



ANNUAL ACTIVITY REPORT 2021

A brief outline of BSPPH's activities and initiatives along 2021 – introduction to the Association, main areas of activity, awareness raising, advocacy, capacity building, information and education, organization and funding



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FOREWORD BY THE BOARD

Dear members, friends and supporters,

Welcome to BSPPH's 2021 annual activity report.

As in past years, BSPPH has been active mainly in the areas of awareness raising, advocacy, capacity building and information and education.

To start with, we are very happy and proud of the results of our annual awareness campaign for World Pulmonary Hypertension Day, May 5th.

Secondly, we had a busy year in the field of advocacy, with a very active and high level involvement in policy discussions on access to treatment - which is one of the really critical areas for our patients.

We have been invited to speak and/or attend numerous conferences and other events and are actively involved in health care policy in Covid-19 era through the participation not only in the working groups mentioned above but also in important scientific professional societies.

As the global pandemic continues, and the world pulls together in the face of a climate crisis, we know that we have a lot to do to help people who are affected by rare lung health issues. We want to do so much more and will be looking to provide information and support to more people than ever in 2022.

BSPPH will focus on conducting activities in the following thematic areas:

Fair, affordable, high-quality, and non-discriminatory healthcare, with a focus on inclusive care for all PH patients and reducing stigma. We all deserve equal access to innovative therapies, especially when it comes to rare diseases. The efforts of the patient movement in Bulgaria must be focused on implementing screening programs and raising public awareness of rare lung diseases with a focus on vulnerable patient communities.

In post COVID-19 era digitalization and innovations at all levels of healthcare, including the introduction of services and solutions for prevention, treatment, surveillance, disease management, digitalization of care, evaluation of the effectiveness of the system.

You, our sponsors, volunteers and supporters, will play an important part in achieving that and we want to make sure you know how valued.

With kind regards,

Board of Directors of BSPPH

BSPPH IN BRIEF

BSPPH is organization of patients living with rare disease pulmonary arterial hypertension. It was founded in Sofia, Bulgaria in 2012 and registered as a non-profit organization. BSPPH works to enhance awareness of PAH in Bulgaria, promote optimal standards of care for people living with the disease, ensure and encourage research for new medicines and therapies. BSPPH strives to achieve its objectives through activities in four main areas: raising awareness, advocacy, capacity building, information and education. BSPPH is a member of the biggest patient association in Bulgaria - National patients' organization that is officially recognized by the Ministry of Health as the only nationally representative patient organization in the country. BSPPH is a full member of PHA EUROPE and EURORDIS . On 10/09/2012 was signed memorandum of cooperation with PHA USA.

AWARENESS RAISING AND ADVOCACY ACTIVITIES 2021

Celebrating the rare

On February 28, 2021, in front of the National Palace of Culture in Sofia, Bulgaria, patients with rare diseases symbolically painted their hands in different colours, which represent their difference and struggle. "The world of people with rare diseases remains invisible to the general society. If we get to know them and hear their stories, and if we learn more about their disease, which makes them different, we will actually realize how strong and determine they are. We will understand that they have a place among us on the labour market" added Natalia Maeva president of BSPPH.



Nutrition and pulmonary hypertension

Food is the main source of satisfaction and positive emotions in our lives, and also a source of physical and spiritual health. The main focus of nutrition, especially when pulmonary hypertension has led to heart failure, is to control the volume of fluids in the body.

Patients with pulmonary hypertension often need to make an extra effort to understand what they need to eat. Some foods and vitamins can interact with medications and contribute to the accumulation of excess fluids in the body or cause nausea or diarrhea. You need to remember three things: control salt and sodium intake. Do not overdo fluids and avoid foods which may cause discomfort in combination with your individual therapy.

It is important to avoid foods rich in vitamin K, as they further reduce the effect of your daily therapy.

The guide of the Austrian nutritionist Claudia English contains handy recipes that will help you eat well. Thanks to our cooperation with PHA AUSTIRA, the guide is now available for Bulgarian patients in the three PH expert centers.



