the Joven Kesse building, The Cathedra of the City Hall in Sant Feliu de Lobregat, the cultural center in Churriana de la Vega, Hospital Universitario Clínico San Cecilio in Granada, and the Santa Cruz Castle in Oleiros – A Coruña. Posters explaining the reason for the blue lighting to raise awareness about Pulmonary Hypertension have been placed around these illuminated buildings in all these cities.

Our members have also organized in-person activities in collaboration with other organizations. Carmen Buján, one of our colleagues, coordinated a Pilates class in partnership with Victory Gym in Guardo (Palencia) and held an exhibition on pulmonary hypertension, emphasising the importance of raising awareness for rare diseases like pulmonary hypertension at the Official School of Languages in Guardo, Palencia. Furthermore, in Salamanca, Janeise Meneses, another colleague, organized a Pilates class in collaboration with the AVIVA Foundation of Salamanca, displayed a banner supporting pulmonary hypertension at a football match organized by the same association, and set up an information booth about pulmonary hypertension at the Salamanca hospital Complex, attended by both doctors and nursing staff from the pulmonary unit. The AVIVA Foundation is a non-profit organization, which aims to defend the rights and improve the quality of life of people with disabilities and their families, aimed at inclusion and participation in the community, who collaborate with HPE-ORG, as we are united by disability. In our case organicFinally, our colleague Lorea Ullibarriarana, affected by idiopathic PH, in active employment, physiotherapist, once again dedicated the 5th of May to engage her patients by celebrating the WPHDay, dedicating her entire company to publicise and make PAH visible. She has carried out several handicrafts and activities in favour of PH together with the residents at the Domus Vi elderly care home in Lalín, Pontevedra.

We still have yet to hold a planned activity promoted by our colleague Silvia Velasco in Moraleja del Vino (Zamora), consisting of a Zumba class in favour of Pulmonary Hypertension which, due to scheduling problems, could not take place in May.

As we did last year, this year we have organized our General Assembly of members as part of World Pulmonary Hypertension Day. This year, we have moved to the city of Valencia where, in addition to holding our General Assembly, we have been able to enjoy a day of recreational activities all together.

Another activity conducted on May 22nd was the meeting of the Multidisciplinary Working Group on Pulmonary Hypertension Needs Sacyl III in the Autonomous Community of Castilla y León. The aim of this meeting was to continue identifying areas for improvement in the care of patients with Pulmonary Hypertension in this region.

Among the activities conducted exclusively through social media, the talk by Company Abogados on “Incapacity and Disability in PH” held on May 6th, was particularly noteworthy. In this talk, Jorge Company, a lawyer specializing in disability, explained the difference between incapacity and disability and provided several tips on how our medical reports should be written, using real reports as examples.

This year, for the first time, a craft challenge was launched on social media for World Pulmonary Hypertension Day, involving patients affected by PH throughout the month of May. Our fellow patient, María Chagartegui, managed to gather several well-known designers, streamers, and craft companies, who collaborated by providing several materials to be raffled among the participants. The challenge has generated great interest on social media, and several live performances have been broadcasted on YouTube.

With the support of the organizing association, the outcome has been a success, both in the organization and participation of the activities as well as their dissemination.

With this World Pulmonary Hypertension Day campaign, we have achieved significant growth across all our social media platforms, particularly in interactions with our posts. This shows that we have been able to reach a wide audience, who have gained direct insight of what it means to live with Pulmonary Hypertension.

Additionally, other organizations have echoed our posts and supported us on social media by sharing our content, thereby increasing visibility for this disease.

Lastly, we are extremely pleased with the results and the engagement of everyone who participated in multiple cities. Once again, we have successfully increased awareness about Pulmonary Hypertension by the end of May. More people now understand the significance and seriousness of this condition, and we have also raised visibility for our organization ant the services we provide.

SWEDEN

SUCCESSFUL CAMP FOR PH PATIENTS

In May, PAH Sweden held its sixth annual camp on the island of Fårö, north of Gotland, for patients with PH and their loved ones. This year, we introduced a new format focusing on discussions in smaller groups, and we are very pleased with the results. We also reduced the amount of information presented each day, allowing for more free time. During our days on Fårö, in addition to discussions and educational sessions, we enjoyed excursions and introductions to qigong, acupressure, and facial massage.

This year, we had a record number of 36 participants, including two PH nurses, who shared their wisdom and knowledge about PAH and CTEPH.

We would like to extend a big thank you to PHA Europe for sponsoring the camp!

UKRAINE PHA

#WorldPHDay2024 in Kyiv, UKRAINE

On May 18, a meeting of the patient community dedicated to World Pulmonary Hypertension Day #WorldPHDay2024 took place in Kyiv. The event was organized by PHA Ukraine with the support of the Pulmonary Hypertension Association Europe.

The event was filled with joyful embraces, emotional moments, and a meaningful program that made the day unforgettable for all participants. Various activities took place during the event, including yoga sessions, inspiring art therapy, and an introduction to Nordic walking. Yoga, which combines physical exercises, breathing techniques, and meditation, is an ideal choice for the rehabilitation of patients with pulmonary hypertension, helping to improve respiratory function, reduce stress levels, and enhance overall well-being.

Art therapy, in turn, provided participants with inspiration and joy, helping them express their feelings, relieve emotional tension, and boost self-esteem. The good mood and positive emotions that accompanied this event play an important role in supporting the mental health of patients with pulmonary hypertension.

Nordic walking is another accessible form of physical activity for patients with pulmonary hypertension.

The most important part of the meeting was the personal communication among the participants, which is so necessary in these challenging times. Patients had the opportunity to share experiences, support each other, and find new sources of inspiration for their ongoing battle with the disease.

The event was held in a picturesque location on the banks of the Dnipro River. This added a special atmosphere to our meeting, allowing participants to enjoy nature and fresh air.

Such meetings are extremely important for patients with pulmonary hypertension, as they provide an opportunity to feel supported, overcome emotional difficulties, and find new sources of joy and inspiration in their lives. They remind us that we are not alone in our struggle and that together we can overcome any challenges.

UKRAINE PHURDA

World PH Day - 10 years together!

The importance of supporting PH patients hugely increases in times of war. In such trying conditions, ensuring uninterrupted access to medication, psychological support, and information about treatment options are critical. Our association continues to do everything possible to ensure that PH patients receive the necessary care and support, regardless of the circumstances.

The World PH Day has become a special event for PH patients. Unfortunately, we met online again because of the war. We shared memories and challenges we have overcome together over the past 10 years. We also talked about new opportunities, such as the EPAP (European Patient Ambassador Program) – an online training program which had become available this year in Ukrainian. To make our meeting even more useful, we invited two doctors specializing in pulmonary hypertension in adults and children. Patients got a great opportunity to simply chat with doctors live and ask important questions. Authors of the most interesting questions received special gifts from our association. For those who were unable to join the meeting online, we made a recording, which we then posted on our YouTube channel.

We also developed a special information banner about pulmonary hypertension and told people on the street about pulmonary hypertension.

Our PH association is actively working to provide patients with the necessary medications and oxygen concentrators. We hold regular trainings for doctors and patients in order to improve medical literacy. This includes close cooperation with the Ministry of Health in the direction of procurement and expansion of the nomenclature of necessary medicines.

We work closely with ELF, EURORDIS, GAAPP and other organizations to improve the quality of life of PH patients. We have already signed memorandums with medical institutions and public organizations with the aim of popularizing information about PH in the Ukraine and abroad.

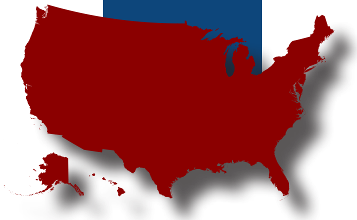
This year for the WPHD, patients with PH have received a wonderful gift - the EPAP educational program was launched in Ukrainian. We have worked very close with ELF over the past two years to make this possible. We believe that this tool will be a great help for patients and their families on the way to self-development and advocacy of their rights and interests. In order to popularize this program in the Ukraine, the representative of ELF and the doctor from the PH center participated in the evening TV program, where they talked about the importance and necessity of such an educational tool. During the program, they also discussed the peculiarities and symptoms of PH, as well as the importance of spreading information about the disease and the World PH Day celebration.

We are proud that the younger generation of PH patients is not afraid to talk about their disease. Children with PH took part in a photo flash mob for World PH Day wearing symbolic T-shirts.

Many thanks go out to PHA Europe for supporting our activities!

We call on all associations and organizations involved in the support of patients with pulmonary hypertension to help the Ukraine in this difficult time. Your support is extremely important to our community. By working together, we can provide our patients with the resources they need and help them overcome the challenges they face.

This year's World PH Day, which we are celebrating for the 10th time in the Ukraine, became special thanks to daily and dedicated work for the sake of patients. PHURDA continues to work on implementing new initiatives and raising awareness of this important topic.

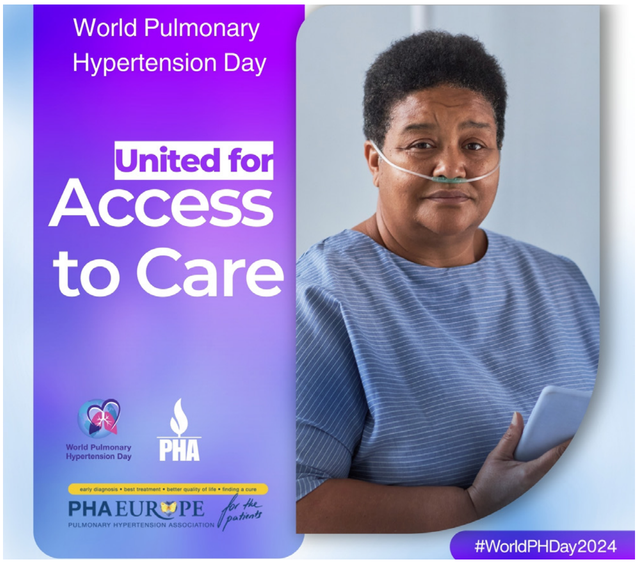


USA

PHA’S WORLD PH DAY HIGHLIGHTED GLOBAL DISPARITIES IN PH CARE

The Pulmonary Hypertension Association joined PHA Europe and other pulmonary hypertension organizations worldwide for World PH Day to raise awareness about PH and advocate for improved access to care. PHA shared information and resources under the subthemes “United for Early Diagnosis,” “United for Hope,” “United for Access to Care,” “United for the Patients,” and “United for a Cure.” These themes highlighted the importance of unity in addressing the diverse challenges faced by those living with this rare, life-threatening disease.

World PH Day celebrations in the U.S. commenced on May 4, with the AnMed Walk for Your Health in Anderson, South Carolina, held in memory of Tina Lisenby, a PH patient and former support group leader. The walk brought together people with PH, caregivers, families and health care professionals to raise awareness and funds for programs that support PHA and the PH community.



PHA Europe’s “United for access to care” World PH Day graphic. This is one of many graphics shared on PHA’s social media channels throughout the month of May.

IMPROVING ACCESS TO CARE IN THE U.S.

Of the themes shared for World PH Day, “United for Access to Care” resonated the most with U.S. and international PH communities. PHA actively addresses disparities in health care access through its Pulmonary Hypertension Care Centers program, which celebrates its 10th anniversary this year. Accredited PHCCs can enroll patients in the PHA Registry, which collects data to evaluate outcomes for those with PH. Over 70 PHA-accredited care centers participate in the registry, providing real-world data that has improved care standards.

The PHA Registry celebrated a significant milestone for World PH Day, exceeding 3,000 enrolled patients. PHA continues to expand the PHCC program, with plans to include pediatric programs and establish care centers in underserved areas.

U.S. ADVOCATES PUSH FOR IMPROVED ACCESS TO SUPPLEMENTAL OXYGEN

PHA hosted virtual legislative visits throughout May, starting on World PH Day. Advocates discussed critical legislation with lawmakers, including the Supplemental Oxygen Reform Act. This act removes supplemental oxygen from Medicare’s competitive bidding process, making oxygen and related equipment more accessible. (Medicare is the U.S. government’s health insurance program primarily for those 65 and older.) The SOAR Act also seeks to improve access to specialist care by adjusting the pay rate for respiratory therapy services.

The advocacy campaign was a success. From May 5 to June 5, advocates held over 30 meetings with senators, representatives and legislative staff, who responded positively to the new bill. The SOAR Act continues to gain support in both chambers of Congress.

GLOBAL STORIES ADDRESSING ACCESS TO CARE

PHA also shared stories from people with PH around the world on its social media channels, highlighting their experiences with access to care in their respective countries.

- ACCESS GAPS IN AUSTRALIA: Erin Baker from Sydney emphasized the necessity of care for all PH patients. “Pulmonary hypertension is so intricate and requires specialized treatments that many people in Australia, and worldwide, don’t have equal, ready and adequate access to,” said Baker, who has idiopathic pulmonary arterial hypertension. Her story highlighted health care access disparities, especially in vast countries like Australia.

- CHALLENGES IN CHILE: Teresa Muller, director of the Chilean Pulmonary Hypertension Association, highlighted the lack of specialists and referral systems. Delayed diagnoses often lead to significant disease progression before patients receive proper care. “Advocating for the specialization of doctors could lead to more accurate diagnoses and faster, more effective care for our citizens,” said Muller, who has PH. She also stressed the need for a patient registry for comprehensive care and follow-up.

- ADVOCACY IN NIGERIA: Ayotunde Omitogun from Lagos, Nigeria, shared her self-advocacy journey and challenges in managing PH. Without adequate guidance from health care providers, Omitogun relied on her research and advocacy to receive the necessary treatment. Determined to improve the situation, she co-founded “Yo Sabi PH,” an organization dedicated to raising PH awareness. “Managing treatment barriers and cultural stigmas is a constant challenge,” said Omitogun.

People with PH, their families and health care professionals gathered for the AnMed Walk for Your Health in Anderson, South Carolina.

World PH Day 2024 underscored the global commitment to improving the lives of those affected by PH by highlighting the importance of guaranteeing accessible treatment and providing comprehensive care worldwide. This initiative celebrated the progress made and emphasized the ongoing work needed to ensure that every person with PH can lead a healthy, fulfilling life.

U.S. advocates from various states met virtually with lawmakers to gain support for the SOAR Act.

Art gallery
Podcast Studio
Vittorio's Coffee bar
Reception desk
Live presentations
Recorded presentations
Industry partners
PH associations
Nurse & Poster room
Training session room

• Media clippings •

Austria

RHEUMATOLOGIE

Entgeltliche Einschaltung

Pulmonal arterielle Hypertonie

Eine bedrohliche Komplikation bei rheumatischen Multisystemerkrankungen

Bis zu 20 % der Patient:innen mit systemischer Sklerose entwickeln eine pulmonal arterielle Hypertonie (PAH). Da eine frühzeitige Diagnose und Therapie die Prognose der PAH verbessern können, empfiehlt sich bei SSc-Patient:innen ein regelmäßiges Screening auf PAH, wie Priv.-Doz. Dr. Hans-Peter Kiener im Interview mit UNIVERSUM INNERE MEDIZIN festhält. Redaktion: Dr.in Eva Maria Riedmann

Priv.-Doz. Dr. Hans-Peter Kiener
Klinische Abteilung für Rheumatologie, Universitätsklinik für Innere Medizin III, Medizinische Universität Wien

UNIVERSUM INNERE MEDIZIN: Welche Bedeutung hat die pulmonal arterielle Hypertonie als Komplikation bei Kollagenosen?

Priv.-Doz. Dr. Hans-Peter Kiener: Wir verstehen die Kollagenosen als systemische Autoimmunerkrankungen, bei denen ein fehlgeleitetes Immunsystem Schäden an verschiedenen Organen hervorruft. Die organschädigende Wirkung tritt in Form einer Entzündung, einer Fibrose oder als Vaskulopathie in Erscheinung.

Gibt es spezielle Screening-Methoden für PAH bei Patient:innen mit Kollagenosen?

Danke für das Gespräch!

- **Mit fast 1.000 Teilnehmer:innen** war die Jahrestagung der Österreichischen Gesellschaften für Pneumologie und Thoraxchirurgie ein voller Erfolg.
- **Wissenschaftliche Vorträge und Fallpräsentationen** wurden interdisziplinär diskutiert.
- **Hands-on-Kurse und Workshops** boten die Möglichkeit zur praktischen Wissensaneignung.

SHORT CUT

47. Jahrestagung der Österreichischen Gesellschaft für Pneumologie

„Lunge am Limit" – ein Überblick

Von 23. bis 25. Oktober 2023 fand in Graz die 47. Jahrestagung der Österreichischen Gesellschaft für Pneumologie (ÖGP) und der Österreichischen Gesellschaft für Thoraxchirurgie (OGTC) statt. Mit fast 1.000 Teilnehmer:innen zählt der Kongress zu den meistbesuchten und erfolgreichsten Tagungen der Gesellschaft.

Reges Interesse an aktuellen und vielseitigen Fragestellungen

Hands-on-Kurse

Update Lungenfunktion 2023

Dr. Martin Trinker, MSc

Weiter auf Seite 72 ▶

Der Kardiopulmonale Arbeitskreis der ÖKG stellt sich vor

ÖKG-Arbeitsgruppen-- Der Schwerpunkt des kardiopulmonalen Arbeitskreises (KP-AG) liegt in der Erfassung von Epidemiologie, Pathogenese, Früherkennung, Diagnose und Therapie von kardio-pulmonalen Erkrankungen, mit speziellem Interesse für Lungengefäßerkrankungen.

ASSOC. PROF. PRIV. DOZ. NIKA SKORO-SAJER (AG-LEITERIN), AP. PROF. PRIV.-DOZ. DR. CHRISTIAN GERGES (AG-LEITER-STV.)

Die KP-AG möchte mehr Awareness für pulmonale Hypertension schaffen.

Aus- und Fortbildung, Forschung

Die Amyloidose-Gruppe des kardiopulmonalen Arbeitskreises rund um Prof. Johannes Kastner.

Hausärzt:in extra

Leitthema Atemnot ...

... beim 23. Consensus Meeting der AG Herzinsuffizienz

Am 27. Jänner 2024 fand das 23. Consensus Meeting der Arbeitsgruppe Herzinsuffizienz der Österreichischen Kardiologischen Gesellschaft (ÖKG) in Wien statt.* Fünf Fachvorträge behandelten das Thema Atemnot bei Herzinsuffizienz, moderiert von Univ.-Doz. Dr. Martin Hülsmann, AKH Wien, und Priv.-Doz. Dr. Deddo Mörtl, Universitätsklinikum St. Pölten.

Notfallmedizin

Weitere Vorträge

Die anderen Themen des Consensus Meetings im Überblick:

NACHBERICHT

* 23. Consensus Meeting der Arbeitsgruppe Herzinsuffizienz der ÖKG, 27. Jänner 2024, Novotel Wien Hauptbahnhof.

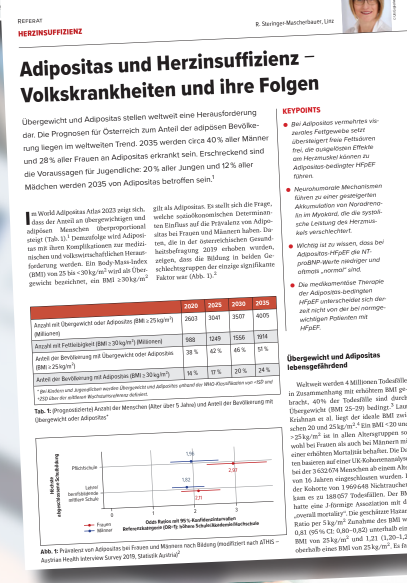
Pneumo trifft Kardiologie: Atemnot als interdisziplinäres Symptom

Oft können Symptome wie Atemnot nicht nur auf Probleme der Lunge, sondern insbesondere auch auf Herzerkrankungen hindeuten. Prim. Univ.-Prof. Dr. Julia Mascherbauer, Klinische Abteilung für Innere Medizin 3, UK St. Pölten, berichtet über häufige kardiologische Erkrankungen und deren innovative Therapiemöglichkeiten.

Von Mag. Katharina Hoffmann

Innovationen gibt es in der interventionellen Klappenbehandlung einschließlich der Haltbarkeit des interventionellen Aortenklappenersatzes (TAVI) und der Daten zur interventionellen Mitralklappenreparatur mit dem MitraClip.

„Pneumo trifft Kardiologie", Vortrag im Rahmen der 11. Pneumo-Aktuell-Tagung der Österreichischen Gesellschaft für Pneumologie (ÖGP), Wien, 27.1.24



REFERAT

HERZINSUFFIZIENZ

R. Steringer-Mascherbauer, Linz

Adipositas und Herzinsuffizienz – Volkskrankheiten und ihre Folgen

Übergewicht und Adipositas stellen weltweit eine Herausforderung dar. Die Prognosen für Österreich zum Anteil der adipösen Bevölkerung liegen im weltweiten Trend. 2035 werden circa 40 % aller Männer und 28 % aller Frauen an Adipositas erkrankt sein. Erschreckend sind die Voraussagen für Jugendliche: 20 % aller Jungen und 12 % aller Mädchen werden 2035 von Adipositas betroffen sein.[1]

Im World Adipositas Atlas 2023 zeigt sich, dass der Anteil an übergewichtigen und adipösen Menschen überproportional steigt (Tab. 1).[1] Demzufolge wird Adipositas mit ihren Komplikationen zur medizinischen und volkswirtschaftlichen Herausforderung werden. Ein Body-Mass-Index (BMI) von 25 bis <30 kg/m² wird als Übergewicht bezeichnet, ein BMI ≥30 kg/m² gilt als Adipositas. Es stellt sich die Frage, welche sozioökonomischen Determinanten Einfluss auf die Prävalenz von Adipositas bei Frauen und Männern haben. Daten, die in der österreichischen Gesundheitsbefragung 2019 erhoben wurden, zeigen, dass die Bildung in beiden Geschlechtsgruppen der einzige signifikante Faktor war (Abb. 1).[2]

KEYPOINTS

- Bei Adipositas vermehrtes viszerales Fettgewebe setzt übersteigert freie Fettsäuren frei, die ausgelösten Effekte am Herzmuskel können zu Adipositas-bedingter HFpEF führen.
- Neurohumorale Mechanismen führen zu einer gesteigerten Akkumulation von Noradrenalin im Myokard, die die systolische Leistung des Herzmuskels verschlechtert.
- Wichtig ist zu wissen, dass bei Adipositas-HFpEF die NT-proBNP-Werte niedriger und oftmals „normal" sind.

