



ANNUAL ACTIVITY REPORT 2018

A BRIEF OUTLINE OF BSPPH'S ACTIVITIES AND INITIATIVES ALONG 2018 – 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 2018 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.

As part of our focus on access to treatment this year we decided to initiate a campaign to raise awareness specifically on the problems of organ donation and transplantation and reimbursement of oxygen treatment at home. We officially launched a Petition for free oxygen therapy for PAH patients and we collect 3 500 signatures.

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

We thank our members and our valued partners for their continuing support, without whom none of this would have been possible and look forward to another year of close and successful collaboration.

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 .

MAIN AREAS OF ACTIVITY 2018

BSPPH has successfully conducted annual awareness campaigns for the last 7 years. The first campaigns were organized on International Rare Disease Day (February 28). Since 2013 BSPPH is active part of campaigns have revolved around World PH Day (May 5). The theme is sport, with the slogan "Get breathless for PH".

ADVOCACY

Advocacy is one of BSPPH's key activities and vital to drive change in health policies both at national and EU level. At

national level we are active part of health policy making. The president of BSPPH is member of few consultative committees and working groups established in Ministry of healthcare. With the support of a EU affairs consultant PHA Europe (BSPPH is a full member) is active in providing input into EU policy through position papers and submissions to public consultations as well as contact programs with key Commission officials and MEPs.

AWARENESS RAISING 2018

The 2018 was an intensive year for BSPPH. The most important event for us is organization and implementation of WPHD campaign. It was our 6th time when we organized a sport event. Our project was focused on a sporting event - climbing on the interactive climbing walls as a solidarity action with the PH patients. We select FUNTOPIA in Paradise shopping center, Sofia, Bulgaria. This is unique place 300 m² where the visitors can fill the thrill of the heights and climbing into a fully secure environment. Unfortunately the climbing is a “mission impossible” for PH patients. Our climbing “Get Breathless for PH” event had aiming at raising awareness and general understanding of what is it like to be diagnosed with pulmonary arterial hypertension and to live with its symptoms. How to stand up for improving time to diagnosis and having proper treatment.





The second important project for BSPPH was reimbursement of oxygen treatment at home. The full reimbursement of oxygen therapy by the National Health Insurance Fund (NHIF) was the topic of a round table held on 12 October 2018 in the National Assembly of Bulgaria. The all summer we work hard on the implementation of the Petition for free oxygen therapy for PAH patients.



Since 2013 BSPPH has been actively involved in initiatives related to the implementation of the “Week of Organ Donation”. This year we set ourselves the ambitious task of putting together a long-term project called “Fountains for organ donation”, together with the Association of Patients

with Respiratory Failure and Pulmonary Transplantation. The Week of Organ Donation was sadly marked by the death of three patients from the Bulgarian waiting list for lung transplantation.

On October 18 we officially marked the beginning of the national movement “Fountains for organ donation”, which will be carried out jointly by the Association of Patients with Respiratory Failure and Pulmonary Transplantation, BSPPH, the Ministry of Healthcare and the Executive Agency for Transplantation. The Deputy Minister of Healthcare, Dr. Boyko Penkov, and Dr. Daniela Daritkova-Prodanova, Chairman of the Health Commission in the National Assembly, attended the opening ceremony of the first “fountain” - a monument dedicated to the people who save lives through organ donation.



FELLOWSHIP PROGRAM

Since 2013 BSPPH is part of the Fellowship program lunched by PHA Europe. As you know, since November 2016 Mrs.

Vyara Vragova is our fellow. We can say that we need the helpful hand of someone stable, disciplined and concerned like her in the future. We support her because she has been working with patients organizations for years now. Her English is perfect and she has excellent knowledge of the Internet, social media, Microsoft Office, etc. And she translates, designs, brainstorms, solves day-to-day problems with documents and e-mails. Our part time assistant also has a nursing background which guarantees her perfect comprehension of the difficulties that both patients and careers face on an everyday basis.