20 sports' enthusiasts joined the initiative „Get Breathless for PH“

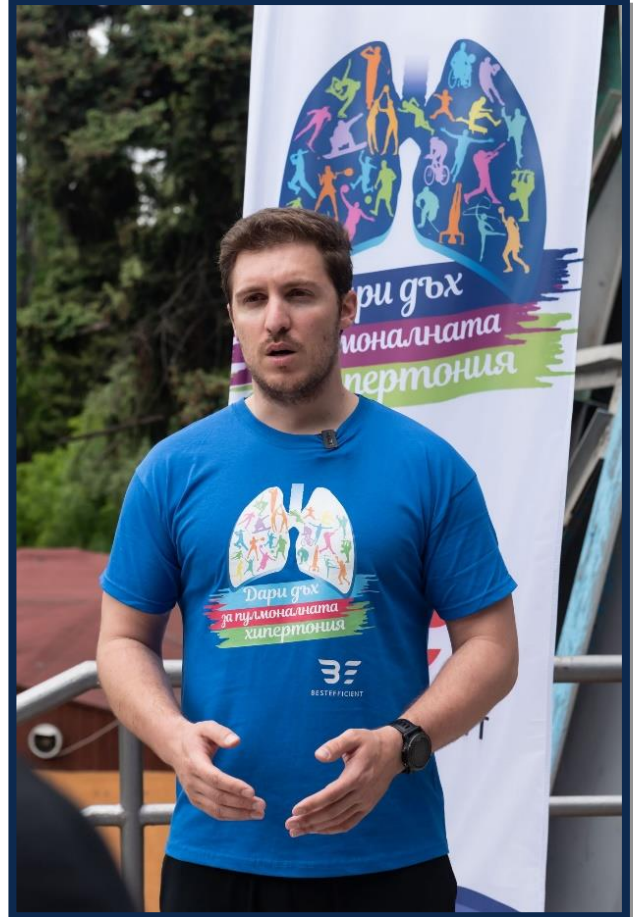
For the ninth consecutive year, BSPPH is part of the global campaign Get Breathless for PH. Throughout the month of May, we talked about the insidious 'blue lips' disease—pulmonary hypertension.

On May 5, 2021, from 7 PM to 11 PM, the building of the National Palace of Culture in Sofia was illuminated in blue, as a sign of sympathy with the patients who are struggling with the 'blue lips' disease—pulmonary hypertension. The most recognizable symptom of this rare disease is when the lips, hands and feet become bluish, which occurs due to lack of oxygen in the human body. Patron of the 2021 campaign **Get Breathless for PH** is the Mayor of the capital Yordanka Fandakova, who made a special video address to the participants in the campaign. The buildings of the Naval Forces Command in Varna, the Municipality in



Burgas, Saint George the Victorious Chapel and Mausoleum in Pleven and the Bell Tower near the Monument of the Holy Mother of God in Haskovo were also illuminated in blue.

As part of the campaign, on May 15, during the sports event **Get Breathless for PH**, 20 sports **enthusiasts** donated their time to do an intense workout under the guidance of fitness coach Stefan Terziyski from BestEfficient. The event was hosted by the Spartak gym and all COVID-19 sanitary requirements were met.



“I am happy that you play sports instead of those who cannot climb even a few stairs and live hidden from society”, said at the beginning of the sporting event Natalia Maeva, chairwoman of the patient organization, who is with organ transplantation as well.

A special guest of the event was the actor Filip Bukov, who played the role of the charming urologist Dr. Hadzhihrstev in the ” Stolen Life” television medical drama . Philip Bukov is an avid athlete with various sports talents, and he spoke about the initiative live on the Wake Up show on Nova TV.



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

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



The sports event **Get Breathless for PH** took place in the form of high-intensity interval training, which in addition to increasing the heart rate, helps increase the levels of some key human hormones, which in turn creates conditions for burning fat and developing muscle mass. During part of such a workout, the heart rate rises to 85–90%, and the metabolism remains active for hours after the end of the workout. From 5th to 15th May 2019 every person who attends the sport complex joined the initiative by donating his/her 5 km running and mark that at the dedicated place in the fitness hall. For each run

kilometer, the BSPPH donated resources for buying two portable oxygen concentrators, which will be provided to PH patients.



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

Despite the efforts of the patient organization, the National Health Insurance Fund continues to not fund oxygen devices for patients with pulmonary hypertension. Most of the patients in functional classes III and IV of the

disease need expensive intravenous therapy, which is also not available in our country. For them, lung transplantation is life-saving—a problem that has been unsolvable in our country for years.