Abb. 1: Prävalenz von Adipositas bei Frauen und Männern nach Bildung (modifiziert nach ATHIS – Austrian Health Interview Survey 2019, Statistik Austria)[2]

Lungenhochdruck ist gar nicht so selten

Der 5. Mai ist Tag des Lungenhochdrucks. Fachleute bezeichnen diesen als pulmonale Hypertonie.

M. ANMASSER, M. KOUDELKA

Menschen mit Lungenhochdruck fühlen sich häufig rasch erschöpft und energielos. Foto: LariBat/Shutterstock

Bislang galt der Lungenhochdruck als seltene Erkrankung. Das heißt, dass nicht mehr als fünf von 10.000 Menschen davon betroffen sind. Einer Studie zufolge liegt die geschätzte Prävalenz bei 50 bis 70 Millionen Erkrankten. Das bedeutet also, dass mittlerweile fast ein Prozent der weltweiten Bevölkerung an Lungenhochdruck leidet und die Erkrankung somit nicht mehr als selten betrachtet werden sollte. Häufig ist die Diagnose schwierig und langwierig. In den USA beispielsweise vergehen durchschnittlich zwei bis drei Jahre bis zur Diagnosestellung, 75 Prozent der Betroffenen sind bei der Erstdiagnose bereits fortgeschritten erkrankt. Weiters geht eine pulmonale Hypertonie, die in Verbindung mit Herz-Kreislauf- sowie Atemwegserkrankungen auftritt, mit einer deutlich erhöhten Erkrankungsrate und Sterblichkeit einher. Das unterstreicht, wie wichtig es ist, ein Bewusstsein für dieses Krankheitsbild zu schaffen. Zu den Symptomen zählen unter anderem Atemnot bei Anstrengung sowie beim Vorwärtsbeugen, rasche Erschöpfung, Herzrasen sowie Abhusten von bluthaltigem Sekret.

Deutsche Gesellschaft für Pneumologie und Beatmungsmedizin (DGP) II

Quo vadis, PH?

Einen Blick in die Zukunft der Pneumologie wagte Prof. Dr. Werner Seeger aus Gießen in seinem Vortrag im Rahmen des Jahreskongresses der Deutschen Gesellschaft für Pneumologie und Beatmungsmedizin (DGP) am Beispiel der pulmonalen Hypertonie (PH).

Von Mag. Nicole Bachler

„Die verschiedenen Formen der PH betreffen mehr als 100 Millionen Menschen weltweit. Gegenwärtig werden vasoaktive Therapien bei PH eingesetzt, die darauf abzielen, eine Vasodilatation zu erreichen", so Prof. Dr. Werner Seeger, Vorstandsvorsitzender und Sprecher des Deutschen Zentrums für Lungenforschung (DZL), Gießen, Deutschland.

ILD-PH

Epigenetische Analysen

5.Mai:Welt-Lungenhochdruck-Tag

Kurzatmig? Müde? Schwindlig? Nicht alles ist Frühjahrsmüdigkeit. Achten Sie auf die Symptome!

Achten Sie auf die Symptome! Eine Früherkennung ist wichtig. Experten verhelfen zu mehr Lebensqualität für Betroffene. Informieren Sie sich auf lungenhochdruck.at

Lungenhochdruck oder genauer gesagt der pulmonale arterielle Lungenhochdruck (PAH) ist eine seltene Erkrankung mit unspezifischen Anzeichen. Die fortschreitende Erkrankung, die durch eine Verengung der Lungengefäße gekennzeichnet ist, kann insbesondere die rechte Herzhälfte schädigen und unbehandelt zum Rechtsherzversagen führen. PAH kann in jedem Alter auftreten und trifft mehr Frauen als Männer. Pro einer Million Menschen sind zwischen 48 und 55 Personen betroffen.

Unspezifische Symptome

Viele Menschen schenken den … prägten Symptomen zudem keine Aufmerksamkeit, da diese unspezifisch, also nicht typisch für genau diese Erkrankung sind. Das kann dazu führen, dass die Erkrankung erst in einem späten Stadium erkannt wird.

Bei Verdacht

Ein rasches Handeln ist aber entscheidend für die Lebensqualität und -erwartung der Betroffenen. Wichtig ist daher, die Zeichen der PAH so früh wie möglich zu erkennen und rechtzeitig mit einer entsprechenden Therapie zu beginnen. Sprechen Sie mit Ihrer Ärzt*in, wenn Sie folgende Symptome beobachten (siehe Grafik).

In das Expertenzentrum

Da Diagnose und Behandlung der Erkrankung Expertise und eine spezifische Infrastruktur benötigen, raten Fachärzt*innen, Patient*innen bei Verdacht auf eine PAH an ein Expertenzentrum zu überweisen.

Unterstützung

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WERBUNG

Atemnot? Es könnte Lungenhochdruck sein.

Sie bemerken Atemnot? Es steckt keine bekannte Krankheit wie Asthma oder COPD dahinter? Dann könnte vielleicht pulmonal arterielle Hypertonie (PAH) die Ursache sein – eine seltene, schwere Unterform von Lungenhochdruck, von der schätzungsweise 500 Menschen in Österreich betroffen sind.[1] Verengte Blutgefäße in der Lunge führen zu erhöhtem Blutdruck in den Lungengefäßen, der lebensbedrohlich werden kann.[2]

• Die Anzeichen (z.B. Atemnot, rasche Ermüdung, Brustschmerzen) sind nicht eindeutig einer Erkrankung zuzuordnen.[3] Daher ist es besonders wichtig, das abzuklären. Denn bleibt PAH unentdeckt, kann es zu Rechtsherzversagen kommen.[1] Es gibt Menschen mit erhöhtem Risiko, zum Beispiel mit bestimmten Vorerkrankungen wie angeborene Herzfehler oder Bindegewebserkrankungen. Bei dieser Patientengruppe ist der Verlauf der PAH oft schwerwiegend.[1]

Symptome bei ärztlichen Kontrollen erkennen. ©Johnson&JohnsonServicesInc.2023

Informationen

Lungenhochdruck.at oder im Janssen-Patientenratgeber unter dem QR-Code.

PATIENTENRATGEBER

[1] Humbert M et al. Eur Heart J 2022; 00:1-114. [2] Gailè N et al. Eur Heart J 2010; 31(17):2080-2086. [3] Frost A et al. Eur Respir J. 2019;53(1):1801904.

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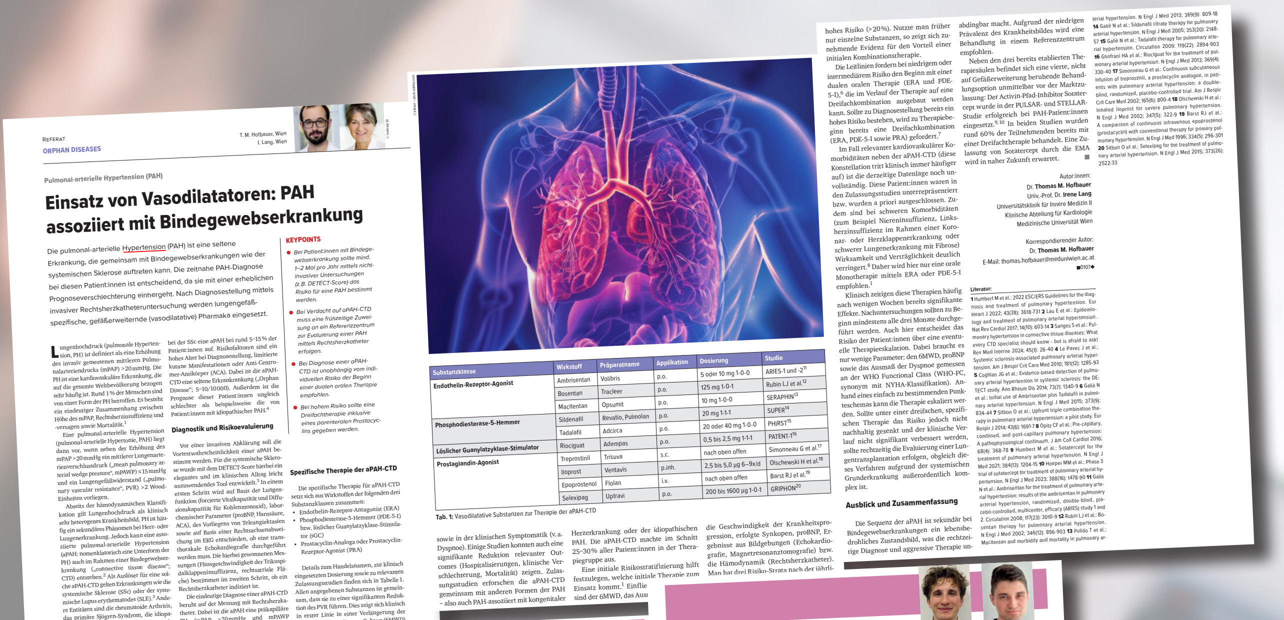


Referat
ORPHAN DISEASES

T. M. Hofbauer, Wien
I. Lang, Wien

Pulmonal-arterielle Hypertension (PAH)

Einsatz von Vasodilatatoren: PAH assoziiert mit Bindegewebserkrankung

Die pulmonal-arterielle Hypertension (PAH) ist eine seltene Erkrankung, die gemeinsam mit Bindegewebserkrankungen wie der systemischen Sklerose auftreten kann. Die zeitnahe PAH-Diagnose bei diesen Patient:innen ist entscheidend, da sie mit einer erheblichen Prognoseverschlechterung einhergeht. Nach Diagnosestellung mittels invasiver Rechtsherzkatheteruntersuchung werden lungengefäß-spezifische, gefäßerweiternde (vasodilatative) Pharmaka eingesetzt.

KEYPOINTS

- *Bei Patient:innen mit Bindegewebserkrankung sollte mind. 1–2 Mal pro Jahr mittels nicht-invasiver Untersuchungen (z.B. DETECT-Score) das Risiko für eine PAH bestimmt werden.*
- *Bei Verdacht auf aPAH-CTD muss eine frühzeitige Zuweisung an ein Referenzzentrum zur Evaluierung einer PAH mittels Rechtsherzkatheter erfolgen.*
- *Bei Diagnose einer aPAH-CTD ist unabhängig vom individuellen Risiko der Beginn einer dualen oralen Therapie empfohlen.*
- *Bei hohem Risiko sollte eine Dreifachtherapie inklusive eines parenteralen Prostacyclins gegeben werden.*

Lungenhochdruck (pulmonale Hypertension, PH) ist definiert als eine Erhöhung des invasiv gemessenen mittleren Pulmonalarteriendrucks (mPAP) >20 mmHg. Die PH ist eine kardiovaskuläre Erkrankung, die auf die gesamte Weltbevölkerung bezogen sehr häufig ist. Rund 1 % der Menschen sind von einer Form der PH betroffen. Es besteht ein eindeutiger Zusammenhang zwischen Höhe des mPAP, Rechtsherzinsuffizienz und -versagen sowie Mortalität.[1]

Eine pulmonal-arterielle Hypertension (pulmonal-arterielle Hypertonie, PAH) liegt dann vor, wenn neben der Erhöhung des

bei der SSc eine aPAH bei rund 5–15 % der Patient:innen auf. Risikofaktoren sind ein hohes Alter bei Diagnosestellung, limitierte kutane Manifestationen oder Anti-Centromer-Antikörper (ACA). Dabei ist die aPAH-CTD eine seltene Erkrankrankung („Orphan Disease"; 5–10/10 000). Außerdem ist die Prognose dieser Patient:innen ungleich schlechter als beispielsweise die von Patient:innen mit idiopathischer PAH.[4]

Diagnostik und Risikoevaluierung

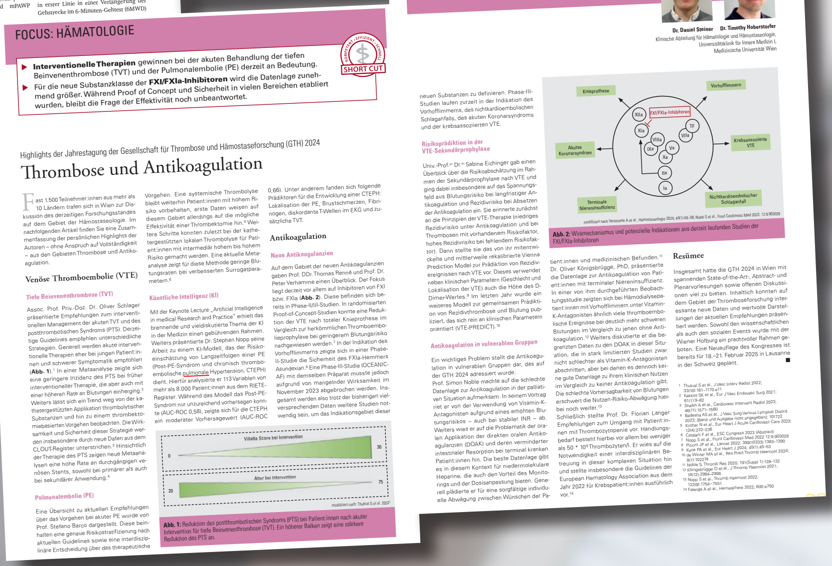
- Endothelin-Rezeptor-Antagonist (ERA)
- Phosphodiesterase-5-Hemmer (PDE-5-I) bzw. löslicher Guanylatzyklase-Stimulator (sGC)
- Prostacyclin-Analoga oder Prostacyclin-Rezeptor-Agonist (PRA)

Details zum Handelsnamen, zur klinisch eingesetzten Dosierung sowie zu relevanten Zulassungsstudien finden sich in Tabelle 1. Allen angegebenen Substanzen ist gemeinsam, dass sie zu einer signifikanten Reduktion des PVR führen. Dies zeigt sich klinisch in erster Linie in einer Verlängerung der Gehstrecke im 6-Minuten-Gehtest (6MWD)

Tab. 1: Vasodilatative Substanzen zur Therapie der aPAH-CTD

sowie in der klinischen Symptomatik (v. a. Dyspnoe). Einige Studien konnten auch eine signifikante Reduktion relevanter Outcomes (Hospitalisierungen, klinische Verschlechterung, Mortalität) zeigen. Zulassungsstudien erforschen die aPAH-CTD gemeinsam mit anderen Formen der PAH – also auch PAH-assoziiert mit kongenitaler Herzerkrankung oder der idiopathischen PAH. Die aPAH-CTD machte im Schnitt 25–30% aller Patient:innen in der Therapiegruppe aus.

Eine initiale Risikostratifizierung hilft festzulegen, welche initiale Therapie zum Einsatz kommt.[1] Einflie… sind der 6MWD, das Aus…



FOCUS: HÄMATOLOGIE

- **Interventionelle Therapien** gewinnen bei der akuten Behandlung der tiefen Beinvenenthrombose (TVT) und der Pulmonalembolie (PE) derzeit an Bedeutung.
- Für die neue Substanzklasse der **FXI/FXIa-Inhibitoren** wird die Datenlage zunehmend größer. Während Proof of Concept und Sicherheit in vielen Bereichen etabliert wurden, bleibt die Frage der Effektivität noch unbeantwortet.

SHORT CUT

Highlights der Jahrestagung der Gesellschaft für Thrombose und Hämostaseforschung (GTH) 2024

Thrombose und Antikoagulation

Fast 1.500 Teilnehmer:innen aus mehr als 10 Ländern trafen sich in Wien zur Diskussion des derzeitigen Forschungsstandes auf dem Gebiet der Hämostaseologie. Im nachfolgenden Artikel finden Sie eine Zusammenfassung der persönlichen Highlights der Autoren – ohne Anspruch auf Vollständigkeit – aus den Gebieten Thrombose und Antikoagulation.

Venöse Thromboembolie (VTE)

Vorgehen. Eine systemische Thrombolyse bleibt weiterhin Patient:innen mit hohem Risiko vorbehalten, erste Daten weisen auf diesem Gebiet allerdings auf die mögliche Effektivität einer Thrombektomie hin.[5] Weitere Schritte konnten zuletzt bei der kathetergestützten lokalen Thrombolyse für Patient:innen mit intermediär hohem bis hohem Risiko gemacht werden. Eine aktuelle Metaanalyse zeigt für diese Methode geringe Blutungsraten bei verbesserten Surrogatparametern.[6]

0,66). Unter anderem fanden sich folgende Prädiktoren für die Entwicklung einer CTEPH: Lokalisation der PE, Brustschmerzen, Fibrinogen, diskordante T-Wellen im EKG und zusätzliche TVT.

Antikoagulation

Neue Antikoagulanzien

Auf dem Gebiet der neuen Antikoagulanzien gaben Prof. DDr. Thomas Renné und Prof. Dr. Peter Verhamme einen Überblick. Der Fokus liegt derzeit vor allem auf Inhibitoren von FXI

Dr. Daniel Steiner   Dr. Timothy Hoberstorfer

Abb. 2: Wirkmechanismus und potenzielle Indikationen aus derzeit laufenden Studien der FXI/FXIa-Inhibitoren

Abb. 1: Reduktion des postthrombotischen Syndroms (PTS) bei Patient:innen nach akuter Intervention für tiefe Beinvenenthrombose (TVT). Ein höherer Balken zeigt eine stärkere Reduktion des PTS an.

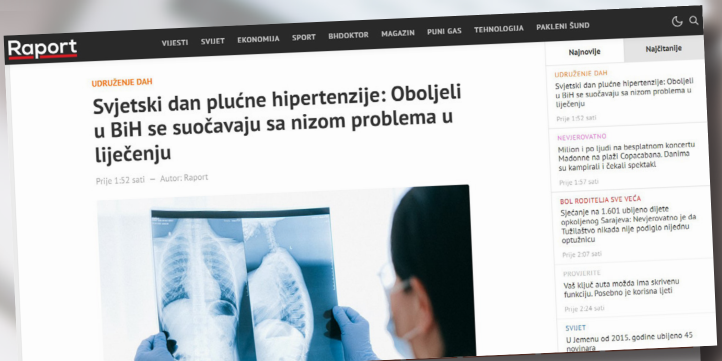
Bosnia and Herzegovina

SVIJET, ZDRAVLJE

Svjetski dan plućne hipertenzije: Oboljeli u BiH se suočavaju sa nizom problema u liječenju

Prema statističkim pokazateljima, od primarne plućne hipertenzije obolijeva do pet pacijenata na milion stanovnika, a od sekundarne plućne hipertenzije obolijeva do 50 pacijenata na milion stanovnika

Vesna Besic | 05.05.2024 - Update : 05.05.2024



UDRUŽENJE DAH

Svjetski dan plućne hipertenzije: Oboljeli u BiH se suočavaju sa nizom problema u liječenju

Prije 1:52 sati — Autor: Raport

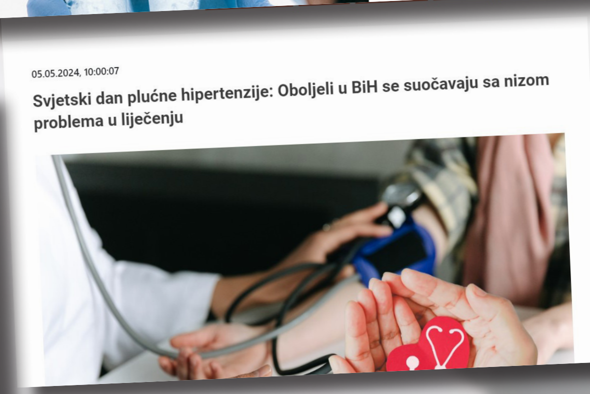
UDRUŽENJE DAH
Svjetski dan plućne hipertenzije: Oboljeli u BiH se suočavaju sa nizom problema u liječenju
Prije 1:52 sati

NEVJEROVATNO
Milion i po ljudi na besplatnom koncertu Madonne na plaži Copacabana. Danima su kampirali i čekali spektakl
Prije 1:57 sati

BOL RODITELJA SVE VEĆA
Sjećanje na 1.601 ubijeno dijete opkoljenog Sarajeva: Nevjerovatno je da Tužilaštvo nikada nije podiglo nijednu optužnicu
Prije 2:07 sati

PROVJERITE
Vaš ključ auta možda ima skrivenu funkciju. Posebno je korisna ljeti
Prije 2:24 sati

SVIJET
U Jemenu od 2015. godine ubijeno 45 novinara



05.05.2024, 10:00:07

Svjetski dan plućne hipertenzije: Oboljeli u BiH se suočavaju sa nizom problema u liječenju

ŽIVOT

Svjetski dan plućne hipertenzije: Oboljeli u BiH se suočavaju sa nizom problema u liječenju

Svjetski dan plućne hipertenzije obilježava se 5. maja, tim povodom Udruženje građana oboljelih od plućne hipertenzije "Dah" u Bosni i Hercegovini svake godine realizuje niz događaja s ciljem podizanja svijesti o ovoj rijetkoj, teškoj i neizlječivoj bolesti krvnih sudova pluća od koje strada i srce.

Autor: Anadolija
05.Maj,2024. • 11:27

Vera Hodžić već deset godina ima dijagnozu idiopatska plućna arterijska hipertenzija. Za mnoge nepoznato oboljenje, čiji simptomi nisu vidljivi osim

RIJETKA I TEŠKA BOLEST

Svjetski dan plućne hipertenzije: Oboljeli u BiH se suočavaju s nizom problema u liječenju

U BiH sa 3,8 miliona stanovnika živi od 20 do 200 pacijenata oboljelih od plućne hipertenzije, prema statističkim pokazateljima

Svjetski dan plućne hipertenzije: Oboljeli u BiH se suočavaju sa n problema u liječenju

Midhat Hajdarević · 4 sata ago

Društvo

05.05.2024. u 10:21

Svjetski dan plućne hipertenzije: Oboljeli u BiH se suočavaju sa nizom problema u liječenju

Svjetski dan plućne hipertenzije obilježava se 5. maja, tim povodom Udruženje građana oboljelih od plućne hipertenzije "Dah" u Bosni i Hercegovini svake godine realizuje niz događaja s ciljem podizanja svijesti o ovoj rijetkoj, teškoj i neizlječivoj bolesti krvnih sudova pluća od koje strada i srce, javlja Anadolu.