As you know there are language problems between different national patients organizations members, and as BSPPH wants to be active at European level, we need a contact person (fellow) with good command of English who could contribute to a better engagement of the national associations in PHAE driven projects. Also, the fellow can assist at national level providing support to local initiatives and day-to-day work. BSPPH was of first associations who become part of Fellowship Program of PHAE. BSPPH needs a person who can provide translations of e-mails, monthly newsletters, Mariposa Journal and other materials, related to PHAE activities.

Despite the short deadlines, Mrs.Vjara Vragova did not neglect regular responsibilities as a Part Time Assistant of BSPPH:

- providing support for the Facebook page of the Association – both in terms of text and design.
- providing web support and upgreat for the www.bspph.net platform.
- mailing and setting arrangements with authorities

(incl. Ministry of Healthcare and NHIF), print houses, etc., on the behalf of and for the needs of the Association (incl. receiving and evaluating offers, management of invoices and providing feedback).

- mailing with PHAE

BSPPH needs a fellow to assist the preparation of all types of materials, including, but not limited to, articles, reports, summaries, questionnaires, responses to inquiries, all of the above related or linked to, derived from and/or made in connection with the activities of PHAE.

Throughout the WPHD 2018 campaign Mrs. Vjara Vragova works hard and she gave a lot of herself to organize everything perfectly. Mrs. Vjara Vragova was responsible to coordinate the patronage of the Ministry of Youth and Sport and the Ministry of Healthcare of the Republic of Bulgaria.

During the summer we work hard on the implementation of the Petition for free oxygen therapy for PAH patients. Mrs. Vjara Vragova was one the motors of this project. She was responsible for preparing, organizing and submitting the Petition (3 500 signatures) for free oxygen therapy covering by National Health Insurance Fund for patients with PAH. The full reimbursement of oxygen therapy by the National Health Insurance Fund (NHIF) was the topic of a round table held on 12 October 2018 in the National Assembly of Bulgaria.

November and December were intense months for the Bulgarian Society of Patients with Pulmonary Hypertension not in terms of public events but in terms of meeting deadlines for project proposal submissions. Fortunately, we succeeded in submitting 4 project proposals for

different funding programs both at a national and international level, and Mrs. Vyara Vragova actively participated in brainstorming, translating (both English to Bulgarian and Bulgarian to English) and designing the project proposals' document packs (incl. a general presentation of BSPPH and Project Timelines in several formats). For now, the proposals submitted await approval.

Mrs. Vyara Vragova was accurate, well organized and dedicated enough in her effort, focus, and attention to details and deadlines, so that the Bulgarian Society of Patients with Pulmonary Hypertension could estimate 2018 as a successful.

The Board of Directors of BSPPH requests to participate in Fellowship Programme for 2019 because we need a secretary but as a NGO we have no money to pay her, that is why our association is interested in receiving help from the PHAE.



CAPACITY BUILDING

In 2018 the European Patient Forum (EPF) launched a new capacity building module on “Empowering Leadership and Positive Governance”. The module aims at strengthening patient organizations by enhancing their leaders’ leader-

ship skills and consequently enabling positive governance in their organization, with the final objective of supporting patient organizations in positioning themselves as legitimate stakeholders, strong advocates and reliable partners on the national and European health policy environment. The program targets patient organizations' leaders from across Europe, specifically Bulgaria, Hungary, Poland, Romania, Slovakia and the Western Balkan. The Chair-person of BSPPH Natalia Maeva passed the six-month training course successfully and received her certificate from the EPF.





FINANCIAL REPORT 2018

Income:

(All is in BGN*)

Pharma income	4 000.00
Membership fee	no
Event income	no
Government income	no
BSPPH income	500.00
Fund raising / Donation	3 400.00
PHAE	3 726.39
	11 626.39

Expenses

Office cost (Web-site, rent, equipment, bookkeeping)	3 970
Taxes and bank costs	753
Staff	no
Event costs	3 703.00
Patients meeting costs	600.00
	9 026.00

Total income minus expenses

2 600.39