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

Video: <https://www.youtube.com/watch?v=CGOu73c5koY&t=26s>

Transplant recipients took part in the "Vitosha 100" ultra mountain marathon

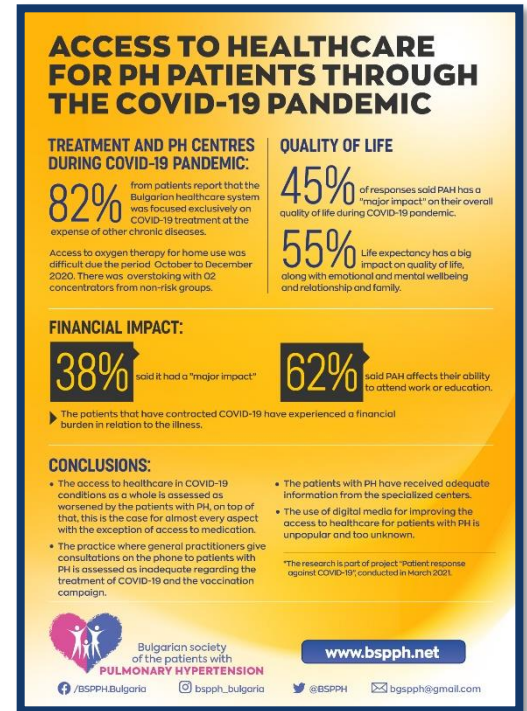
On 20 June 2021, more than 40 transplant recipients and their doctors, as well as representatives of the Executive Agency Medical Supervision participated in the "Vitosha 100" ultra-marathon in support of donation and transplants in Bulgaria. "This way, we not only showed that transplantation allows a person to lead a completely normal, healthy life, but also that we can be of benefit to the society and our country. It is therefore important to have more transplantations in Bulgaria and fewer people waiting for their second chance for life. Organ donation is the most humane and supreme act of a modern society which helps people with disabilities and their loved ones. A society without morality and without human values is doomed to die. I believe that we Bulgarians are capable of empathy, compassion, and humanity! All of us who participated in the marathon together showed this!", said Natalia Maeva chairman of the BSPPH.



ELF Patient Organisation Networking Day 2021

The BSPPH was part of the ELF Patient Organisation Networking Day 2021. It took place online on September 2nd. This year event was focused on digital health and the role of patient organisations explore how they can take an active role in this changing environment.

This year BSPPH present e-poster named: " Access to healthcare for PH patients through the COVID-19 pandemic ". The access to healthcare in COVID-19 conditions as a whole is assessed as worsened by the patients with PH, on top of that, this is the case for almost every aspect with the exception of access to medication. 82% from patients report that the Bulgarian healthcare system was focused exclusively on COVID-19 treatment at the expense of other chronic diseases. Access to oxygen therapy for home use was difficult due the period October to December 2020. There was overstocking with O2 concentrators from non-risk groups.



A donor's park was opened in Plovdiv

On 5th November was opened a special area for donors has been set up in the "2019 park" in the Trakia district, Plovdiv. The event was attended by Government Spokesman Anton Kutev, Deputy Executive Director of the Medical Supervision Executive Agency Miroslav Mutafchiyski and representatives of patient organizations. The donation park is an expression of gratitude to the people who gave someone else the opportunity to continue their life. The campaign "Because we are alive" is twining project of BSPPH and the Association of Patients with Respiratory Failure and Lung Transplantation. The donor park includes the construction of a fountain and 12 benches in memory of donors. The members of the BSPPH donated money for two benches.