Vera Hodžić već deset godina ima dijagnozu idiopatska plućna arterijska hipertenzija. Za mnoge nepoznato oboljenje, čiji simptomi nisu vidljivi osim kada je oboljeli izložen bilo kakvom i najmanjem naporu. Hodžić boluje od primarne plućne hipertenzije, ali istovremeno je i osnivač i predsjednik Udruženja "Dah".

Govorila je o problemima sa kojima se susreću oboljeli od plućne hipertenzije u Bosni i Hercegovini.

Navela je da je plućna hipertenzija rijetko, teško i neizlječivo oboljenje krvnih sudova pluća od kojeg strada i srce. Može biti primarna (idiopatska) i sekundarna. Kod primarne plućne hipertenzije uzrok je uglavnom nepoznat, dok je kod sekundarne plućne hipertenzije uzrok poznat, te je bolest "lakše" držati pod kontrolom, ali bez obzira na to, medicinski protokoli dijagnosticiranja i liječenja, kao i terapija, su isti.

- Udruženje građana oboljelih od plućne hipertenzije "Dah" u Bosni i Hercegovini je od osnivanja

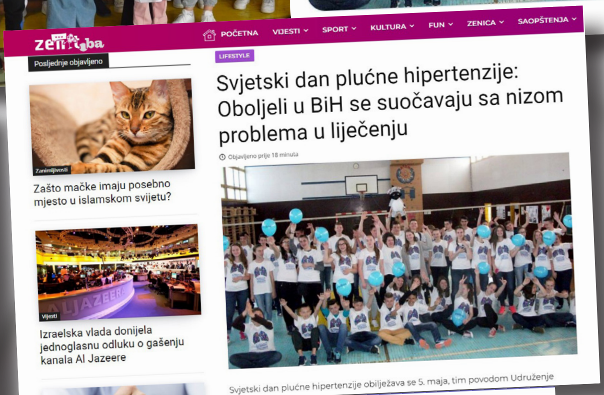
Oboljeli u BiH se suočavaju sa nizom problema u liječenju

bosna vijesti · 9 hours PRIJE 0 0 4 minut vrem

Svjetski dan plućne hipertenzije


Anadolu BHSC
@aa_balkans

Svjetski dan plućne hipertenzije: Oboljeli u BiH se suočavaju sa nizom problema u liječenju



Zašto mačke imaju posebno mjesto u islamskom svijetu?

Izraelska vlada donijela jednoglasnu odluku o gašenju kanala Al Jazeere

Svjetski dan plućne hipertenzije: Oboljeli u BiH se suočavaju sa nizom problema u liječenju

Objavljeno prije 18 minuta

Svjetski dan plućne hipertenzije obilježava se 5. maja, tim povodom Udruženje

Danas je Svjetski dan plućnd hipertenzije

Objavljeno prije 1 sat 05.05.2024.
Piše Urednik

BIH / prije 39 minuta
Migranti se potukli u Sarajevu

SPORT / prije 1 sat
Blijedi Hajduk doživio sedmi poraz na Poljudu ove sezone

DRUŠTVO / prije 1 sat
Danas je Svjetski dan plućnd hipertenzije

DRUŠTVO / prije 2 sata
U Dubravi u Novoj Biloj počeo I. boćarsl 'Duhovi',

Obilježava se Svjetski dan plućne hipertenzije – Povećanje svijesti o rijetkoj bolesti

By admin 5 Maja, 2024 4 0

Za ovu veoma opasnu bolest nema lijeka: Ovo su njeni simptomi

Radiosarajevo.ba

Prije oko 4h | 0 komentara

Svjetski dan plućne hipertenzije: Oboljeli u BiH se suočavaju sa nizom problema u liječenju

VIJESTI | Autor: Anadolija | 05. maj 2024 11:22 | 0 komentara


ZDRAVLJE | Published On: 5/5/2024

Svjetski dan plućne hipertenzije: Oboljeli u BiH se suočavaju sa nizom problema u liječenju

Svjetski dan plućne hipertenzije obilježava se 5. maja, tim povodom Udruženje građana oboljelih od plućne hipertenzije "Dah" u Bosni i Hercegovini svake godine realizuje niz događaja s ciljem podizanja svijesti o ovoj rijetkoj, teškoj i neizlječivoj bolesti krvnih sudova pluća od koje strada i srce.

Croatia

PANONSKA PUSTOLOVINA NERETVANSKOM LAĐOM

Glavni cilj i misija Panonske pustolovine je kontinuirano ukazivati na važnost očuvanja prirode i čovjekova okoliša.

zdravlje

Na Plitvicama Plava krila organizirala 39. maraton

Kod plućne hipertenzije pluća opterećuju srce, što na kraju završi kobno

PLUĆNA HIPERTENZIJA RIJETKA JE I TEŠKA BOLEST

U roku od tri godine umire pedeset posto oboljelih, a spas je transplantacija pluća

Plućna hipertenzija znači da je došlo do porasta tlaka u krvnim žilama u plućima, što u konačnici dovodi do većeg opterećenja rada desnog dijela srca i njegova popuštanja, a može biti posljedica drugih bolesti, npr. popuštanja lijeve strane srca ili kronične plućne bolesti

Na Plitvicama je obilježen dan teške plućne bolesti

Glavni je simptom osjećaj nedostatka zraka koji se najprije javlja pri naporu, istaknula je prof. Mateja Janković Makek

Nažalost, još postoje bolesnici kojima lijekovi ne mogu u značajnoj mjeri usporiti bolest, jer izliječiti je zasad ne znamo. U tim je slučajevima trenutno jedina terapijska opcija transplantacija pluća, rekla je dr. Janković Makek

plućne cirkulacije), ona može biti idiopatska (nepoznat uzrok) ili može biti udružena s drugim bolestima poput bolesti vezivnog tkiva, infekcije HIV-om, ciroze jetara ili pak određenih srčanih grešaka s povećanim protokom krvi kroz pluća. Ipak, prototip plućne arterijske hipertenzije jest idiopatski PAH koji dominantno zahvaća osobe mlađe i srednje dobi i ne zna mu se uzrok. Glavni je simptom osjećaj nedostatka zraka koji se najprije javlja pri naporu i pogoršava se s vremenom", istaknula je Mateja Janković Makek.

Nažalost, kako je navela, danas još nisu poznati rizični čimbenici za obolijevanje od idiopatskog PAH-a, dok su rizični čimbenici za obolijevanje od takozvanih sekundarnih oblika PH različiti u mjeri u kojoj se razlikuju i same bolesti koje mogu biti povezane s razvojem plućne hipertenzije. Idiopatski PAH najčešće zahvaća osobe mlađe i srednje dobi, češće žene nego muškarce. No posljednjih desetak godina iz različitih se svjetskih i europskih registara vidi i porast incidencije bolesti u starijoj životnoj dobi. Nije sasvim jasno je li to novi trend ili su ti ljudi bolovali od toga i prije, samo nisu bili pravilno dijagnosticirani.

Kako bi što više senzibilizirali, ali i educirali javnost, Atletski klub Plitvice u suradnji s Udrugom pacijenata oboljelih od plućne hipertenzije Plava krila organizirao je 39. maraton koji se održao u Nacionalnom parku Plitvička jezera

VAŽNO JE PRIDRŽAVATI SE UPUTA LIJEČNIKA

Uz ovu tešku bolest trudnoća je rizična

Ne može se planirati obitelj bez konzultacije s liječnikom

Zanimalo nas je i postoji li preventiva za tu bolest, na što je doktorica Janković Makek odgovorila da s obzirom na to da ne znamo uzrok nastanka idiopatskog PAH-a, ne možemo govoriti ni o mjerama prevencije.

"Ako je već postavljena dijagnoza idiopatskog PAH-a, treba se držati savjeta liječnika o razini tjelesne aktivnosti i planiranju obitelji, a trudnoća je iznimno rizična za žene s iPAH-om. Najvažnije je pravilno uzimati lijekove. Danas se, uz lijekove, znatno produljilo očekivano preživljenje osoba s iPAH-om, a kao terapijska opcija pojavila se i transplantacija pluća", naglasila je. Zanimljivo je da ne postoji državni registar oboljelih pa nemamo sasvim točan podatak o incidenciji idiopatskog PAH-a u Hrvatskoj. Ipak, kako ističe assist. prof. Janković Makek, prema broju oboljelih koji se na godišnjoj razini dijagnosticiraju u nekoliko najvećih centara u Hrvatskoj, smatra se da je slična europskom i svjetskom trendu i iznosi oko 2 do 4 slučaja na milijun stanovnika. Sam idiopatski PAH (tada zvan i primarni PAH) opisan je tek 1951. godine. No pretpostavlja se da je bolest postojala i prije, samo nije bila prepoznata. Iako je bolest teška i bolesnici je moraju prihvatiti kao sastavni dio nečega što će do kraja života biti s njima, treba istaknuti kako je danas na raspolaganju nekoliko skupina lijekova za bolesnike s iPAH-om. Njihovom primjenom postignut je značajan napredak u liječenju i značajno produljenje života uz, što je još važnije, dobru kvalitetu života.

Podmuklo i postupno

"Vrijedi naglasiti da je prije pojave lijekova očekivano srednje preživljenje nakon postavljanja dijagnoze iznosilo tri godine, što znači da je 50 posto osoba umiralo od iPAH-a tri godine od dijagnoze. Nažalost, još postoje bolesnici kojima lijekovi ne mogu u značajnoj mjeri usporiti bolest, jer izliječiti je zasad ne znamo. U tim je slučajevima trenutno jedina terapijska opcija transplantacija pluća", rekla je doktorica. Za kraj je napomenula kako trebamo osluškivati svoje tijelo i signale koje nam ono šalje.

"Nemojte zanemarivati simptome čak i kad se podmuklo i postupno ušuljaju u vaš život. Ako ne podnosite napor jednako dobro kao vama slične osobe, nemojte to nužno pripisivati nedostatku kondicije. Osobito ako se tegobe postupno pogoršavaju", zaključila je Janković Makek.

Kako bi što više senzibilizirali, ali i educirali javnost, Atletski klub Plitvice u suradnji s Udrugom pacijenata oboljelih od plućne hipertenzije Plava krila organizirao je 39. maraton koji se održao 1. i 2. lipnja u Nacionalnom parku Plitvička jezera. Ove godine natjecatelji su mogli birati između staze od 5 km, polumaratona (21 km) i maratona (42 km). Plitvički maraton kao najstarija, najzelenija i najljepša hrvatska utrka iz godine u godinu privlači sve više natjecatelja, a ove godine stigli su natjecatelji iz više od 40 zemalja.

Leopold Špehar, predsjednik AK-a Plitvice i direktor Plitvičkog maratona, istaknuo je kako je još kao dijete u osnovnoj školi bio pozvan da sudjeluje na Plitvičkom maratonu.

"Istrčao sam svoju prvu utrku od 7 km u sklopu maratona kao desetogodišnjak. Ostvario sam lijep plasman i tu je počela ljubav prema atletici. Uz podršku svoje obitelji, a najviše tetka Milana Abrića koji nas je vozio po utrkama diljem Hrvatske, bio sam član AK-a Veteran te kasnije AK-a Ka Tim iz Karlovca. Nakon srednje škole i studiranja u Gospiću, povratkom na Plitvice osnivamo AK Plitvice 2017. godine", rekao je Špehar.

Sve veće zanimanje

Naglasio je da su kao lokalni klub 2020. prvi put organizirali 35. Plitvički maraton.

"Iza nas je već pet organizacija i svake se godine trudimo oko noviteta i sa željom da nam utrka raste. Uz pomoć brojne ekipe iz kluba, prijatelja i volontera, bez većih problema organiziramo ovakvo natjecanje. Uvijek nas veseli vidjeti sve više mladih uključenih u organizaciju. Veselimo se posebno 40. Plitvičkom maratonu. Istrčao sam osobno puno utrka, ali Plitvice su svakom nešto posebno. Ne kaže se bez razloga da je jedna od najtežih, ali i najljepših utrka u Hrvatskoj i šire. Plitvice su najstariji, najveći i najljepši NP u Hrvatskoj te jedan od rijetkih koji ima vlastiti maraton na području NP-a", rekao je.

Dodao je kako se rekreira nekoliko puta tjedno, posljednjih godinu dana malo slabije zbog obaveza, ali trčanje je svakako odličan ispušni ventil.

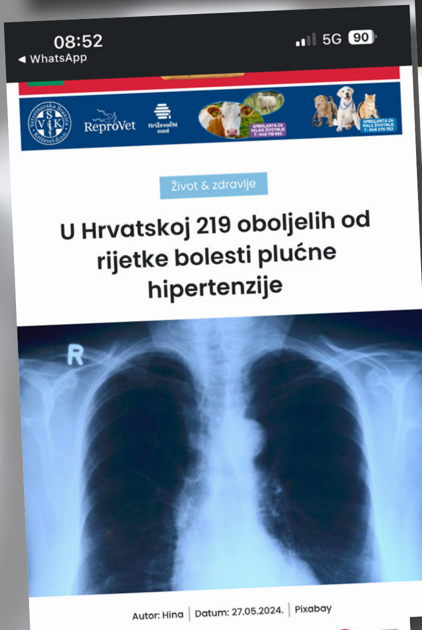
"Prije tri godine istrčao sam prvu ultru na 100 km, za koju sam se pripremao šest mjeseci. Tih šest mjeseci ne bih mijenjao ni za što. Osjećaj kad završiš utrku i uđeš u cilj nešto je neopisivo. Svakom bih preporučio bavljenje sportom, bilo rekreativno ili nešto ozbiljnije. Spomenuo bih i veliku podršku NP-a Plitvička jezera i Općine Plitvička Jezera bez koje ne bi bilo moguće organizirati ovako veliko natjecanje", zaključio je Špehar.

U Hrvatskoj 219 oboljelih od rijetke bolesti koja zahvaća pluća i srce

Autor: **Poslovni.hr/Hina**, 27. svibanj 2024. u 13:27

Foto: Pixabay

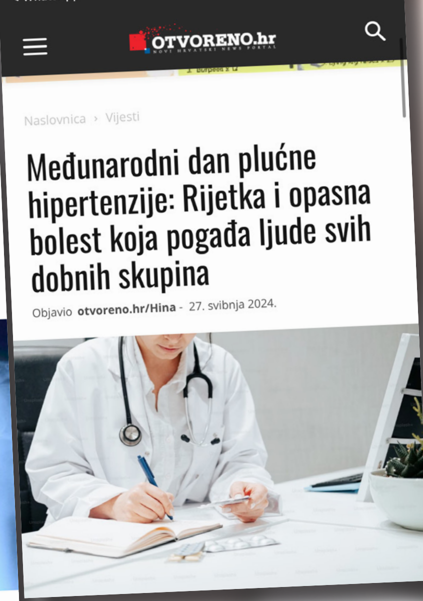
Riječ je o teškoj bolesti čija je prognoza lošija od one za većinu karcinoma, a najčešći simptomi su kratkoća daha, umor, vrtoglavica, bol u prsima, ubrzan ritam srca, oticanje nogu.



Život & zdravlje

U Hrvatskoj 219 oboljelih od rijetke bolesti plućne hipertenzije

Autor: Hina | Datum: 27.05.2024. | Pixabay



Naslovnica › Vijesti

Međunarodni dan plućne hipertenzije: Rijetka i opasna bolest koja pogađa ljude svih dobnih skupina

Objavio **otvoreno.hr/Hina** - 27. svibnja 2024.

Bolest koja uništava pluća i srce, a češće zahvaća žene: U Hrvatskoj 219 oboljelih od plućne hipertenzije

VIJESTI | Autor: Hina | 27. svi 2024 13:12 | 0 komentara

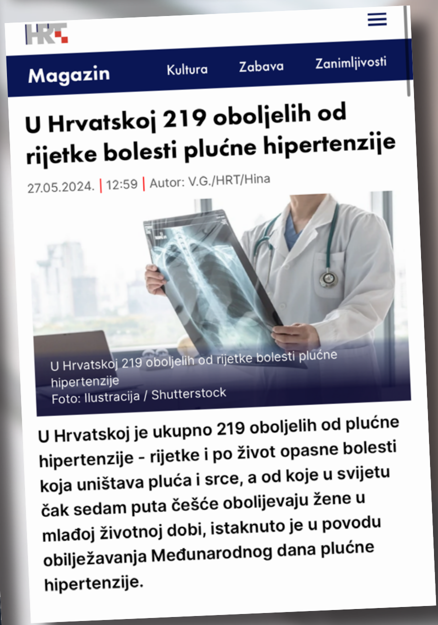
Podijeli :

U Hrvatskoj je ukupno 219 oboljelih od plućne hipertenzije - rijetke i po život opasne bolesti

Obratite pažnju na ove simptome! Mogu biti povezani s bolešću od koje u Hrvatskoj boluje preko 200 ljudi

Poslušaj ovaj članak

00:00 / 00:00



U Hrvatskoj 219 oboljelih od rijetke bolesti plućne hipertenzije

27.05.2024. | 12:59 | Autor: V.G./HRT/Hina

U Hrvatskoj 219 oboljelih od rijetke bolesti plućne hipertenzije
Foto: Ilustracija / Shutterstock

U Hrvatskoj je ukupno 219 oboljelih od plućne hipertenzije - rijetke i po život opasne bolesti koja uništava pluća i srce, a od koje u svijetu čak sedam puta češće obolijevaju žene u mlađoj životnoj dobi, istaknuto je u povodu obilježavanja Međunarodnog dana plućne hipertenzije.

Czech Republic

SEZNAM, PŘÍBĚHY

Příběh čtenáře: Martin (23) s hadičkou v srdci bojuje s nemocí

9. 5. 2024 Stanislav Makovický

Když se Martin začal v dětství častěji zadýchávat, zpočátku tomu nevěnoval pozornost ani
ani jeho rodiče. Rychle však zpozorněli, když se, tehdy nadějný sportovec, musel každých s
metrů zastavit a nemohl ani vyjít schody. Začal kolotoč vyšetření, na jehož konci si vyslechl
diagnózu, se kterou bojuje dosud. *„Bylo mi asi osm let, když jsme moje potíže poprvé začal*
řešit s lékaři. Nejprve měli podezření na astma, ale brzy jsme se přesunuli na kardiologické
oddělení. Skončil jsem tehdy v Dětské nemocnici v Brně a poprvé slyšel diagnózu plicní
hypertenze,“ vzpomíná Martin. Tehdy mu vážnost nemoci nijak nedocházela, spíše mu vadilo,
že musí trávit letní prázdniny v nemocnici. Plicní hypertenze je nemoc, při které se zvyšuje
krevní tlak v plicích. To vede k nadměrné námaze pravé komory srdeční, která se postupně
zvětšuje a může postupně selhat. Zároveň se nedostatečně okysličuje krev, proto pacienti trpí

Budovy v Praze se zbarvily do modra, připomněly Světový den plicní hypertenze

7.5.2024

Eliška Novotná
Webeditorka

Pražské budovy se zahalily do modré barvy u příležitosti Světového dn
plicní hypertenze - nevyléčitelné nemoci, která v Česku ohrožuje
tisíce lidí.

Modrá barva rozsvítila v neděli 5. května budovu Divadla Husa na provázku a Obchodní centrum Omega. Stalo se tak u příležitosti Světového dne plicní hypertenze - nevyléčitelné nemoci, která v Česku ohrožuje tisíc lidí. Kvůli nedostatečnému okysličení krve mají pacienti často také modře zbarvené rty a kůži, proto byla zvolena právě modrá barva nasvícení.

Důležité je na to přijít včas

Diagnóza plicní hypertenze se podle studií týká až 1 % populace a ne
lékaři objeví jako komplikaci jiného onemocnění srdce a plic. Má ovš
celou řadu jiných příčin. Za jejím vznikem mohou stát auto
onemocnění nebo plicní embolie. Při chorobě se pacientům
nedostatečně okysličuje krev, což se mimo jiné projevuje modrým zb
rtů. „Při plicní hypertenzi dochází ke zvýšené námaze pravé komory
která se postupně zvětšuje. To může vést k jejímu postupnému
Zároveň se nedostatečně okysličuje krev, proto pacienti trpí dušností
nebo závratěmi a mdlobami,“ říká prof. MUDr. Pavel Jansa, Ph.D., kardi
interní kliniky – kliniky kardiologie a angiologie Všeobecné fakultní ne
a 1. LF UK v Praze. Častým, ale již pozdním příznakem jsou podle n
kotníků a nohou. Protože je onemocnění relativně vzácné, lékaři tuto možnost podle prof. Jansy z
mezi posledními. „Léčba choroby v pokročilém stadiu je mnohem složitější, proto je důležité se k
dopracovat co nejdříve. Bohužel se stává, že pacienti se nejdříve léčí například na astma,“ vysvět
Jansa. Pokud však dušnost nelze odůvodnit jiným onemocněním, měl by pacient absolvovat
srdce a následně navštívit specialisty. I proto byly nedávno aktualizovány doporučené postupy p
těžkého astmatu a pro praktické lékaře doporučené postupy pro chronickou tromboembolick
nemoc.

Vysoký tlak v plicích může ohrožovat i děti

5. květen je už dvanáct let Světovým dnem plicní hypertenze. Připomněli si ho i Češi

PRAHA Martin Pláteník z jihu Moravy byl jako malý nadějný sportovec, hrál hokej i tenis. Do chvíle, než se začal zadýchávat. Když musel každých sto metrů zastavit, aby se vydýchal, a nemohl vyjít schody, začal kolotoč vyšetření.

„V osmi letech se mi změnil život. Lékaři mysleli, že mám astma. Ale kardiologové v Dětské nemocnici v Brně zjistili, že mám zvýšený krevní tlak v plicích,“ vzpomíná 23letý muž (na snímku).

Lékaři mu tehdy poprvé zavedli do srdce katetr z pumpy, která přímo do plicních cév dávkuje lék. Díky tomu se hoch poměrně rychle vrátil do školy, ale nemohl jezdit například na tábory či školy v přírodě. Rodiče ho totiž chtěli mít pod dohledem. I se
dy konec.
dičkou jsem si zvy-
alo, než jsem se do-
dy jsem mohl začít
tě déle, než jsem se
osamostatnil,“ říká Martin s tím, že nemoc ovlivnila i volbu jeho profese. Je kameramanem a filmařinu studuje na univerzitě ve Zlíně. „Při hospitalizacích jsem sledoval filmy. I později mě to k nim táhlo. Začal jsem dělat osvětlovače a pak kameramana,“ líčí muž.

Se vzácnými formami plicní hypertenze se léčí v Česku asi tisíc lidí. Každý rok přibývá až 200 nových pacientů. Stovky dalších lidí však o své chorobě nevědí.

„Je důležité ji odhalit včas, protože léčba nemoci v pokročilém stadiu je mnohem složitější. Bohužel se někteří pacienti nejdříve léčí například na astma,“ vysvětluje kardiolog Pavel Jansa z Všeobecné fakultní nemocnice v Praze.

Proto se lékaři i pacienti snaží na málo známou nemoc upozorňovat 5. května u příležitosti Světového dne plicní hypertenze. Včera si členové Sdružení pacientů s plicní hypertenzí vyšláply na Vyšehrad. (les)

Budovy v metropoli se zbarvily do modr
Připomněly Světový den plicní hyperter

ELIŠKA NOVOTNÁ

Praha – Pražské budovy se zahalily do modré barvy u příležitosti Světového dne plicní hypertenze – nevyléčitelné nemoci, která v Česku ohrožuje tisíce lidí.

Světový den plicní hypertenze připadá na 5. května, odborníci upozorňují na fakt, že pokud se chorobu podaří odhalit včas, mají pacienti díky léčbě velkou naději na normální život.

Se vzácnými formami plicní hypertenze se v Česku léčí přibližně 1000 pacientů, každý rok jich pak 150 až 200 přibude. Podle odhadu lékařů další stovky lidí o své nemoci vůbec neví. Včasná diagnóza podle expertů přináší pacientům s plicní hypertenzí delší a kvalitnější život.

„I v letošním roce symbolicky věnujeme dech pacientům, kteří touto chorobou trpí, a to výstupem na Vyšehrad. Snažíme se o osvětu, která u případů plicní hyper-
tenze pomůže l
gnóze a rychlej
léčby,“ říká Mil
ze Sdružení pac
hypertenzí.
Modře se trad
významné bud
Brně a Olomou
pak letos konk
Tančící dům a l
Modrá barva se
pacientům kvů
často modrají r
Při plicní hyp
chází ke zvýšen
pravé komory s
se postupně zv
může v čase vé
selhání. Zároveň se nedostatečně okysličuje krev, proto pacienti trpí dušností, únavou nebo závratěmi a mdlobami.

V BLANKYTNÉ. Do modra se zbarvila například kancelářská budova FIVE na Smíchově. Foto: MaVePR

Vysoký tlak v plicích mohou mít i děti. Důležité je na přijít včas

(5. května 2024, Redakce Ordinace.cz | přečteno: 220x)

Nestačíte s dechem, bolí vás na hrudi? Nemusí to být jen nedostatkem fyzické kondice. Podobné příznaky s sebou může nést zvýšený krevní tlak v plicích neboli plicní hypertenze, která se může vyskytnout také u mladších pacientů, dokonce i u dětí. Pokud se chorobu podaří odhalit včas, mají díky inovacím v léčbě velkou naději na normální život. Experti na to poukazují u příležitosti Světového dne plicní hypertenze (5. května), který tradičně připomenou modře nasvícené významné budovy v Praze, Brně a Olomouci. Modrou barvu pro nasvícení volí proto, že pacientům kvůli nemoci často modrají rty.

živě Brno

Světový den plicní hypertenze

Pavel Jansa vedoucí lékař, Centrum pro plicní hypertenzi

16:44 ČMKOS SVOLALA NA 21. KVĚTNA DEMONSTRACI PROTI ZMĚNÁM V ZÁKONÍKU PRÁCE A DŮCHODECH.

ZdravíŽivot
Vitalita a harmonie

ÚVOD Z MEDICÍNY ONEMOCNĚNÍ ZDRAVÁ STRAVA ŽIVOTNÍ STYL

ONEMOCNĚNÍ

Lékaři varují: vysoký tlak v plicích postihuje i děti, klíčové je včasné odhalení

Publikuje: Nikola Macáková — 29. 04. 2024
Zdroj: Mgr. Vojtěch Šprdlík

ZDRAVOTNICTVÍ

ZPRÁVY MEDICÍNA VZDĚLÁVÁNÍ NÁZORY PROFI MEDICÍNA PERSONÁLNÍ INZER

Vysoký tlak v plicích mohou mít i děti, varují lékaři

Redakce 29. 4. 2024 Zprávy

Vysoký tlak v plicích se týká rovněž dětí

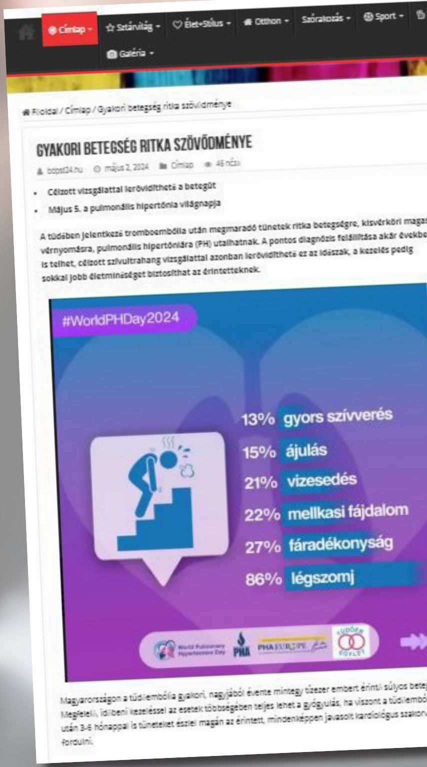
Nestačíte s dechem, bolí vás na hrudi? Nemusí to být jen nedostatkem fyzické kondice. Podobné příznaky s sebou může nést zvýšený krevní tlak v plicích neboli plicní hypertenze.

A protože se projevy příliš neliší od řady dalších nemocí, lékaři volají po včasné diagnostice – ta může pacienty ochránit od vážných zdravotních následků, nebo dokonce smrti. Současné pokroky v léčbě přitom skýtají šanci pro tisíce lidí, kteří trpí závažnými formami této nemoci. Plicní hypertenze se může vyskytnout také u mladších pacientů, dokonce i u dětí. Pokud se chorobu podaří odhalit včas, mají díky inovacím v léčbě velkou naději na normální život. Experti na to poukazují u příležitosti Světového dne plicní hypertenze (5. května), který tradičně připomenou modře nasvícené významné budovy v Praze, Brně a Olomouci. Modrou barvu pro nasvícení volí proto, že pacientům kvůli nemoci často modrají rty.

Diagnóza plicní hypertenze se podle studií týká až jednoho procenta populace a nejčastěji ji lékaři objeví jako komplikaci jiného onemocnění srdce a plic. Má ovšem také celou řadu jiných příčin. Za jejím vznikem mohou stát autoimunitní onemocnění nebo plicní embolie. Při chorobě se pacientům často nedostatečně okysličuje krev, což se mimo jiné projevuje modrým zbarvením rtů. „Při plicní hypertenzi dochází ke zvýšené námaze pravé komory srdeční, která se postupně zvětšuje. To může vést k jejímu postupnému selhání. Zároveň se nedostatečně okysličuje krev, proto pacienti trpí dušností, únavou nebo závratěmi a mdlobami,“ říká Pavel Jansa, kardiolog z II. interní kliniky – kliniky kardiologie a angiologie Všeobecné fakultní nemocnice a 1. lékařské fakulty Univerzity Praha. Častým, ale již pozdním příznakem jsou podle něj otoky kotníků a nohou. Protože je onemocnění relativně vzácné, lékaři tuto možnost podle Jansy zvažují až mezi posledními. „Léčba choroby v pokročilém stadiu je mnohem složitější, proto je důležité se k diagnóze dopracovat co nejdříve. Bohužel se stává, že pacienti se nejdříve léčí například na astma,“ vysvětluje Jansa. Pokud však dušnost nelze odůvodnit jiným onemocněním, měl by pacient absolvovat ultrazvuk srdce a následně navštívit specialisty. I proto byly aktualizovány doporučené postupy pro léčbu těžkého astmatu a pro praktické lékaře doporučené postupy pro chronickou tromboembolickou plicní nemoc.

V posledních letech díky fungujícímu systému referujících pracovišť pozorují lékaři nejen rostoucí počty diagnostikovaných pacientů s plicní hypertenzí u dospělých. Objevují se i pacienti v adolescentním či dětském věku. „V posledním roce jsme ve spolupráci s dětskými kardiology zahájili léčbu u několika dětí. Současná terapie, zejména ta včasná, skýtá velkou šanci na významné zlepšení obtíží malých a velkých pacientů,“ říká Pavel Jansa. „V posledních několika letech odstartovala řada slibných studií s moderními léčivými přípravky, které pomáhají snižovat tlak v plicích. Pokroky děláme také v oblasti léčby plicní hypertenze po plicní embolii,“ dodává Pavel Jansa. PH

Hungary



Főoldal / Címlap / Gyakori betegség ritka szövődménye

GYAKORI BETEGSÉG RITKA SZÖVŐDMÉNYE

bopst24.hu · május 2, 2024 · Címlap · 46 nézés

- **Célzott vizsgálattal lerövidíthető a betegút**
- **Május 5. a pulmonális hipertónia világnapja**

A tüdőben jelentkező tromboembólia után megmaradó tünetek ritka betegségre, kisvérköri magas vérnyomásra, pulmonális hipertóniára (PH) utalhatnak. A pontos diagnózis felállítása akár évekbe is telhet, célzott szívultrahang vizsgálattal azonban lerövidíthető ez az időszak, a kezelés pedig sokkal jobb életminőséget biztosíthat az érintetteknek.

Magyarországon a tüdőembólia gyakori, nagyjából évente mintegy tízezer embert érintő súlyos betegség. Megfelelő, időbeni kezeléssel az esetek többségében teljes lehet a gyógyulás, ha viszont a tüdőembólia után 3-6 hónappal is tüneteket észlel magán az érintett, mindenképpen javasolt kardiológus szakorvoshoz fordulni.

Ritkán, de előfordul, hogy krónikus szövődményként pulmonális hipertónia alakul ki, mely az általános tünetek, mint a légszomj, fáradékonyság, csökkent terhelhetőség, mellkasi fájdalom, krónikus köhögés miatt nehezen diagnosztizálható. Az esetek többségében túl sok idő, akár 1-2 év is eltelik, mire pontos diagnózis után megfelelő kezelést kaphat a beteg.

Dr. Karlócai Kristóf a Pulmonológiai Klinika kardiológus főorvosa azt javasolja, hogy nagy akut tüdőembólia után 3 hónappal legyen szakorvosi vizsgálat, lehetőleg az akut ellátási helyen. Szövődmény gyanúja esetén érdemes szívultrahanggal ellenőrizni, hogy nem alakult-e ki pulmonális hipertónia. Ezzel a célzott vizsgálattal lerövidíthető az út a megfelelő terápiához jutáshoz.

„Magyarországon egy évben körülbelül 10.000 embert kezelnek akut tüdőembóliával. Sok beteg esetében a tüdő artériába beékelődött vérrög nem tud teljesen feloldódni, hanem kötőszövetesen átalakulva folyamatos keringési akadályt képez. Pontos számot nem lehet mondani, de akár a 2-300-at is elérheti ezen esetek száma. Az akadály hosszabb távon krónikus tromboembóliás pulmonális hipertónia (CTEPH betegség) kialakulásához vezet. Ez egy súlyos, kezelés nélkül halálos kimenetelű betegség, nagyon fontos, hogy minél előbb észrevegyük! A tüdőembóliát követően három hónapon túl megmaradó fulladásos, nehézlégzéses panaszok felvetik a CTEPH kialakulásának gyanúját, melyet kardiológiai rendelésen elvégzett szívultrahang vizsgálattal lehet igazolni.”

Ritkán, de előfordul olyan eset is, amikor a beteg észre sem veszi az általában nagy fájdalommal, jelentős tünetekkel járó tüdőembóliát. *"A jobb lábamban alakult ki trombózis, de az ebből kialakuló tüdőembóliát én nem is észleltem" – mesélte el Dr. Kerner Gábor a saját történetét. "Aktívan sportoltam korábban is, a legfeltűnőbb éppen az volt, hogy egyre kevésbé tudok olyan szinten teljesíteni a sportban, mint szerettem volna. Végül egy gyorsan kialakuló hasvízkór miatt vizsgáltak ki újra, és szívultrahang és MR vizsgálatok után lett gyanús a kardiológián, hogy nem CTEPH-em van-e. Közel két évbe telt, mire a diagnózis megszületett; addigra már nagyon fulladtam, és gyorsan romlott az állapotom. Először Pécsett, majd Budapesten kezeltek, és végül Bécsben műtöttek meg 2015 decemberében. Ma már ismét sportolok, aktív életet élek."*

Tüdőér Egylet betegszervezet – tájékoztatás, támogatás és érdekvédelem

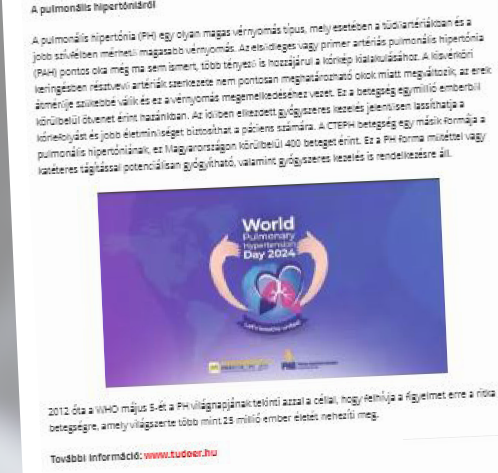
A Tüdőér Egylet a magas tüdővérnyomásban, pulmonális hipertóniában (PH) szenvedő betegek országos érdekképviseleti egyesülete, közhasznú szervezet, mely 2008-ban alakult. A ritka betegségek, így a PH esetében is kiemelt jelentősége van a betegszervezetnek. *„A betegség nehezen diagnosztizálható, így az érintettek akár éveket is bolyonghatnak az ellátórendszerben. Közben az állapotuk, életminőségük akár drasztikusan is romolhat”* – mondta **Csabuda Eszter, a Tüdőér Egylet elnöke.**

Az egyesület leginkább ismeretátadással, tévhitek eloszlatásával, tapasztalatok megosztásával támogatja a tagokat, melyre a betegség ritkaságából adódóan kiemelten szükség van. A betegszervezet az érintettek érdekeinek képviselete és felvilágosítás mellett egészségügyi ellátásukhoz, a megváltozott életkörülmények szociális és érzelmi terheik enyhítéséhez és általánosságban a PH kutatásához nyújt támogatást. Azon dolgozik, hogy a betegség valamennyi gyógyszere rendelkezésre álljon Magyarországon. Önkéntes alapon működik, anyagi forrásai szűkösek, így az adományok és az adó 1%-os felajánlások minden évben nagy mértékben segítik munkájukat.

A Tüdőér Egylet május 25-én tartja a 12. országos betegtalálkozóját, melyre május 15-ig várják az érintettek regisztrációját a www.tudoer.hu oldalon.

A ritka betegségekről

Azokat a betegségeket tekintjük ritka betegségeknek, amelyekben legfeljebb minden kétezredik ember érintett. 6-8 ezer féle ilyen kóros állapot is ismert, így az érintettek köre összességében az egyik legnagyobb betegcsoportot jelenti. Az Európai Unióban közel 27-36 millió ember, többségben gyerek (50-75%) szenved valamilyen ritka betegségben, és gyakran nincs számukra elérhető gyógymód. Magyarországon körülbelül 700 ezer az érintettek száma.



A pulmonális hipertóniáról

A pulmonális hipertónia (PH) egy olyan magas vérnyomás típus, mely esetében a tüdőartériákban és a jobb szívfélben mérhető magasabb vérnyomás. Az elsődleges vagy primer artériás pulmonális hipertónia (PAH) pontos oka még ma sem ismert, több tényező is hozzájárul a kórkép kialakulásához. A kisvérköri keringésben résztvevő artériák szerkezete nem pontosan meghatározható okok miatt megváltozik, az erek átmérője szűkebbé válik és ez a vérnyomás megemelkedéséhez vezet. Ez a betegség egymillió emberből körülbelül ötvenet érint hazánkban. Az időben elkezdett gyógyszeres kezelés jelentősen lassíthatja a kórlefolyást és jobb életminőséget biztosíthat a páciens számára. A CTEPH betegség egy másik formája a pulmonális hipertóniának, ez Magyarországon körülbelül 400 beteget érint. Ez a PH forma műtéttel vagy katéteres tágítással potenciálisan gyógyítható, valamint gyógyszeres kezelés is rendelkezésre áll.

2012 óta a WHO május 5-ét a PH világnapjának tekinti azzal a céllal, hogy felhívja a figyelmet erre a ritka betegségre, amely világszerte több mint 25 millió ember életét nehezíti meg.

További információ: www.tudoer.hu

Hírvilág

Vissza a rovat többi cikkéhez

2024. MÁJUS 05.

Gyakori betegség ritka szövődménye - célzott vizsgálattal lerövidíthető a betegút

SAJTÓKÖZLEMÉNY eLitMed

JOGKÉRÉS | MEGOSZTÁS

A tüdőben jelentkező tromboembólia után megmaradó tünetek ritka betegségre, kisvérköri magas vérnyomásra, pulmonális hipertóniára (PH) utalhatnak. A pontos diagnózis felállítása akár évekbe is telhet, célzott szívultrahang vizsgálattal azonban lerövidíthető ez az időszak, a kezelés pedig sokkal jobb életminőséget biztosíthat az érintetteknek.

Magyarországon a tüdőembólia gyakori, nagyjából évente mintegy tízezer embert érintő súlyos betegség. Megfelelő, időbeni kezeléssel az esetek többségében teljes lehet a gyógyulás, ha viszont a tüdőembólia után 3-6 hónappal is tüneteket észlel magán az érintett, mindenképpen javasolt kardiológus szakorvoshoz fordulni.

Ritkán, de előfordul, hogy krónikus szövődményként pulmonális hipertónia alakul ki, mely az általános tünetek, mint a légszomj, fáradékonyság, csökkent terhelhetőség, mellkasi fájdalom, krónikus köhögés miatt nehezen diagnosztizálható.

után megfelelő kezelést ka

Gyakori betegség ritka szövődménye - fontos a célzott vizsgálat

EGÉSZSÉGMAGAZIN · FORRÁS: TÜDŐÉR EGYLET

Ritkán, de előfordul olyan eset is, amikor a beteg észre sem veszi az általában nagy fájdalommal, jelentős tünetekkel járó tüdőembóliát.

A tüdőben jelentkező tromboembólia után megmaradó tünetek ritka betegségre, kisvérköri magas vérnyomásra, pulmonális hipertóniára (PH) utalhatnak. A pontos diagnózis felállítása akár évekbe is telhet, célzott szívultrahang vizsgálattal azonban lerövidíthető ez az időszak, a kezelés pedig sokkal jobb életminőséget biztosíthat az érintetteknek.

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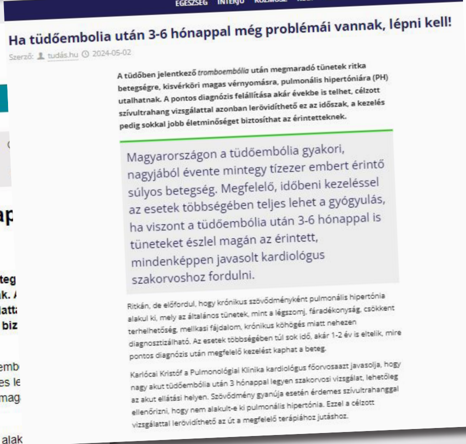
Dr. Karlócai Kristóf, a Pulmonológiai Klinika kardiológus főorvosa azt javasolja, hogy nagy akut tüdőembólia után 3



Ha tüdőembolia után 3-6 hónappal még problémái vannak, lépni kell!

Szerző: tudás.hu 2024-05-02

A tüdőben jelentkező *tromboembólia* után megmaradó tünetek ritka betegségre, kisvérköri magas vérnyomásra, pulmonális hipertóniára (PH) utalhatnak. A pontos diagnózis felállítása akár évekbe is telhet, célzott szívultrahang vizsgálattal azonban lerövidíthető ez az időszak, a kezelés pedig sokkal jobb életminőséget biztosíthat az érintetteknek.

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Karlócai Kristóf a Pulmonológiai Klinika kardiológus főorvosaazt javasolja, hogy nagy akut tüdőembólia után 3 hónappal legyen szakorvosi vizsgálat, lehetőleg az akut ellátási helyen. Szövődmény gyanúja esetén érdemes szívultrahanggal ellenőrizni, hogy nem alakult-e ki pulmonális hipertónia. Ezzel a célzott vizsgálattal lerövidíthető az út a megfelelő terápiához jutáshoz.

Medical Online > gyógyítás > Május 5. a pulmonális hipertónia világnapja

Május 5. a pulmonális hipertónia világnap

2024. május 04. 10:11

A tüdőben jelentkező tromboembólia után megmaradó tünetek ritka beteg kisvérköri magas vérnyomásra, pulmonális hipertóniára (PH) utalhatnak. diagnózis felállítása akár évekbe is telhet, célzott szívultrahang vizsgálatt lerövidíthető ez az időszak, a kezelés pedig sokkal jobb életminőséget biz érintetteknek.