O2 kids project helps to small PH patients

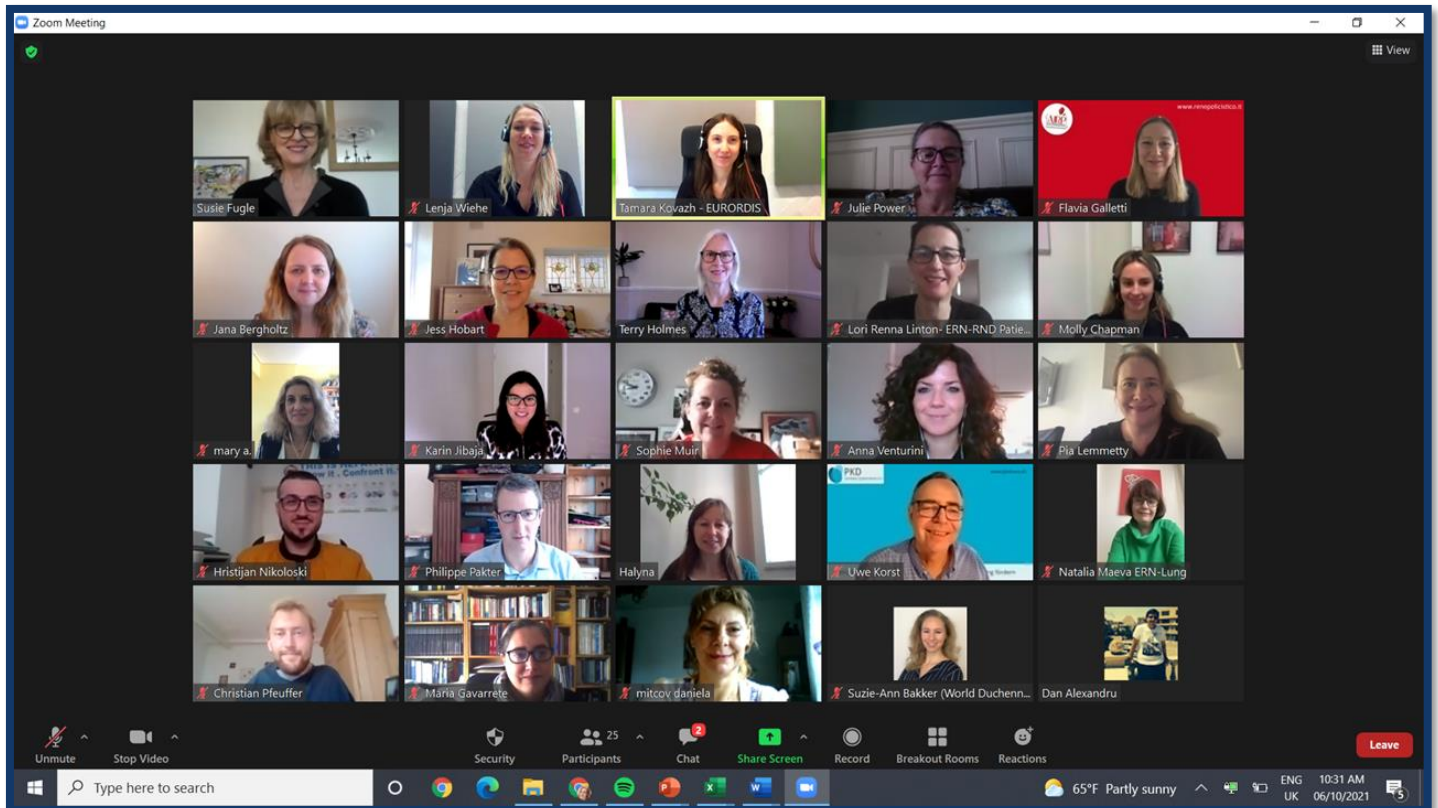
BSPPH is one of the beneficiaries of the O2kids project, organized by PHAE this year. Thanks to this fact we managed to make the biggest dream of 11-year-old Georgi from Sofia a reality.

“My name is Georgi, I’m 11 years old and I live with my mother in Sofia. If I had a magic wand, like the fairies, I would make that no child learns difficult diagnoses and fights for his life. I have a rare disease PH that prevents me from playing with other children. All day I am connected to a large machine that helps me breathe. I have learned there is a small machine that I can carry in a backpack, and I can breathe freely and I will be able to go with other children to the park. I want to have such a machine - it's called a portable oxygen concentrator. Complicated name, isn't it? The money I collected for last Christmas is not enough to buy it. That's why I am asking for your help”, wrote in Georgi in his touchable letter. It is wonderful when we can see the joy in the eyes of our small PH patients.



Other activities

The president of BSPPH Natalia Maeva as ePAG in ERN-Lung was among the 23 patient advocates, from 15 countries, representing more than 23 rare diseases who successfully completing the EURORDIS Leadership School. It aims of this training is empowering European Patient Advocacy Groups (ePAGs) advocates and other rare disease patient advocates to be valued partners in European Reference Networks (ERNs) and when engaging with healthcare providers and other rare disease stakeholders. the participants were trained on the following topics “360° self-awareness” and “Emotional leadership”.



ANNUAL FINANCIAL REPORT 2021

Income:	<i>(All is in BGN*)</i>
Pharma income	2 500.00
Donation	1 200.00
Membership Fees	430.00
Event income	650.00
Government income	no
PHA Europe income	10 725
	15 505
Expenses:	
Office cost (website, rent, equipment, bookkeeping)	1020
Taxes	-
Bank costs	230
Staff	4 800,00
Event costs	7 678,60
Patient meeting cost	no
	13 728,00
TOTAL	1 777,00