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SKĀBEKĻA
festivāls
5 MAY
World Pulmonary Hypertension Day

OXYGEN FESTIVAL IN LATVIA: MEDIA CLIPPING

Dzīvei nav melnraksta | Ieva Plūme

EVA PLŪME
DZĪVEI NAV MELNRAKSTA

Skatīties pakalpojumā YouTube

Dzīvei nav melnraksta
Dzīvei nav melnraksta. Sintija Bergmane
Trešdiena, 20. marts

Dzīvei nav melnraksta. Ieva Plūme

Iedzimtas sirdskaites dēļ cerībai izdzīvot neticēja ne ārsti, ne pati. Ievas Plūmes stāsts

Dzīvei nav melnraksta

Dalīties:

Tolaik depresiju viņa nemācēja atpazīt, viņai vienkārši šķita, ka dzīvei un tam, ko viņa dara, nav jēgas. Tad, kad viņai palika 38 gadi, saistībā ar iedzimto slimību viņai konstatēja vēl vienu kaiti – pulmonālo arteriālo hipertensiju. Tas bija vēl viens šoks.

"Tas ir tāds sindroms, kad plaušu asinsvadi ir sašaurināti, arī plaušu artērijas, un arī paši sīkākie asinsvadi ir sašaurināti. Līdz ar to ar skābekli bagātinātās asinis, kas iet caur plaušām uz sirdi, ir grūtāk [pārvadīt]. Organisms grūtāk tiek apgādāts ar skābekli. Līdz ar to ir nogurums, ir sirdsklauves, ir sirds mazspēja, un, protams, arī savi ierobežojumi," atklāja Ieva.

Abas diagnozes apgrūtina Ievas dzīvi fiziskās aktivitātes ziņā – viņa vairs nevar peldēt vai braukt ar velosipēdu, jo ātri nogurst, piedzīvo aizdusu un nespēku.

"Tie ir fiziskie ierobežojumi, bet es domāju, ka kaut kāda šī nespējas identitāte mentāli arī neatvieglo dzīvi, jo es esmu pēc dabas ļoti enerģiska, man ir daudz ideju, man patīk radīt pasākumus, man patīk veidot kaut ko jaunu, bet lai kaut ko radītu, ir vajadzīgs diezgan daudz spē
ierobežojumi – es nespēju nostrādāt tik

Latvijas hokeja izlase brīvdienā trenējas uz ledus un trenažieru zālē
Šodien, 14:38

ASV valsts sekretārs brīdina: Gazas joslā pēc kara var iestāties iznīcinošs haoss
Šodien, 14:02

medicine.lv

Skābekļa festivālā 10. maijā bez maksas varēs pārbaudīt sirds un plaušu veselību

07.05.2024 10:30

Pulmonālās hipertensijas dienas 2024
SKĀBEKĻA FESTIVĀLS!
2024.gada 10.maijā, 10.00 - 13.00
Stradiņa slimnīcas A korpusā

Atzīmējot Pulmonālās hipertensijas dienu, Paula Stradiņa Klīniskās universitātes slimnīcā (Stradiņa slimnīca) 2024. gada 10. maijā notiks Skābekļa festivāls, ko Pulmonālās hipertensijas biedrība sadarbībā ar Stradiņa slimnīcu. Lai

DIENASKĀRTĪBĀ Par aktuālo valstī un iestādēs (preses relīzes)

VSIA "Paula Stradiņa Klīniskā universitātes slimnīca"
07. maijā, 2024 Lasīšanai: 5 minūtes
RUBRIKA: Relīze TĒMA: Veselība

Skābekļa festivālā 10. maijā bez maksas va… veselību

Atzīmējot Pulmonālās hipertensijas dienu, Paula S… slimnīca) 2024.gada 10. maijā notiks Skābekļa f… ar Stradiņa slimnīcu. Lai informētu sabiedr… hipertensijas atpazīstamību un diagnostiku… 10.00 līdz 12.00 Stradiņa slimnīcas A korp… noteikšanai, skābekļa saturācijas un asi… nodarbība, kā arī kardiologa un pneim… interesents, dalība tajā ir bez maksa…

PSKUS bez maksas varēs pārbaudīt sirds un plaušu veselību

Ziņu aģentūra LETA
10.mai

© pexels.com

Atzīmējot Pulmonālās hipertensijas dienu, Paula Stradiņa

CITI ŠOBRĪD

Paula Stradiņa Klīniskā universitātes slimnīca
45 min ·

10. maijā Stradiņa slimnīcā notika Pulmonālās hipertensijas dienas 2024 Skābekļa festivāls, kas pulcēja vairāk nekā 100 dalībniekus. Vecākais no tiem bija sasniedzis 86 gadu vecumu, bet jaunākajam dalībniekam bija 23 gadi. 🫁❤️ Vislielākā interese bija par bezmaksas analīžu nodošanu, skābekļa saturācijas noteikšanu, bioimpedences svaru mērījumiem. Dalībnieki aktīvi apmeklēja arī Stradiņa slimnīcas ārstu vadītās ekspreskonsultācijas.

💙 Sirsnīgs paldies visiem mediķiem, kas īstenoja šo vienreizējo pasākumu – mūsu pašu kardioloģei Dr. Santai Strazdiņai un pneimonologiem Dr.med. Dacei Žentiņai, Dr.Zaigai Kravalei un Dr. Rūdolfam Vīldem. Kā arī fizioterapeitei Līnai Pugai par fizioterapijas nodarbību.

💙 Īpašs paldies galvenajiem organizatoriem – Pulmonālās hipertensijas biedrība komandai un vadītājai Ieva Plūme. Jūsu ieguldījums sabiedrības veselības uzlabošanā ir ļoti svarīgs!

💙 Foto: Agnese Zeltiņa
#SIF_NVOFonds

"Mūsu mērķis Skābekļa festivāla laikā ir identificēt pacientus, kuriem ir nepieciešami papildu izmeklējumi un padziļināta konsultācija, piemēram, pie pneimonologa. Ja …di pacienti būs, sniegsim viņiem informāciju par …sultāciju un izmeklējumu iespējām Stradiņa slimnīcas …u slimību un torakālās ķirurģijas centrā vai dienas …ārā," informē Kravale.

…s hipertensijas sākotnējās pazīmes ir …s un līdzinās citām sirds un plaušu slimībām. …ūkums un aizdusa slodzes laikā, hronisks …es krūtīs, sirdsklauves, bet, slimībai …enojas daudz manāmāki simptomi - ģīboņi, …u krāsa un samazinās slodzes …cēta novēloti, slimība rada …iņas plaušu artērijās un sirdī ar

…eta vadītājs, kardiologs Andris …audz apakštipu un katram ir …bemboliskas plaušu …ta jauna ārstēšanas metode …citām slimības formām …pija. Tomēr, neskatoties uz …ba nereti progresē un …āt arvien jaunas ārstēšanas metodes.

…vusi par nozīmīgu pētniecības centru jaunu …mentu izstrādē tieši plaušu hipertensijas jomā. …nžēl ļoti nozīmīga ārstēšanas metode - plaušu

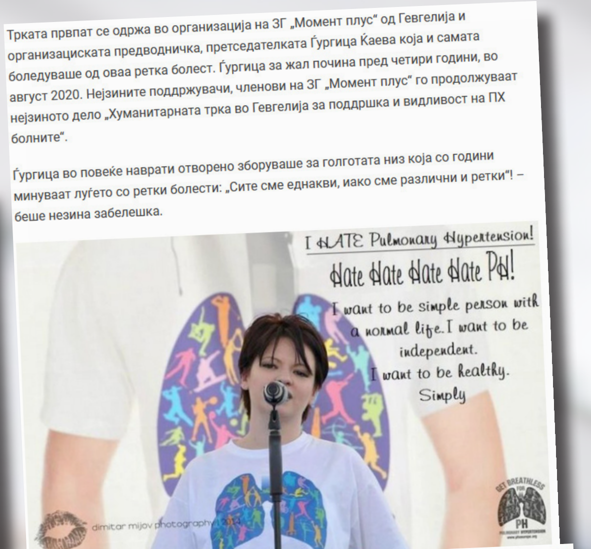
Skābekļa festivālā bez maksas varēs pārbaudīt sirds un plaušu veselību

TVNET/LETA
2024. gada 7. maijs 14:17

Хуманитарна трка за болните од ПХ одржана во Гевгелија

За поддршка, за здив, истрчаа 70-на атлетичари на патека долга 5 километри за видливост на болните од Пулмонална хипертензија

април 28, 2024 in ЗДРАВЈЕ И УБАВИНА

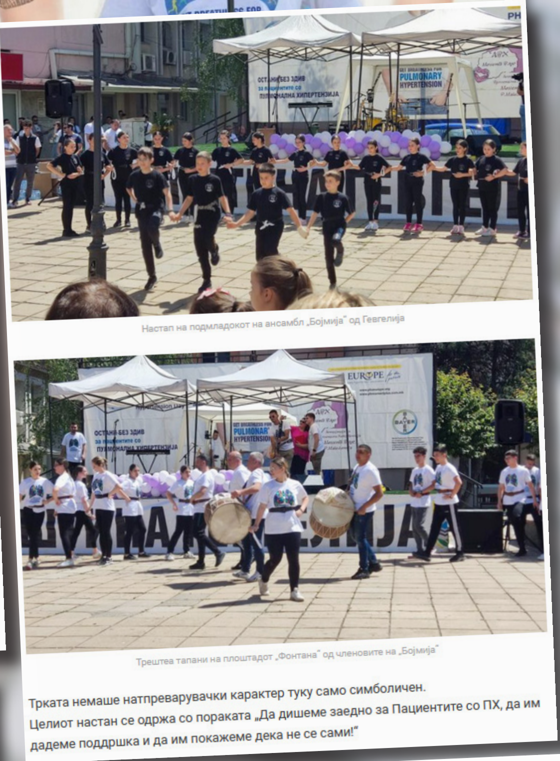


Трката првпат се одржа во организација на ЗГ „Момент плус“ од Гевгелија и организациската предводничка, претседателката Ѓургица Ќаева која и самата боледуваше од оваа ретка болест. Ѓургица за жал почина пред четири години, во август 2020. Нејзините поддржувачи, членови на ЗГ „Момент плус“ го продолжуваат нејзиното дело „Хуманитарната трка во Гевгелија за поддршка и видливост на ПХ болните“.

Ѓургица во повеќе наврати отворено зборуваше за голготата низ која со години минуваат луѓето со ретки болести: „Сите сме еднакви, иако сме различни и ретки“! – беше незина забелешка.

Во забавниот дел од одбележувањето на Светскиот ден на пулмонална хипертензија, на плоштадот „Фонтана“ во Гевгелија настапија: Хитс, Фонија, Филип Ангов, Теда, Мартин Костадинов и „Forever“, Оливера Станковска, ансамбл „Бојмија“ и танцовата група „Мистик“ од Гевгелија.

Локални изведувачи на забавната програма од настанот за поддршка на ПХ болните – Филип Аногов, Марија Ичкова, Оливера Станковска, Теодора Гошева



Настап на подмладокот на ансамбл „Бојмија“ од Гевгелија

Трештеа тапани на плоштадот „Фонтана“ од членовите на „Бојмија“

Трката немаше натпреварувачки карактер туку само симболичен.
Целиот настан се одржа со пораката „Да дишеме заедно за Пациентите со ПХ, да им дадеме поддршка и да им покажеме дека не се сами!“

СО ТРКА И КОНЦЕРТ ВО ЧЕСТ НА ЃУРГИЦА ЌАЕВА ВО ГЕВГЕЛИЈА СЕ ОДБЕЛЕЖА СВЕТСКИОТ ДЕН НА ПУЛМОНАЛНА ХИПЕРТЕНЗИЈА

WEB Телевизија во живо

(кликни на сликата)

5 мај, Светскиот ден на Пулмоналната хипертензија, во Гевгелија денес, на 28 април 2024 година се одбележа со концерт и трчање. Организатори на овој настан беа Асоцијацијата на пулмонална хипертензија „Момент плус“, помогнати од Општина Гевгелија. Во 11:00 часот започна културно забавниот настан на плоштадот во Гевгелија, на кој учество зедоа локалните музички имиња, групите „Хитс“ и „Фониа“, како и пејачите Филип Ангов, Теда, Оливера Станковска, Марија Ичкова, Мартин Костадинов форевер, како и ансамблот „Бојмија“ и денс студиото „Мистик“.

Ѓуѓица Ќаева беше борец и активист за правата на пациентите кои боледуваат од Пулмонална хипертензија и таа вака зборуваше до последниот здив:
„На 5 Мај на Светскиот ден за Пулмонална хипертензија, нема да барам од министрите да трчаат со нас, затоа што немаме ист маратон, нема да барам да ги офарбаат пурпурни зградите, па и цела Македонија да ја офарбаат тој ден, се е тоа џабе. Затоа што, тоа е нешто како цреша на торта и кое се прави во држави каде пациентите имаат се, од третман, до социолошка, психолошка подршка, социјално подржани.
До последен здив ќе се борам и зборувам.“

Portugal

14:29 | DIRETO

CÁTIA RODRIGUES · PRES. ASS. PORTUGUESA HIPERTENSÃO

Primeiro Jornal

HIPERTENSÃO PULMONAR

CANSAÇO EXTREMO É O SINTOMA MAIS COMUM

HIPERTENSÃO PULMONAR

Em Portugal, há apenas 300 pessoas diagnosticadas com hipertensão pulmonar, uma doença que pode ser fatal

COLOQUE A SUA QUESTÃO SOBRE PNEUMOLOGIA ATRAVÉS DO 22 508 32 97 OU CONSULTORIO@PORTOCA

14H40

HIPERTENSÃO PULMONAR

DIARIAMENTE MÓNICA FAZ OXIGÉNIO E USA UM BRONCODILATADOR

PRÉMIO EM JOGO 21.250€ (EM CARTÃO)

JORNAL do ALGARVE

APHP alerta ministra da Saúde para a importância de criar centros de rastreio

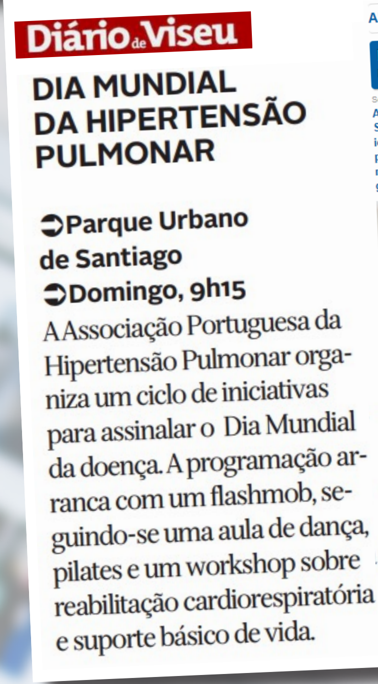
por David Carvalho | 4 Mai. 2024, 9:01

ouvir notícia

A Associação Portuguesa de Hipertensão Pulmonar (APHP) alertou a ministra da Saúde, Ana Paula Martins, para a importância de criar mais centros de rastreio que permitam a identificação de diagnósticos precoces. A APHP apela ao novo executivo para que a doença seja considerada crónica.

Identificar a doença numa fase inicial pode atenuar os sintomas e retardar a sua progressão, daí a necessidade de criar mais centros de rastreio. Além disso, a Associação apela ao novo executivo para que esta doença, "rara e incurável", seja considerada crónica, de modo a "garantir a qualidade de vida de cada português identificado".

O alerta surge no seguimento do Dia Mundial da Hipertensão Pulmonar, que se assinala a 5 de maio, e que coincide com o 20º aniversário da APHP. Para celebrar as duas décadas de existência, a associação vai juntar mais de uma centena de doentes numa "Caminhada Néon", com o mote "raros, mas não invisíveis", às 21h, de dia 4 de maio, no Largo do Rossio, em Viseu. No dia 5, as atividades vão continuar no Parque Urbano de Santiago.



Diário de Viseu

DIA MUNDIAL DA HIPERTENSÃO PULMONAR

Parque Urbano de Santiago

Domingo, 9h15

A Associação Portuguesa da Hipertensão Pulmonar organiza um ciclo de iniciativas para assinalar o Dia Mundial da doença. A programação arranca com um flashmob, seguindo-se uma aula de dança, pilates e um workshop sobre reabilitação cardiorespiratória e suporte básico de vida.

ATLAS DA SAÚDE

APHP lança repto à Ministra da Saúde

Hipertensão Pulmonar requer diagnóstico precoce e centros de rastreio

Versão de impressão

Sexta, 3 Maio, 2024 - 15:14

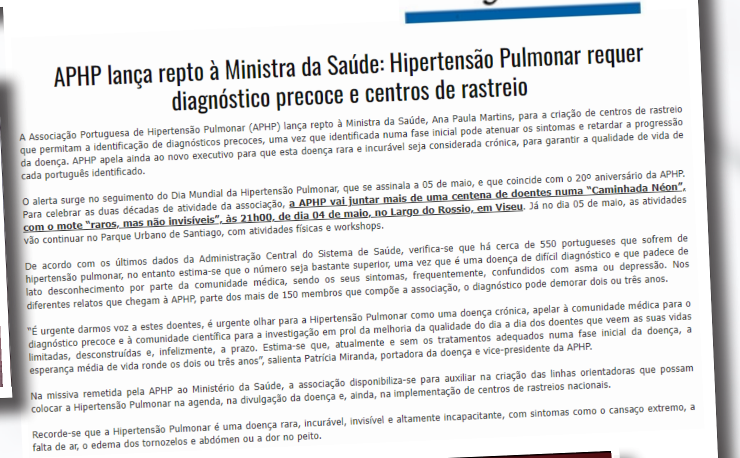
A Associação Portuguesa de Hipertensão Pulmonar (APHP) lança repto à Ministra da Saúde, Ana Paula Martins, para a criação de centros de rastreio que permitam a identificação de diagnósticos precoces, uma vez que identificada numa fase inicial pode atenuar os sintomas e retardar a progressão da doença. APHP apela ainda ao novo executivo para que esta doença rara e incurável seja considerada crónica, para garantir a qualidade de vida de cada português identificado.

O alerta surge no seguimento do Dia Mundial da Hipertensão Pulmonar, que se assinala a 05 de maio, e que coincide com o 20° aniversário da APHP. Para celebrar as duas décadas de atividade da associação, a APHP vai juntar mais de uma centena de doentes numa "Caminhada Néon", com o mote "raros, mas não invisíveis", às 21h00, de dia 04 de maio, no Largo do Rossio, em Viseu. Já no dia 05 de maio, as atividades vão continuar no Parque Urbano de Santiago, com atividades físicas e workshops.

De acordo com os últimos dados da Administração Central do Sistema de Saúde, verifica-se que há cerca de 550 portugueses que sofrem de hipertensão pulmonar, no entanto estima-se que o número seja bastante superior, uma vez que é uma doença de difícil diagnóstico e que padece de lato desconhecimento por parte da comunidade médica, sendo os seus sintomas, frequentemente, confundidos com asma ou depressão. Nos diferentes relatos que chegam à APHP, parte dos mais de 150 membros que compõe a associação, o diagnóstico pode demorar dois ou três anos.

"É urgente darmos voz a estes doentes, é urgente olhar para a Hipertensão Pulmonar como uma doença crónica, apelar à comunidade médica para o diagnóstico precoce e à comunidade científica para a investigação em prol da melhoria da qualidade do dia a dia dos doentes que veem as suas vidas limitadas, desconstruídas e, infelizmente, a prazo. Estima-se que, atualmente e sem os tratamentos adequados numa fase inicial da doença, a esperança média de vida ronde os dois ou três anos", salienta Patrícia Miranda, portadora da doença e vice-presidente da APHP.

Na missiva remetida pela APHP ao Ministério da Saú
na criação das linhas orientadoras que possam col
divulgação da doença e, ainda, na implementação de



Medjournal

APHP lança repto à Ministra da Saúde: Hipertensão Pulmonar requer diagnóstico precoce e centros de rastreio

A Associação Portuguesa de Hipertensão Pulmonar (APHP) lança repto à Ministra da Saúde, Ana Paula Martins, para a criação de centros de rastreio que permitam a identificação de diagnósticos precoces, uma vez que identificada numa fase inicial pode atenuar os sintomas e retardar a progressão da doença. APHP apela ainda ao novo executivo para que esta doença rara e incurável seja considerada crónica, para garantir a qualidade de vida de cada português identificado.

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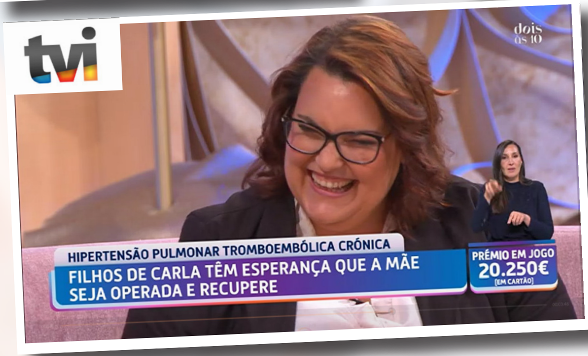
Na missiva remetida pela APHP ao Ministério da Saúde, a associação disponibiliza-se para auxiliar na criação das linhas orientadoras que possam colocar a Hipertensão Pulmonar na agenda, na divulgação da doença e, ainda, na implementação de centros de rastreios nacionais.

Recorde-se que a Hipertensão Pulmonar é uma doença rara, incurável, invisível e altamente incapacitante, com sintomas como o cansaço extremo, a falta de ar, o edema dos tornozelos e abdómen ou a dor no peito.



HIPERTENSÃO PULMONAR TROMBOEMBÓLICA CRÓNICA

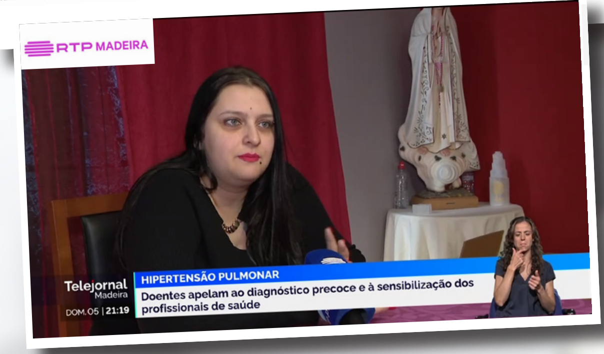
FILHOS DE CARLA TÊM ESPERANÇA QUE A MÃE SEJA OPERADA E RECUPERE

PRÉMIO EM JOGO 20.250€ (EM CARTÃO)

SEGUIR. COM TODOS OS PORMENORES. UM INC

DIRETO HIPERTENSÃO PULMONAR

É ESSENCIAL DIAGNÓSTICO PRECOCE



Telejornal Madeira

DOM. 05 | 21:19

HIPERTENSÃO PULMONAR

Doentes apelam ao diagnóstico precoce e à sensibilização dos profissionais de saúde

SAPOLIFESTYLE

Viver com hipertensão pulmonar: um testemunho rea na primeira pessoa

A crónica de Rita Rodrigues

Um artigo escrito por Rita Rodrigues, doente de Hipertensão Pulmonar e membro da Associação Portuguesa de Hipertensão Pulmonar.

Desde o momento em que vim ao mundo, a Hipertensão Pulmonar (HP) tornou-se uma companheira constante, uma sombra que me acompanha em todos os momentos da minha vida. Contudo, durante os meus primeiros 10 anos, eu não sabia o seu nome, nem entendia a sua complexidade.

Os sintomas da hipertensão pulmonar foram, muitas vezes, atribuídos a outras condições. Nunca imaginei que por trás desses sinais, como a falta de ar, fadiga, e a cor azulada dos lábios e mãos, existisse uma doença rara e intrincada, que afetaria profundamente a minha vida em todos os aspetos.

É verdade, a resiliência das crianças diante de doenças é muitas vezes admirável. Elas encontram formas de se adaptar e superar obstáculos, lutando para se integrarem plenamente na sociedade. No entanto, à medida que crescem e se tornam adultos, enfrentam novos desafios que podem

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Renascença

Hipertensão pulmonar. A "doença zebra" que se confunde pelos sintomas

05 mai, 2024 - 08:11 • Redação

Doença é rara, incurável e afeta desempenho do coração e dos pulmões. Sintomas são facilmente confundidos com outras doenças. Diagnóstico tardio pode acabar num transplante de órgãos.

Foto: Mário Cruz/Lusa

Sentir **tonturas, sensação de aperto no coração** ou **cansaço extremo** pode ser um sinal de hipertensão pulmonar que, muitas vezes, é desvalorizado como sintoma desta doença que é **rara, incurável, evolutiva** e que resulta de uma hipertensão na artéria que transporta o sangue do coração aos pulmões.

Saúde E BEM-ESTAR

Hipertensão pulmonar: reaprender a vive com uma doença crónica

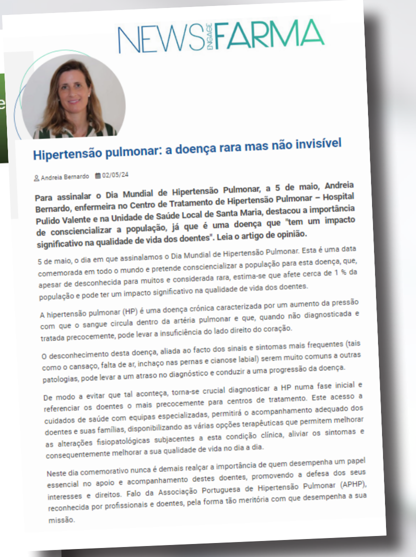
2 de Maio, 2024

Gosto 3

A hipertensão pulmonar (HP) é um problema de saúde que, a nível mundial, afeta todos os grupos etários, desde crianças a idosos, e que se destaca pela ausência de cura e pelo impacto que pode assumir nas várias dimensões de vida do doente. O diagnóstico de HP pode não ser fácil e demorar tempo até à sua concretização, devido ao facto de alguns dos sintomas serem comuns a outras doenças e, também, de os sinais e/ou sintomas em alguns doentes poderem ser ténues numa fase inicial.

Artigo da responsabilidade de Cátia Rodrigues. Presidente da Associação Portuguesa de Hipertensão Pulmonar

A HP consiste numa doença rara, sem um tratamento curativo e por isso é uma condição de saúde crónica com sintomatologia diversa (e.g., dispneia, fadiga, dor torácica, perda de peso, palpitações). Muitas vezes, o doente não consegue aguentar as condições e responsabilidades do seu trabalho, podendo mesmo ter que se despedir do emprego devido à severidade dos sintomas, complexidade do tratamento ou sofrimento psicológico associado à doença[i], reformando-se precocemente devido a esta incapacidade (pensão por invalidez), o que se traduz num impacto negativo no rendimento familiar.



NEWS ENGAGE FARMA

Hipertensão pulmonar: a doença rara mas não invisível

Andreia Bernardo 02/05/24

Para assinalar o Dia Mundial de Hipertensão Pulmonar, a 5 de maio, Andreia Bernardo, enfermeira no Centro de Tratamento de Hipertensão Pulmonar – Hospital Pulido Valente e na Unidade de Saúde Local de Santa Maria, destacou a importância de consciencializar a população, já que é uma doença que "tem um impacto significativo na qualidade de vida dos doentes". Leia o artigo de opinião.

5 de maio, o dia em que assinalamos o Dia Mundial de Hipertensão Pulmonar. Esta é uma data comemorada em todo o mundo e pretende consciencializar a população para esta doença, que, apesar de desconhecida para muitos e considerada rara, estima-se que afete cerca de 1 % da população e pode ter um impacto significativo na qualidade de vida dos doentes.

A hipertensão pulmonar (HP) é uma doença crónica caracterizada por um aumento da pressão com que o sangue circula dentro da artéria pulmonar e que, quando não diagnosticada e tratada precocemente, pode levar a insuficiência do lado direito do coração.

O desconhecimento desta doença, aliada ao facto dos sinais e sintomas mais frequentes (tais como o cansaço, falta de ar, inchaço nas pernas e cianose labial) serem muito comuns a outras patologias, pode levar a um atraso no diagnóstico e conduzir a uma progressão da doença.

De modo a evitar que tal aconteça, torna-se crucial diagnosticar a HP numa fase inicial e referenciar os doentes o mais precocemente para centros de tratamento. Este acesso a cuidados de saúde com equipas especializadas, permitirá o acompanhamento adequado dos doentes e suas famílias, disponibilizando as várias opções terapêuticas que permitem melhorar as alterações fisiopatológicas subjacentes a esta condição clínica, aliviar os sintomas e consequentemente melhorar a sua qualidade de vida no dia a dia.

Neste dia comemorativo nunca é demais realçar a importância de quem desempenha um papel essencial no apoio e acompanhamento destes doentes, promovendo a defesa dos seus interesses e direitos. Falo da Associação Portuguesa de Hipertensão Pulmonar (APHP), reconhecida por profissionais e doentes, pela forma tão meritória com que desempenha a sua missão.

Slovakia

Pľúcna hypertenzia väčšinou vzniká, ako následok iného ochorenia

Orawan Pattarawimonchai/shutterstock

Pľúcna hypertenzia je závažné ochorenie vznikajúce následkom postihnutia drobných pľúcnych tepien. Viete, ako sa prejavuje a aké sú spôsoby liečby?

V nasledujúcom článku sa dozviete:

- čo je pľúcna hypertenzia
- ako sa pľúcna hypertenzia prejavuje
- aké typy pľúcnej hypertenzie poznáme
- ako prebieha diagnostika ochorenia
- aké možnosti liečby existujú

hypertenzia Vnútorné lekárstvo pľúcna hypertenzia

Pľúcna hypertenzia je ochorenie, ktoré sa **najčastejšie diagnostikuje medzi 40. až 50. rokom života, v pokročilom štádiu.** Výrazne **skracuje život pacienta** a obmedzuje ho pri bežných činnostiach.

Neliečení pacienti zomierajú do dvoch či troch rokov na zlyhanie srdca a len 40 % pacientov sa dožíva piatich rokov od **diagnostikovania choroby.**

Súvisiace články

01 Medicínske **Pomáha alkohol znížiť krvn tlak?** 15. 01. 2024 • 7 minút na prečítanie

02 Medicínske **6 príznakov vysokého krvné tlaku a aké komplikácie môž spôsobiť** 5. 02. 2024 • 7 minút na prečítanie

03 Medicínske **Tichá choroba - vysoký krvn tlak** 17. 05. 2016 • 5 minút na prečítanie

04 Medicínske **Krvný tlak môže pri záťaži stúpnuť až o 20 mmHg. Je to**

KATOLÍCKE NOVINY 9. 6. 2024 DESIATA NEDEĽA V CEZROČNO

16 / PROFIL

SO ZRIEDKAVÝM OCHORENÍM POMOHLA LEN TRANSPLANTÁCIA

Obráť sa k slnku a tiene padnú za teb

Iveta Makovníková s manželom Vladimírom, synom Petrom a jeho priateľkou Michaelou. Snímka: archív –IM–

Keď Iveta Makovníková (63) oslávila štyridsiatku, netušila, že o tri roky sa jej pekný, vyrovnaný život zmení. Nevyliečiteľné ochorenie ovplyvnilo celú rodinu.

LÍVIA DVORSKÁ

Rodáčka a lokálpatriotka žije od detstva vo Veľkom Krtíši. Tu vyrastala aj zapustila korene. Tu žije s manželom Vladimírom a tu vychovala aj svoje deti Martina a Petra. Vyštudovaná učiteľka druhého stupňa žila svoj život s bežnými radosťami i starosťami. Okrem rodiny sa venovala aj obľúbenej práci – vyučovaniu matematiky a základov techniky na základnej škole v neďalekej obci Čebovce.

> Najkrajšia chvíľa v mojom živote bola, keď som opäť vystúpila na Brestovú.

NECHCENÁ SPOLOČNÍČK

KATOLÍCKE NOVINY 9. 6. 2

PROFIL / 1

> Darovanie orgánu je ušľachtilá vec. Som za záchranu svojho života nesmierne vďačná.

mala som závraty a neskôr som sa začala zadýchavať aj pri chôdzi po rovine," spomína na prvé prejavy svojej nechcenej „spoločníčky".

Niekoľkokrát počas roka navštívila praktického lekára, ktorý podľa nej nebral jej problémy vážne a neposlal ju na žiadne odborné vyšetrenie.

Sympatická bojovníčka hovorí, že „mala šťastie v nešťastí", keď dostala obličkovú koliku a ocitla sa v martinskej nemocnici. Počas dvoch mesiacov absolvovala množstvo vyšetrení na I. internej klinike s podozrením na viaceré závažné diagnózy.

Lekári najprv nevedeli, či ide o pľúcnu embóliu, sarkoidózu alebo pľúcnu fibrózu. Nakoniec vyslovili podozrenie na pľúcnu artériovú hypertenziu (PAH). „Poslali ma do Bratislavy do Národného ústavu srdcových a cievnych chorôb, na oddelenie zlyhávania a transplantácie srdca. Tam mi po ďalších invazívnych vyšetreniach potvrdili, že naozaj ide o uvedené ochorenie ťažkého stupňa." S prívlastkom idiopatické, teda vzniknuté bez známej príčiny. U nikoho z rodiny sa predtým a ani následne táto choroba nevyskytla.

SEDEM ROKOV UTRPENIA

Po stanovení diagnózy sa jej, paradoxne, uľavilo. „Myslela som si, že keď dostanem liečbu, všetko sa napraví. No pravda bola šokujúca. PAH je nevyliečiteľné ochorenie, rýchlo sa zhoršuje a pacient sa bez liečby dožije priemerne dva roky, s liečbou asi päť," vysvetľuje.

Ochorenie Ivetky, ktorá má rada aktívny život, trvalo rovnaký čas ako v známom príbehu zo Starého zákona o siedmich rokoch neúrody a hladu. Keď energickej žene

PAH je zriedkavé ochorenie, ktoré postihuje päť percent obyvateľstva. Združenie pacientov s pľúcnou hypertenziou (ZPPH) založila Iveta Makovníková, pretože v čase svojho ochorenia nepoznala nikoho s touto diagnózou a nemala o nej s kým hovoriť. „Potrebovala som viac informácií a akúsi spolupatričnosť. Verila som, že podobne to cítia aj ostatní. A keďže sa PAH diagnostikuje veľmi ťažko, cítila som potrebu šírenia osvety, aby sa zachránilo čo najviac životov. Podstatou je včasná diagnostika a liečba," hovorí.

Združenie má celoslovenskú pôsobnosť, združuje dospelých od 18 rokov, deti s PAH zastupujú rodičia. V súčasnosti má 76 členov vo veku od 29 do 80 rokov, z toho rodičov dvoch detí. Okrem pacientov sú členmi združenia aj ich rodinní príslušníci, lekári, zdravotníci a všetci, ktorým je problematika pľúcnej hypertenzie blízka.

ZPPH je členom PHA Europe, EURORDIS (Európska organizácia pre zriedkavé choroby), Slovenskej aliancie zriedkavých chorôb a partnerom OZ Zriedkavé choroby.

„Mala som problém prejsť pár metrov, srdce bolo veľmi preťažené a pri vstávaní som niekoľkokrát stratila vedomie. Hľadala som preto akúkoľvek pomoc." Vyskúšala viacero alternatív, ako si v chorobe polepšiť, až sa napokon dočkala vhodného lieku. Priniesol jej nádej a pomohol zlepšiť jej stav.

Pracovať mohla aspoň na čiastočný úväzok, potom strávila osemnásť hodín na oxygenoterapii – od odchodu z práce až do nasledujúceho rána. Domácnosť však už nezvládala. Postupom času, žiaľ, lieky prestali zaberať a stav sa zhoršoval, až choroba dosiahla vrchol. Ivetka sa musela vzdať práce aj obľúbenej mimoškolskej činnosti s deťmi. „Mala som problémy už aj s osobnou hygienou, obliekaním, obúvaním, bola som 24 hodín na kyslíku."

JEDINÉ RIEŠENIE

Koncom marca 2011 oslávila Iveta

Bolo to jediné riešenie. PAH je nevyliečiteľná choroba, na ktorú zatiaľ neexistuje liek. Špeciálna liečba môže len zlepšiť prejavy ochorenia a predĺžiť prežívanie pacienta, ktoré sa však rýchlo zhoršuje. „Len asi tridsať percent pacientov má šancu dostať sa na transplantáciu pľúc, prípadne kombinovanú transplantáciu srdca a pľúc."

Iveta bola jedným z nich. „Mala som dôveru v lekársky tím profesora Waltera Klepetka, je to najlepší tím v Európe. Dostala som pľúca, s ktorými žijem bez problémov už trinásť rokov," hovorí s vďačnosťou. Pľúcnu hypertenziu už nemá a jej zdravotný stav sa upravil do normálu pred ochorením. Opäť je fyzicky aktívna.

SEN, KTORÝ SA SPLNIL

Napriek všetkým ťažkostiam a mnohému utrpeniu, ktoré musela Iveta obetovať, nikdy nepochy

pacientom prekonávať ťažké chvíl spojené s týmto ochorením."

Ona sama ich prežívala, keď nik to nechápal, ako vážne je chorá. Dokonca aj príbuzní, ktorí jej napokon boli veľkou oporou, si dlho mysleli, že svoje trápenie si len vymýšľa. S týmto problémom sa podľa nej stretáva väčšina pacientov.

„Najkrajšia chvíľa v mojom živote po transplantácii bola, keď som päť rokov nato vystúpila na Brestovú v Západných Tatrách. Bol to sen, ktorý sa mi splnil," hovorí s radosťou.

PO DARCOVI NEPÁTRA

Čo všetko obetovala ochoreniu, čoho všetkého sa musela vzdať? „Zmeškala som takmer všetky dôležité udalosti v rodine, stratila som kontakt s väčšinou priateľov, nemohla som si dopriať dovolenku... Tých obmedzení bolo veľa, ale najviac mi chýbalo obyčajné chodenie von, na vychádzky, do prírody," konštatuje.

Po svojom darcovi či darkyni nepátra. „Darovanie orgánu je ušľachtilá vec. Som za záchranu svojho života nesmierne vďačná Bohu i darcovi, no nikdy som nemala v úmysle pátrať po ňom. Nemá to zmysel a ani to nie je možné zistiť."

LÁSKA JE NAJVYŠŠIA HODNOTA

Najvyššia hodnota života je podľa sympatickej tmavovlásky láska, dobré vzťahy medzi ľuďmi, vzájomná pomoc a úcta. Iveta sa snaží žiť podľa motta: Obráť svoju tvár k slnku a všetky tiene padnú za teba. Celý svoj voľný čas venuje združeniu pacientov s rovnakým ochorením a najväčším potešením je dvaapolročný vnúčik Patrik.

Iveta Makovníková má ešte niekoľko cieľov a snov. „Odovzdať svoje dielo nasledovníkom, ktorí budú

Kn

Téma Reportáž Rozhovor Mladým Deťom Misie Profil

Obráť sa k slnku a tiene padnú za teba

Keď Iveta Makovníková (63) oslávila štyridsiatku, netušila, že o tri roky sa jej pekný, vyrovnaný život zmení. Nevyliečiteľné ochorenie ovplyvnilo celú rodinu.

Lívia Dvorská 10.06.2024

Iveta Makovníková s manželom Vladimírom, synom Petrom a jeho priateľkou Michaelou. Snímka: archív –IM–

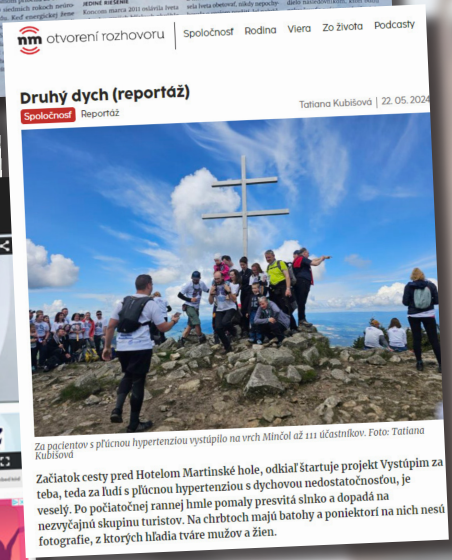
Rodáčka a lokálpatriotka žije od detstva vo Veľkom Krtíši. Tu vyrastala aj zapustila korene. Tu žije s manželom Vladimírom a tu vychovala aj svoje deti Martina a Petra. Vyštudovaná učiteľka druhého stupňa žila svoj život s bežnými radosťami i starosťami. Okrem rodiny sa venovala aj obľúbenej práci – vyučovaniu matematiky a základov techniky na základnej škole v neďalekej obci Čebovce.

NECHCENÁ SPOLOČNÍČKA

6.5.2024 • Štúdio JOJ 24

Štúdio 24 o pľúcnej artériovej hypertenzii

BRATISLAVA / Pľúcna artériová hypertenzia je vzácne ochorenie, ktoré postihuje 52 ľudí z 1 milióna a spája sa s vysokou úmrtnosťou. Medzinárodný deň tohto ochorenia si pripomíname 5. mája. Viac si o tejto chorobe, jej príčinách či možnej prevencii povedala v Štúdiu 24 moderátorka Mária Ölvedyová so svojím hosťom, ktorým bol doktor Milan Luknár z Národného ústavu srdcových a cievnych chorôb.



nm otvorení rozhovoru | Spoločnosť Rodina Viera Zo života Podcasty

Druhý dych (reportáž)

Spoločnosť Reportáž

Tatiana Kubišová | 22. 05. 2024

Za pacientov s pľúcnou hypertenziou vystúpilo na vrch Minčol až 111 účastníkov. Foto: Tatiana Kubišová

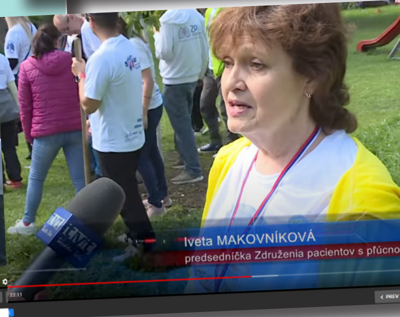
Začiatok cesty pred Hotelom Martinské hole, odkiaľ štartuje projekt Vystúpim za teba, teda za ľudí s pľúcnou hypertenziou s dychovou nedostatočnosťou, je veselý. Po počiatočnej rannej hmle pomaly presvitá slnko a dopadá na nezvyčajnú skupinu turistov. Na chrbtoch majú batohy a poniektorí na nich nesú fotografie, z ktorých hľadia tváre mužov a žien.

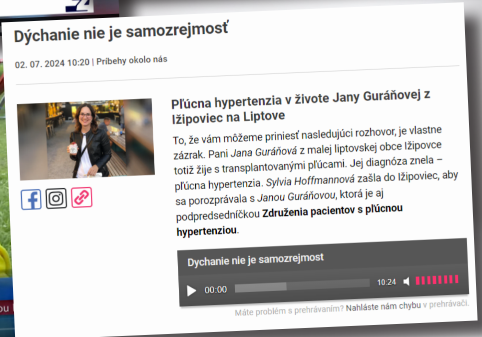
Vystúpili na vrch Minčol, aby pacientom s pľúcnou hypertenziou symbolicky darovali dych

Daruj dych pre pľúcnu hypertenziu! Tak znel názov podujatia, ktoré sa konalo pri príležitosti Sveto pľúcnej hypertenzie pod záštitou primátora mesta Martin. Združenie pacientov s pľúcnou hypertenzi rámci neho 17. a 18. mája zorganizovalo informačný seminár o detskej pľúcnej hypertenzii, výstu Minčol a nechýbalo ani symbolické vysadenie stromu v meste Martin. Prečítajte si o aktivitách zdru kliknutím na nadpis tohto príspevku.

vné správy TVT 22.5.2024

webových stránkach používame súbory cookie, aby sme vám poskytli najlepší konfort tým, že si zapamätáme vaše preferencie a opakované návštevy. Kliknutím na „Prijať všetky" súhlasíte VŠETKÝCH súborov cookie. Môžete však navštíviť „Nastavenia cookies" a poskytnúť kontrolovaný súhlas.





Dýchanie nie je samozrejmosť

02. 07. 2024 10:20 | Príbehy okolo nás

Pľúcna hypertenzia v živote Jany Guráňovej z Ižipoviec na Liptove

To, že vám môžeme priniesť nasledujúci rozhovor, je vlastne zázrak. Pani *Jana Guráňová* z malej liptovskej obce Ižipovce totiž žije s transplantovanými pľúcami. Jej diagnóza znela – pľúcna hypertenzia. *Sylvia Hoffmannová* zašla do Ižipoviec, aby sa porozprávala s *Janou Guráňovou*, ktorá je aj podpredsedníčkou **Združenia pacientov s pľúcnou hypertenziou**.

Máte problém s prehrávaním? Nahláste nám chybu v prehrávači.

Slovenia

SLOVENIJA

Pljučna hipertenzija: kot bi dihali z nosno ščipalko in dvema slamicama v ustih

Ljubljana, 19. 05. 2024 14.08 | Posodobljeno pred 16 dnevi

PREDVIDEN ČAS BRANJA: 2 min

AVTOR N.L.

KOMENTARJI 3

Si predstavljate, da bi dihali z nosno ščipalko in dvema slamicama v ustih? Takšen je namreč prikaz, kako je dihati s pljuči bolnika, ki ima pljučno hipertenzijo. Člani Društva za pljučno hipertenzijo Slovenije so konec tedna v Ljubljani pripravili dogodek 'Vsak vdih šteje', na katerem so mimoidoče ozaveščali o tej bolezni in njenih simptomih.

Sporočilo za javnost po dogodku v Ljubljani objavljeno na portalu z največjim dosegom v Sloveniji – 24ur.com (doseg: 952.216 ljudi)

Error. Please login.

10.05.2024 | Gorenjski glas

STRAN,TERMIN: 9

RUBRIKA,ODDAJA: AKTUALNO

POVRŠINA,TRAJANJE: 90,02

AVTOR: Nika Toporiš

Ključne besede (potrebna prijava)

Simptomi so atipični

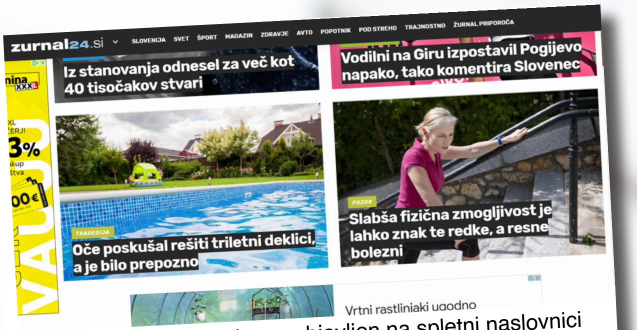
b svetovnem dnevu pljučne hipertenzije Društvo za pljučno hipertenzijo Slov poudarja relativno slabo razumevanje te bolezni tako med splošno javnostjo med družinskimi zdravniki.

Simptomi so atipični

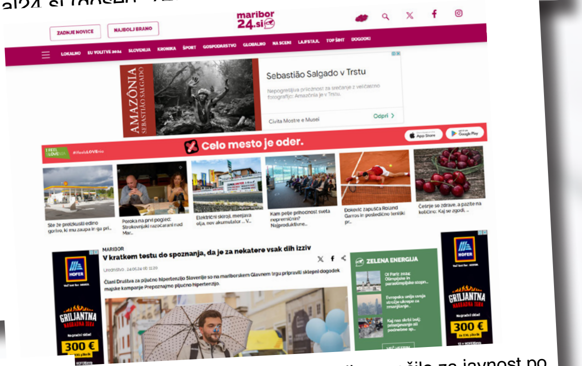
Nika Toporiš

Ob svetovnem dnevu pljučne hipertenzije Društvo za pljučno hipertenzijo Slovenije poudarja relativno slabo razumevanje te bolezni tako med splošno javnostjo kot med družinskimi zdravniki. Posledično se postopek diagnosticiranja bolnikov podaljšuje, možnosti za ustrezno in pravočasno zdravljenje pa se zmanjšujejo. Gre za bolezen, ki prizadene pljuča in srce. »S kampanjo Prepoznajmo pljučno hipertenzijo želimo širiti ozaveščenost o tej bolezni in izboljšati možnosti za zgodnje zdravljenje,« je poudarila Tadeja Ravnik, predsednica društva. Ena največjih ovir pri prepoznavanju in diagnosticiranju bolezni so atipični simptomi, ki jo spremljajo. Simptome pljučne hipertenzije namreč lahko preprosto pripišemo tudi drugim, pogostejšim boleznim, kot so astma, kronična obstruktivna pljučna bolezen ali srčno popuščanje. Kot je še opozorila predsednica društva, naj bodo posamezniki v prvi vrsti pozorni na zmanjšanje fizične zmogljivosti. »Če ste pred nekaj meseci brez težav hodili v hribe in osvojiti tudi najvišje vrhove, zdaj pa se zadihate že pri hoji v prvo nadstropje – ali še huje: pri preoblačenju domače postelje – je to resen opozorilni znak,« je poudarila Tadeja Ravnik in med pogostimi simptomi navedla še omotičnost, omedlevico, pogost kašelj, otekle noge in gležnje ter pospešeno bitje srca.

Lokalni medij Gorenjski glas je novico ob svetovnem dnevu objavil v tisku in na spletu (doseg spletnega medija: 106.101 ljudi)



Članek ob svetovnem dnevu objavljen na spletni naslovnici Žurnal24.si (doseg: 742.910 ljudi)



MARIBOR

V kratkem testu do spoznanja, da je za nekatere vsak dih izziv

Uredništvo, 24.05.24 ob 11:20

Člani Društva za pljučno hipertenzijo Slovenije so na mariborskem Glavnem trgu pripravili sklepni dogodek majske kampanje Prepoznajmo pljučno hipertenzijo.

Lokalni medij maribor24.si je objavil sporočilo za javnost po dogodku v MB (doseg: 423.562 ljudi)

Zmanjšanje fizične zmogljivosti je lahko znak te redke, a resne bolezni

Med.Over.Net, 05. maj 2024 BOLEZNI SRCA IN OŽILJA PULMOLOGIJA

Ključni izziv pri prepoznavanju in diagnosticiranju pljučne hipertenzije so atipični simptomi, ki bolezen spremljajo.

Simptome pljučne hipertenzije namreč zlahka pripišemo tudi drugim veliko pogostejšim boleznim, kot so astma, kronična obstruktivna pljučna bolezen (KOPB) ali popuščanje levega prekata srca. Pa tudi starosti, povišani telesni masi in zmanjšani kondiciji.

Društvo za pljučno hipertenzijo Slovenije **ob svetovnem dnevu pljučne hipertenzije, ki ga obeležujemo 5. maja** opozarja na relativno slabo poznavanje bolezni med širšo javnostjo in družinskimi zdravniki, kar podaljšuje diagnosticiranje bolnikov in zmanjšuje možnost, da bolniki do ustreznega zdravljenja pridejo pravočasno. *"S kampanjo 'Prepoznajmo pljučno hipertenzijo' želimo razširiti zavedanje o obstoju te bolezni in povečati možnost, da bolnik do ustreznega zdravljenja pride v čim bolj zgodni fazi bolezni,"* poudarja **Tadeja Ravnik**, predsednica društva.

Pljučna hipertenzija je bolezen, ki prizadene pljuča in srce. O bolezni govorimo takrat, ko je invazivno izmerjen srednji tlak v pljučni arteriji višji od 20 mmHg. To pomeni, da mora srce kri črpati proti večjemu pritisku (uporu) in je zato vedno bolj obremenjeno. Posledično pride do funkcionalnih in morfoloških sprememb desne polovice srca in v končni fazi do desnostranskega srčnega popuščanja, kar je tudi vzrok smrti bolnikov s pljučno hipertenzijo, opozarja **asist. dr. Polona Mlakar, dr. med.**, spec. interne medicine.

06.05.2024 | Delo

STRAN,TERMIN: 8

RUBRIKA,ODDAJA: GENERACIJA +

POVRŠINA,TRAJANJE: 353,03

AVTOR: STA

Ključne besede (potrebna prijava)

Bolezen, ki jo celo družinski zdravniki slabo poznajo

Pljučna hipertenzija Nobene vrste te bolezni ni mogoče zaznati s telesnim pregledom, ki ga opravi družinski zdravnik

Bolezen, ki jo celo družinski zdravniki slabo poznajo

Ko bolezen resno ogrozi desno stran srca, se lahko pojavijo tudi kronična utrujenost, izraziti edemi gležnjev, utripajoč občutek v vratu ...

- Slabo poznavanje podaljšuje diagnosticiranje.
- Napredek pri zdravljenju edine nozdravljive vrste pljučne hipertenzije.
- Posamezniki naj bodo pozorni na zmanjšanje fizične zmogljivosti.

Pomembno je, da družinski zdravniki ob simptomih, ki jih ne morejo pojasniti z drugimi obolenji, pomislijo na možnost pljučne hipertenzije in bolnika napotijo k zdravniku specialistu.

SLOVENIJA

Bolezen, ki jo celo družinski zdravniki relativno slabo poznajo

Nobene od petih vrst pljučne hipertenzije ni mogoče zaznati s telesnim pregledom, ki ga opravi družinski zdravnik.

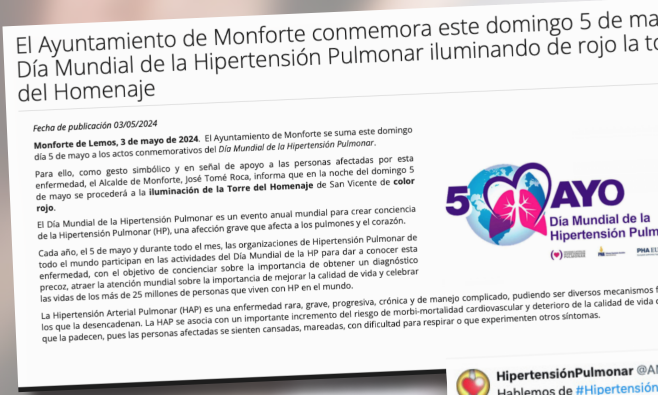
Več kot sto ljudi sredi Ljubljane ostalo brez sape

Društvo za pljučno hipertenzijo, 21. maj 2024 KARDIOLOGIJA PULMOLOGIJA

Brez sape so ostali tudi paraolimpijka Lena Gabršček, športni novinar Anže Bašelj, stand up komedijantka Ana Maria Mitič in nekdanji tekmovalec šova MasterChef Gašper Kramar.

Objava na največjem zdravstvenem portalu v Sloveniji med.over.net po dogodku v LJ(doseg: 410.025 ljudi).

Spain ANHP



El Ayuntamiento de Monforte conmemora este domingo 5 de may Día Mundial de la Hipertensión Pulmonar iluminando de rojo la to del Homenaje

Fecha de publicación 03/05/2024

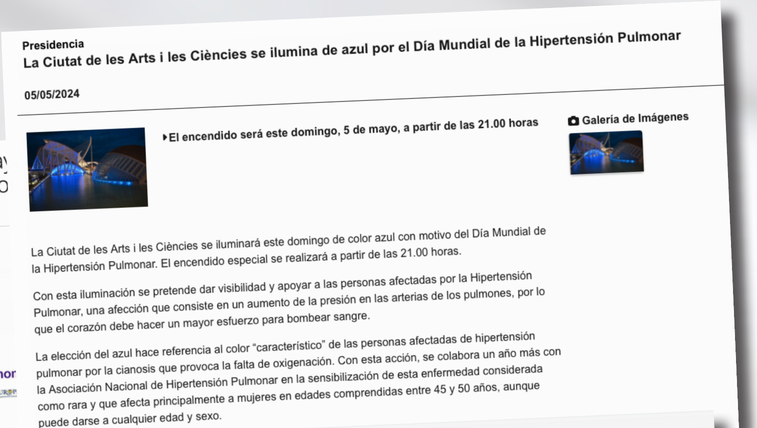
Monforte de Lemos, 3 de mayo de 2024. El Ayuntamiento de Monforte se suma este domingo día 5 de mayo a los actos conmemorativos del *Día Mundial de la Hipertensión Pulmonar*.

Para ello, como gesto simbólico y en señal de apoyo a las personas afectadas por esta enfermedad, el Alcalde de Monforte, José Tomé Roca, informa que en la noche del domingo 5 de mayo se procederá a la **iluminación de la Torre del Homenaje** de San Vicente de **color rojo**.

El Día Mundial de la Hipertensión Pulmonar es un evento anual mundial para crear conciencia de la Hipertensión Pulmonar (HP), una afección grave que afecta a los pulmones y el corazón.

Cada año, el 5 de mayo y durante todo el mes, las organizaciones de Hipertensión Pulmonar de todo el mundo participan en las actividades del Día Mundial de la HP para dar a conocer esta enfermedad, con el objetivo de concienciar sobre la importancia de obtener un diagnóstico precoz, atraer la atención mundial sobre la importancia de mejorar la calidad de vida y celebrar las vidas de los más de 25 millones de personas que viven con HP en el mundo.

La Hipertensión Arterial Pulmonar (HAP) es una enfermedad rara, grave, progresiva, crónica y de manejo complicado, pudiendo ser diversos mecanismos fisiop los que la desencadenan. La HAP se asocia con un importante incremento del riesgo de morbi-mortalidad cardiovascular y deterioro de la calidad de vida de lo que la padecen, pues las personas afectadas se sienten cansadas, mareadas, con dificultad para respirar o que experimenten otros síntomas.



Presidencia

La Ciutat de les Arts i les Ciències se ilumina de azul por el Día Mundial de la Hipertensión Pulmonar

05/05/2024

▸El encendido será este domingo, 5 de mayo, a partir de las 21.00 horas

Galería de Imágenes

La Ciutat de les Arts i les Ciències se iluminará este domingo de color azul con motivo del Día Mundial de la Hipertensión Pulmonar. El encendido especial se realizará a partir de las 21.00 horas.

Con esta iluminación se pretende dar visibilidad y apoyar a las personas afectadas por la Hipertensión Pulmonar, una afección que consiste en un aumento de la presión en las arterias de los pulmones, por lo que el corazón debe hacer un mayor esfuerzo para bombear sangre.

La elección del azul hace referencia al color "característico" de las personas afectadas de hipertensión pulmonar por la cianosis que provoca la falta de oxigenación. Con esta acción, se colabora un año más con la Asociación Nacional de Hipertensión Pulmonar en la sensibilización de esta enfermedad considerada como rara y que afecta principalmente a mujeres en edades comprendidas entre 45 y 50 años, aunque puede darse a cualquier edad y sexo.

DÍA MUNDIAL DE LA HIPERTENSIÓN PULMONAR

Más de 5.000 personas padecen hipertensión pulmonar en España

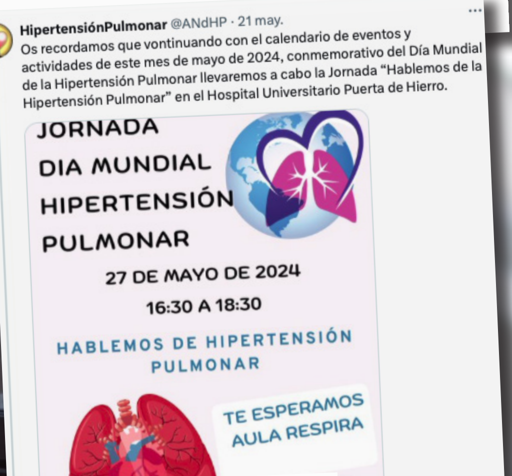
PUBLICADO EL 5 DE MAYO DE 2024 A LAS 16:07 POR SOMOS PACIENTES

Asociaciones, Enfermedades raras

COMENTAR

El 5 de mayo se conmemora el **Día Mundial de la Hipertensión Pulmonar**, una enfermedad rara que padecen más de 5.000 personas en España: unas 4.600 adultas y 500 en edades pediátricas. Se caracteriza por un aumento en la presión de las arterias que comunican el corazón con los pulmones, lo que provoca un sobreesfuerzo cardíaco que, sin el tratamiento adecuado, puede llevar a un fallo cardíaco y, en definitiva, a la muerte.

HipertensiónPulmonar @ANdHP · 27 may.
Hablemos de #HipertensiónPulmonar y conozcamos la importanci #diagnósticoprecoz y cuál es el presente y futuro en #hipertensiónpulmonar de la mano del Dr. Manuel Gómez Bueno
#JornadaPacientes
#WPHD2024
#HipersensibilizateSomosHipertensiónPulmonar



HipertensiónPulmonar @ANdHP · 21 may.
Os recordamos que vontinuando con el calendario de eventos y actividades de este mes de mayo de 2024, conmemorativo del Día Mundial de la Hipertensión Pulmonar llevaremos a cabo la Jornada "Hablemos de la Hipertensión Pulmonar" en el Hospital Universitario Puerta de Hierro.

Comunidad Valenciana | europa press

La Ciutat de les Arts i les Ciències se ilumina de azul por el Día Mundial de la Hipertensión Pulmonar

La Ciutat de les Arts i les Ciències se ilumina de azul por el Día Mundial de la Hipertensión Pulmonar - GVA

C. Valenciana

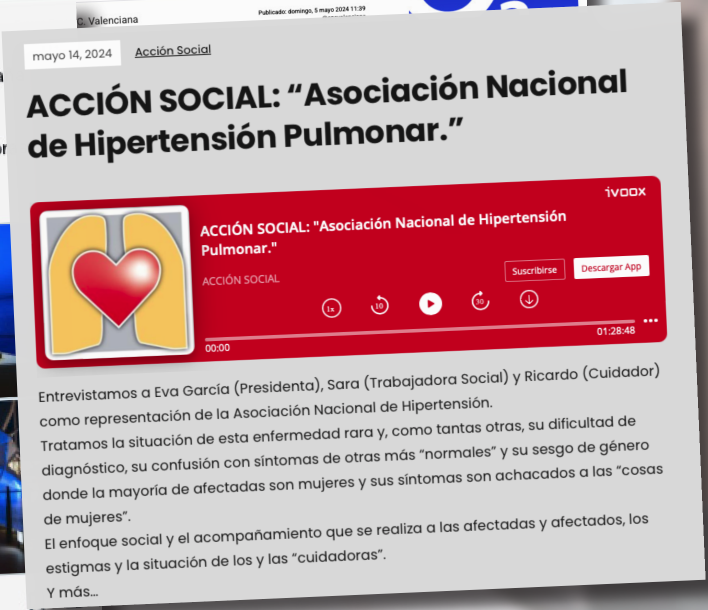
Publicado: domingo, 5 mayo 2024 11:39

Reposteaste

Ciudad Artes Ciencia @CACiencies · 5 may.
En el #DíaMundialHipertensiónPulmonar colaboramos con la campa "Ilumina por la Hipertensión Pulmonar"

El azul será hoy el color de nuestros edificios a partir de las 21.00 hor

@ANdHP



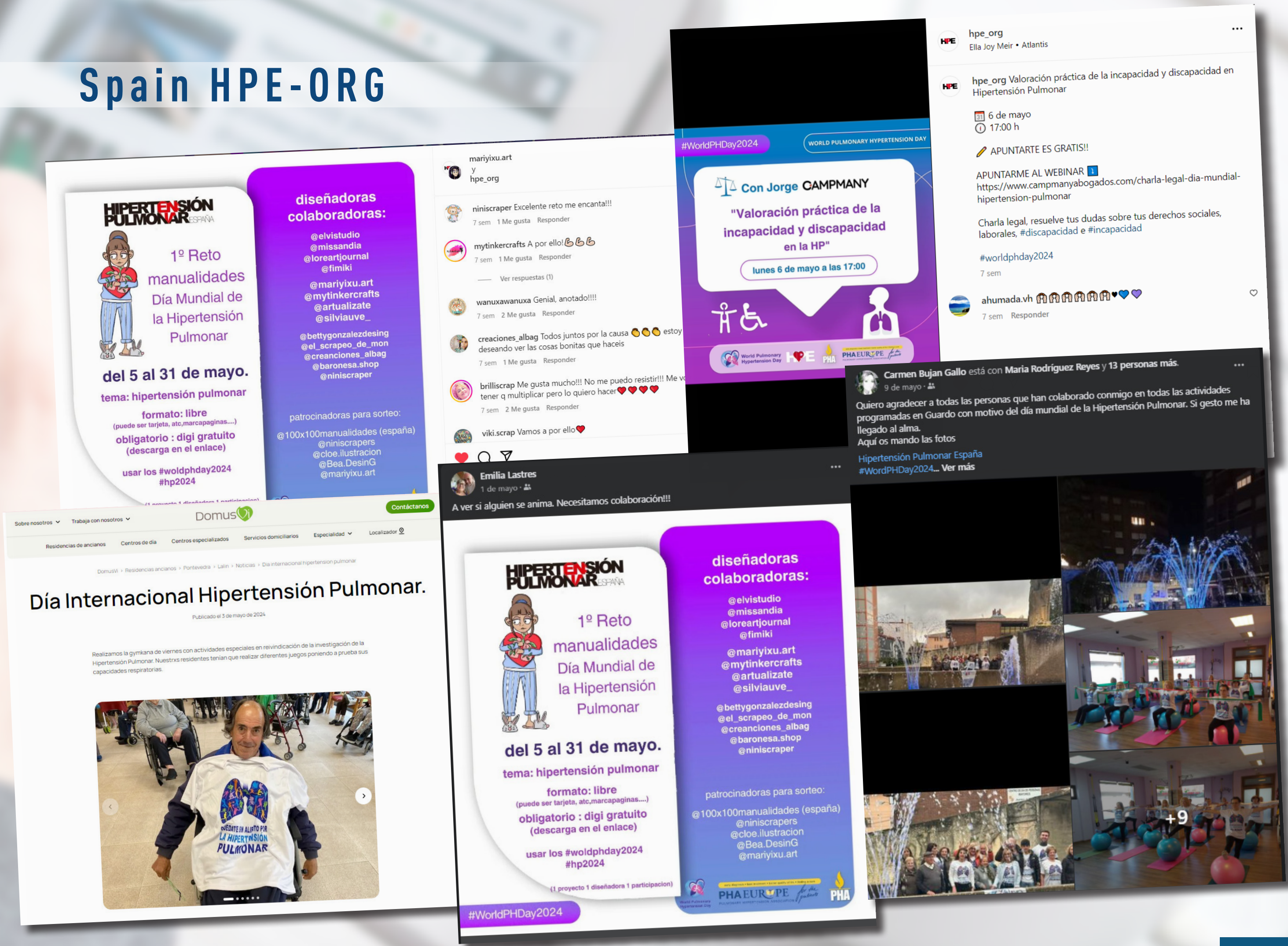
mayo 14, 2024 Acción Social

ACCIÓN SOCIAL: "Asociación Nacional de Hipertensión Pulmonar."

Entrevistamos a Eva García (Presidenta), Sara (Trabajadora Social) y Ricardo (Cuidador) como representación de la Asociación Nacional de Hipertensión.
Tratamos la situación de esta enfermedad rara y, como tantas otras, su dificultad de diagnóstico, su confusión con síntomas de otras más "normales" y su sesgo de género donde la mayoría de afectadas son mujeres y sus síntomas son achacados a las "cosas de mujeres".
El enfoque social y el acompañamiento que se realiza a las afectadas y afectados, los estigmas y la situación de los y las "cuidadoras".
Y más...

Spain FCHP

Spain HPE-ORG



HIPERTENSIÓN PULMONAR ESPAÑA

1º Reto manualidades Día Mundial de la Hipertensión Pulmonar

del 5 al 31 de mayo.

tema: hipertensión pulmonar

formato: libre
(puede ser tarjeta, atc,marcapaginas....)

obligatorio : digi gratuito
(descarga en el enlace)

usar los #woldphday2024
#hp2024

diseñadoras colaboradoras:

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patrocinadoras para sorteo:

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@niniscrapers
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@Bea.DesinG
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mariyixu.art
y
hpe_org

niniscraper Excelente reto me encanta!!!
7 sem 1 Me gusta Responder

mytinkercrafts A por ello!💪💪💪
7 sem 1 Me gusta Responder

Ver respuestas (1)

wanuxawanuxa Genial, anotado!!!!
7 sem 2 Me gusta Responder

creaciones_albag Todos juntos por la causa 👏👏👏 estoy
deseando ver las cosas bonitas que haceis
7 sem 1 Me gusta Responder

brilliscrap Me gusta mucho!!! No me puedo resistir!!! Me vo
tener q multiplicar pero lo quiero hacer❤❤❤❤
7 sem 2 Me gusta Responder

viki.scrap Vamos a por ello❤

#WorldPHDay2024

WORLD PULMONARY HYPERTENSION DAY

Con Jorge CAMPMANY

"Valoración práctica de la incapacidad y discapacidad en la HP"

lunes 6 de mayo a las 17:00

World Pulmonary Hypertension Day HPE PHA PHA EUROPE

hpe_org
Ella Joy Meir • Atlantis

hpe_org Valoración práctica de la incapacidad y discapacidad en Hipertensión Pulmonar

📅 6 de mayo
🕐 17:00 h

✏ APUNTARTE ES GRATIS!!

APUNTARME AL WEBINAR ⬇
https://www.campmanyabogados.com/charla-legal-dia-mundial-hipertension-pulmonar

Charla legal, resuelve tus dudas sobre tus derechos sociales, laborales, #discapacidad e #incapacidad

#worldphday2024

7 sem

ahumada.vh 🙌🙌🙌🙌🙌🙌♥💙💜
7 sem Responder

Carmen Bujan Gallo está con **Maria Rodríguez Reyes** y **13 personas más.**
9 de mayo

Quiero agradecer a todas las personas que han colaborado conmigo en todas las actividades programadas en Guardo con motivo del día mundial de la Hipertensión Pulmonar. Si gesto me ha llegado al alma.
Aquí os mando las fotos

Hipertensión Pulmonar España
#WordPHDay2024... **Ver más**

+9

Emilia Lastres
1 de mayo

A ver si alguien se anima. Necesitamos colaboración!!!

DomusVi

Sobre nosotros · Trabaja con nosotros · Contáctanos
Residencias de ancianos · Centros de día · Centros especializados · Servicios domiciliarios · Especialidad · Localizador

DomusVi › Residencias ancianos › Pontevedra › Lalin › Noticias › Dia internacional hipertension pulmonar

Día Internacional Hipertensión Pulmonar.

Publicado el 3 de mayo de 2024

Realizamos la gymkana de viernes con actividades especiales en reivindicación de la investigación de la Hipertensión Pulmonar. Nuestrxs residentes tenian que realizar diferentes juegos poniendo a prueba sus capacidades respiratorias.

HIPERTENSIÓN PULMONAR ESPAÑA

1º Reto manualidades Día Mundial de la Hipertensión Pulmonar

del 5 al 31 de mayo.

tema: hipertensión pulmonar

formato: libre
(puede ser tarjeta, atc,marcapaginas....)

obligatorio : digi gratuito
(descarga en el enlace)

usar los #woldphday2024
#hp2024

(1 proyecto 1 diseñadora 1 participacion)

diseñadoras colaboradoras:

@elvistudio
@missandia
@loreartjournal
@fimiki

@mariyixu.art
@mytinkercrafts
@artualizate
@silviauve_

@bettygonzalezdesing
@el_scrapeo_de_mon
@creanciones_albag
@baronesa.shop
@niniscraper

patrocinadoras para sorteo:

@100x100manualidades (españa)
@niniscrapers
@cloe.ilustracion
@Bea.DesinG
@mariyixu.art

#WorldPHDay2024

La fuente de la Puerta de Zamora se ilumina mañana de azul por el Día Mundial d
la Hipertensión Pulmonar

Esta iluminación, al igual que otras similares, se enmarca en el compromiso que mantiene el Ayuntamiento de Salamanc
apoyar a los grupos de ayuda mutua en su labor de promoción de la salud

4 mayo 2024 Salud Pública

La fuente de la Puerta de Zamora se ilumina mañana domingo, 5 de mayo, de color azu
motivo del Día Mundial de la Hipertensión Pulmonar, una afección que consiste e
aumento de la presión en las arterias de los pulmones, por lo que el corazón debe hac
mayor esfuerzo para bombear sangre.

Cabe recordar que esta iniciativa, al igual que otras similares, se enmarca en el compro
que mantiene el Ayuntamiento de Salamanca a la hora de apoyar a los grupos de a
mutua en su labor de promoción de la salud de las personas afectadas por al
enfermedad y sus familias.

Fuente de la Puerta de Zamora de color azul


Hipertensión Pulmonar España O...
396 seguidores
1 mes •

La Fundacion Aviva Salamanca ha organizado un partido de básquet para visibilizar la Hipertensión Pulmonar. Ha tenido lugar en el Pavellón de la Alamedilla.

#WorldPHDay2024 #WeBreatheUnited #WPHD #PHAEurope

Nueva reunión en Castilla y León de la mesa de trabajo multidisciplinar HAP Needs Sacyl

hipertension-pulmonar.com

Hipertensión Pulmo
396 seguidores
2 semanas •

📝 Nueva reunión en Castilla y
trabajo multidisciplinar HAP Ne

Más información en el blog de
👇

https://lnkd.in/dE4HC-G3

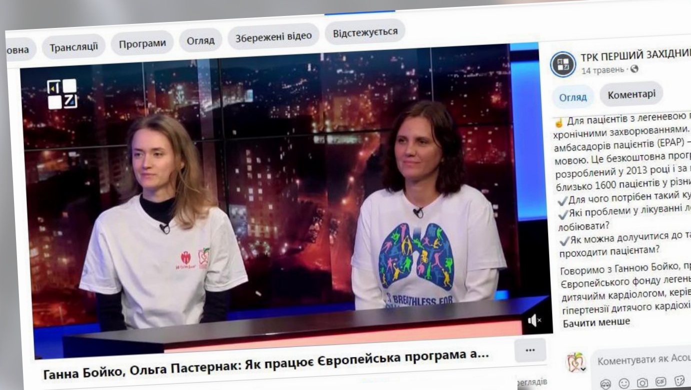
#HipertensiónPulmonar #HP #
#TrabajoMultidisciplinar #Sacy


Hipertensión Pulmonar España O...
396 seguidores
1 mes •

Los alumnos de Pilates del Centro Victory de Guardo (#Palencia) han dado clase con las camisetas de #HipertensiónPulmonar para dar visibilidad a la enfermedad participando en el #DíaMundialdelaHipertensiónPulmonar!

#WorldPHDay2024 #WeBreatheUnited #WPHD #PHAEurope

Ukraine PHURDA



Ганна Бойко, Ольга Пастернак: Як працює Європейська програма а...

ТРК ПЕРШИЙ ЗАХІДНИЙ
14 травень ·

☝ Для пацієнтів з легеневою гі
хронічними захворюваннями. Є
амбасадорів пацієнтів (EPAP) —
мовою. Це безкоштовна програ
розроблений у 2013 році і за це
близько 1600 пацієнтів у різних
✔Для чого потрібен такий кур
✔Які проблеми у лікуванні лег
лобіювати?
✔Як можна долучитися до тако
проходити пацієнтам?
Говоримо з Ганною Бойко, прое
Європейського фонду легень, т
дитячим кардіологом, керівни
гіпертензії дитячого кардіохір
Бачити менше


Oksana Skara разом з **Iryna Zhyvylo** та **ще 2**.
7 червень о 00:55 ·

Запуск програми EPAP на українському телебаченні ТРК ПЕРШИЙ ЗАХІДНИЙ
Нещодавно EPAP було перекладено на восьму мові, українську. Ми ініціювали
переклад на українську мову оскільки розуміємо на скільки це важливо.
Представник European Lung Foundation розповіла про програму EPAP і про те,
чому вона важлива, особливо для україномовних.

Більше про програму Амбасадорка пацієнтів , ви можете побачити на сторінці
Асоціація Легеневої Гіпертензії. Якщо Вам цікава ця програма будь... **Більше**


Асоціація Легеневої Гіпертензії
13 травень ·

На нашій пацієнтській зустрічі, присвяченійДню Легеневої Гіпертензії #WPHD , також було
відзначено важливість новоствореного Центру легеневої гіпертензії при відділенні дитячої
кардіохірургії Дитяча Лікарня Святого Миколая для пацієнтів та їх прогноз

Центр надає нові можливості для пацієнтів, які стикаються з легеневою гі
надаючи доступ до медичної допомоги та лікування.

Цей центр відіграє важливу роль у покращенні прогнозів для пацієнтів, с
виявленню та ефективному лікуванню легеневої гіпертензії. Його робота
збереження здоров'я та покращення якості життя людей з цією серйозно

На зустрічі також лікар з новоствореного центру легеневої гіпертензії, яки
відділення дитячої кардіохірургії Дитячої Лікарні Святого Миколая, поділи
важливістю роботи цього відділення та співпраці з БФ "Сестри Даліли" та

Це надзвичайно важливий крок у підвищенні якості діагностики та лікува
гіпертензії. Співпраця з визначеними організаціями допомагає забезпечит
ресурси та підтримку для пацієнтів, що стикаються з цією хворобою.

Ми віримо, що Центр стане важливим кроком у боротьбі з легеневою гіп
допоможе пацієнтам зберегти надію на краще майбутнє. 💙

#ЦентрЛГ #ПрогнозиПацієнтів #ПідтримкаЗдоров'я #ЛегеневаГіпертензі
#ВідділенняДитячоїКардіології #БФСестриДаліли #PHURDA #pulmonaryhy
#PHUkraine #АсоціаціяЛГ #ЗдоровяЛегень #МіжнароднийДеньЛГ #Підтр

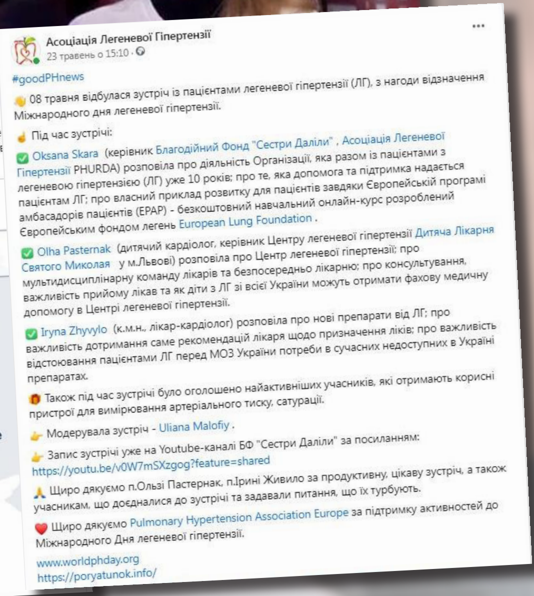

Olha Pasternak
13 травень ·

Велике досягнення Асоціація Легеневої Гіпертензії для пацієнтів не лише з легене
гіпертензією! Ця платформа допоможе пацієнтам навчитися відстоювати свої прав
розширювати свої можливості. I , головне, рідною УКРАЇНСЬКОЮ!

EPAP is a free, online learning programme that introduces patients and carers to some of the basic skills and knowledge needed to represent yourself and others successfully.

Now available in Ukrainian:

Register: elearning.epaponline.eu


Асоціація Легеневої Гіпертензії
23 травень о 15:10 ·

#goodPHnews

👏 08 травня відбулася зустріч із пацієнтами легеневої гіпертензії (ЛГ), з нагоди відзначення Міжнародного дня легеневої гіпертензії.

☝ Під час зустрічі:

✅ Oksana Skara (керівник Благодійний Фонд "Сестри Даліли" , Асоціація Легеневої Гіпертензії PHURDA) розповіла про діяльність Організації, яка разом із пацієнтами з легеневою гіпертензією (ЛГ) уже 10 років; про те, яка допомога та підтримка надається пацієнтам ЛГ; про власний приклад розвитку для пацієнтів завдяки Європейській програмі амбасадорів пацієнтів (EPAP) - безкоштовний навчальний онлайн-курс розроблений Європейським фондом легень European Lung Foundation .

✅ Olha Pasternak (дитячий кардіолог, керівник Центру легеневої гіпертензії Дитяча Лікарня Святого Миколая у м.Львові) розповіла про Центр легеневої гіпертензії; про мультидисциплінарну команду лікарів та безпосередньо лікарню; про консультування, важливість прийому лікав та як діти з ЛГ зі всієї України можуть отримати фахову медичну допомогу в Центрі легеневої гіпертензії.

✅ Iryna Zhyvylo (к.м.н., лікар-кардіолог) розповіла про нові препарати від ЛГ; про важливість дотримання саме рекомендацій лікаря щодо призначення ліків; про важливість відстоювання пацієнтами ЛГ перед МОЗ України потреби в сучасних недоступних в Україні препаратах.

🎁 Також під час зустрічі було оголошено найактивніших учасників, які отримають корисні пристрої для вимірювання артеріального тиску, сатурації.

👉 Модерувала зустріч - Uliana Malofiy .

👉 Запис зустрічі уже на Youtube-каналі БФ "Сестри Даліли" за посиланням:
https://youtu.be/v0W7mSXzgog?feature=shared

🙏 Щиро дякуємо п.Ользі Пастернак, п.Ірині Живило за продуктивну, цікаву зустріч, а також учасникам, що доєдналися до зустрічі та задавали питання, що їх турбують.

❤️ Щиро дякуємо Pulmonary Hypertension Association Europe за підтримку активностей до Міжнародного Дня легеневої гіпертензії.

www.worldphday.org
https://poryatunok.info/

YOUTUBE.COM

День легеневої гіпертензії 2024_пацієнтська зустріч

Розмовляємо з пацієнтами про важливість подолання інформаційни

Асоціація Легеневої Гіпертензії
13 травень

Під час нашої зустрічі з нагоди Дня легеневої гіпертензії #WPHD, Ul
представила учасникам навчальну програму European Patient Ambassa
програма відкриває широкі можливості для пацієнтів отримати важли
щодо медичної грамотності.

"European Patients Ambassador Program" допомагає пацієнтам стати
впливовими голосами у своїх спільнотах, розширюючи їх здібності у р
своїм здоров'ям.

Ми раді поділитися цією ініціативою з нашою аудиторією та заклик
приєднатися до цієї надзвичайно важливої програми!

Ця програма є надзвичайною можливістю стати частиною груп євр
товариства!

Залишайтеся з нами, щоб отримати більше інформації та долучитися д
ініціативи. Разом ми можемо підняти наш вплив та спільно допомогти
пацієнтів у всій Європі.

Дізнайтеся більше та приєднуйтеся за посиланням https://elearning.epa

Не пропустіть свій шанс стати частиною цієї неймовірної спільноти! До
сьогодні та поділіться цією можливістю зі своїми друзями та колегами.

Разом ми можемо робити більше для підвищення рівня медичної грам
пацієнтів у їхньому шляху до здоров'я та благополуччя!

#EuropeanPatientsAmbassador #МедичнаГрамотність #ПідтримкаПацієн
#БФСестриДаліли #pulmonaryhypertension #WPHD #PHUkraine #Асоціа
#ЛегеневаГіпертензія #МіжнароднийДеньЛГ #ПідтримкаПацієнтів #ре

**Ви або хтось, про кого ви піклуєте
маєте довготривале захворювання?**

Медичні працівники та дослідники повинні розуміти досвід пацієнтів та тих, хто за ними доглядає, щоб покращити лікування та догляд.

EPAP - це безкоштовний онлайн-курс, який знайомить пацієнтів та осіб, які здійснюють догляд за ними, з навичками, необхідними для представлення себе та інших у дослідженнях, розробці настанов та засобах масової інформації.

Асоціація Легеневої Гіпертензії разом з **Uliana Malofiy** та **ще 5**.
10 травень

Дякуємо всім, хто долучився до нашої онлайн зустрічі з нагоди Дня Легеневої Гіпертензії #WPHD та відзначення 10-річчя Асоціації Легеневої Гіпертензії!

На нашій зустрічі ми обговорили напрямки підтримки, виклики, що стоять перед пацієнтами у часи війни, та висвітлили важливість Міжнародного дня легеневої гіпертензії.

У цей складний час є надзвичайно важливою наша єдність та підтримка одне одного. Ми не маємо не зупинятися перед жодними викликами, а повинні спільно пр... **Більше**

Ви, Uliana Malofiy, Oksana Skara та ще 38
3 коментарі 2 поширення

У захваті Коментувати Copy Поширити

• Sponsors •

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

PHA EUROPE for the patients

European pulmonary hypertension association

aerovate therapeutics

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respira THERAPEUTICS

United Therapeutics CORPORATION

BEL AIR CENTER

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

PHA EUROPE

PULMONARY HYPERTENSION ASSOCIATION

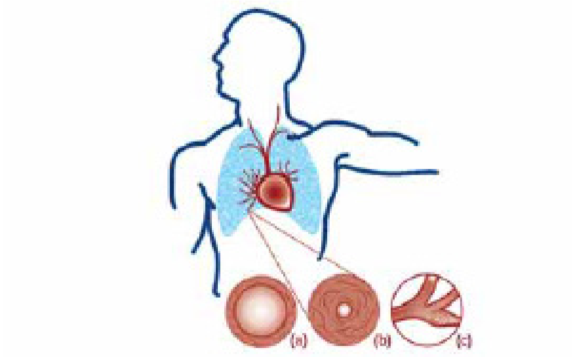
for the patients

AIMS OF PHA EUROPE

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

WHAT IS PULMONARY ARTERIAL HYPERTENSION?

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



a) Cross section of normal pulmonary artery

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

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

TREATMENT OF PULMONARY ARTERIAL HYPERTENSION

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

THE FUTURE FOR PULMONARY ARTERIAL HYPERTENSION

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

Members of PHA Europe and contact details

AUSTRIA

PH Austria
Initiative Lungenhochdruck
Wilhelmstraße 21 - 1120 Wien
www.phaustria.org
info@phaustria.org

BELARUS

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

BELGIUM

Belgische patiëntenvereniging voor Pulmonale Hypertensie vzw (P.H. België)
Kruisbeeldstraat 28, 9220 Hamme, Belgium
info@ph-vzw.be

BOSNIA AND HERZEGOVINA

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

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

BULGARIA

The Bulgarian Society of Patients with Pulmonary Hypertension - BSPPH
Pirinski prohod str., bl.24 A, entr. B, fl.3,
ap.34 Sofia- 1680, Bulgaria
www.bspph.net
bgspph@gmail.com

CROATIA

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

CZECH REPUBLIC

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

ESTONIA

Eesti Pulmonaalhüpertensiooni Ühing
eesti.ph@gmail.com
+37253004221

FINLAND

Suomen PAH-potilasyhdistys ry. PHA Finland
c/o Sonja Koski
Wilhelmstraße 21 -1120 Wien
suomenpahry@gmail.com

HUNGARY

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

ITALY

Associazione Ipertensione Polmonare Italiana Onlus
Via Enrico Mattei, 92 - 40138 Bologna
https://www.aipiitalia.it/

ITALY

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

LATVIA

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

LITHUANIA

Žmonių sergančių plautine hipertenzija asociacija
Biržų g. 2, Papilys, LT-41221, Biržų raj., Lietuva
www.zspha.lt
info@zspha.lt

MOLDOVA

Asociatia Obsteasca
“Asociatia persoanelor cu hipertensiune pulmonara din Republica Moldova”
Moldova, MD-2024, str. Andrei Doga 34, ap. 43
roman.balmush@gmail.com

NETHERLANDS

The Netherlands
Stichting Pulmonale Hypertensie
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NOTES

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

PHA EUROPE

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for the patients

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