

Time to **Talk** 

Best practice case study

**Bulgarian Society of
Patients with
Pulmonary Hypertension**

Spotlight on Bulgaria

Roundtable discussion and press conference raise awareness of the impact of PAH with key stakeholders, as well as the general public

Calls to action from the International Patient and Carer Survey (IPCS) highlighted the need for patient organizations to **raise awareness** of the emotional impact of pulmonary arterial hypertension (PAH) for patients and their carers and therefore the need for greater support. It was also recommended that PAH organizations provide **information sessions** and educational events where possible, to improve their members' knowledge and understanding of PAH. In this case study, Natalia Maeva, President of the Bulgarian Society of Patients with Pulmonary Hypertension (BSPPH), talks about the success of BSPPH's first roundtable event and press release which **united and educated key stakeholders** as well as raised awareness amongst the general public of the impact of PAH.

There are approximately 131 people in Bulgaria living with pulmonary hypertension, including just 30 people living with PAH. BSPPH recognizes the importance of discussing the emotional impact of PAH and agreed on three key approaches which enabled them to do this:

- **Bringing key stakeholders together**, including policy makers, healthcare professionals, journalists and pharmaceutical companies
- **Providing patients and carers a with platform** to tell their story
- **Raising awareness of PAH** among the general public

Bringing key stakeholders together

In September 2013 BSPPH held its first roundtable event at the University Hospital for Active Treatment of Cardiovascular Diseases St. Ekaterina in Sofia, to educate key stakeholders on the impact of PAH and to discuss the IPCS findings. BSPPH saw this meeting as an exciting opportunity to bring together **influential policy makers** and successfully reached out to a variety of distinguished attendees, including: Dr Boiko Penkov, the Deputy Minister of Health; Dr Mariana Simeonova, Director of Executive Agency on Transplantation, Ministry of Health; and Dr Stanimir Hasardzhiev, the President of the National Patients' Organization. A total of 55 participants took part in this meeting from a range of backgrounds including journalists, healthcare professionals, pharmaceutical representatives as well as patients and carers.

By inviting people from **different backgrounds**, the participants benefited from **diverse discussions** and were able to learn from others' experience and knowledge. Patients had the opportunity to discuss access to care with policy makers who in turn were able to learn from patients' stories and experiences.



Attendees heard from different speakers, including patients



55 people from different backgrounds attended the roundtable meeting

The emotional impact of PAH was discussed in relation to the IPCS findings, which were presented to the group during the meeting. Patients and carers were encouraged to talk about their experiences of living with PAH to illustrate some of the difficulties they face in everyday life. For some healthcare professionals, this was the first time that they had been introduced to the **emotional impact of PAH** beyond the physical problems. Furthermore, having psychologists and social workers at this meeting, as well cardiologists and pulmonologists meant that different views around best practice in PAH management could be discussed and debated.

A range of materials were provided for the meeting participants, including an executive summary of the IPCS findings, the Patient and Carer Dialogue Tools and a press pack for journalists.

Providing patients and carers with a platform to tell their story

Following the roundtable event, BSPPH held a press conference to **inform and educate** a wider audience about the emotional impact of PAH. This press conference was held in November 2013, at the Bulgarian News Agency and was entitled; 'Challenges for patients with PH in Bulgaria: problems and solutions'. There were four spokespeople: Dr Vasil Velchev, President of the Bulgarian Cardiology Society; Prof Daniela Petrova, a Pulmonologist from the Aleksandrovska University Hospital; Dr Mariana Simeonova, Director of the Executive Agency on Transplantation; and Natalia Maeva, representing BSPPH. The spokespeople discussed the impact of PAH and answered journalists' questions.

In preparation for this press conference, Patient and Carer Dialogue Tools were distributed to the four specialist centres in Bulgaria to be completed and returned to BSPPH, so that the results could be discussed at the event. In total 65 respondents filled in the Dialogue Tools, comprising 23 patients and 42 patients, who presented their views around the impact of PAH on their daily lives. Responses from the Dialogue Tools sparked discussion and **provided real-life examples** of the impact of living or caring for someone with PAH and the challenges that they face.



The press conference helped to inform and educate the public about PAH

Raising awareness of PAH among the general public

By inviting journalists to the roundtable event and conducting a press conference, BSPPH was able to generate a significant amount of media interest about the emotional impact of PAH, including: x4 TV broadcasts, x2 radio interviews and x15 online and print articles around the impact of PAH for patients and their carers. This media coverage was invaluable in helping to inform and educate the general public about PAH and how it affects the lives of those with the condition as well as their families and carers.

Looking ahead

Due to the success of their first roundtable event, BSPPH hopes to organize a future national roundtable discussion to reach a wider audience, including family doctors in order to promote discussions around the importance of early detection and diagnosis of PAH.



Top tips for conducting your own roundtable event and press conference from **Natalia Maeva, President of BSPPH**

“The Patient and Carer Dialogue Tools, which were completed and collected in preparation for the press conference, provided important feedback on living with PAH. They were used to illustrate the impact of PAH and to spark discussion around the challenges still faced by those living with PAH. It is very important to talk more about PH and to provide the patients in Bulgaria and their families with the psychological, medical and social support they need. In addition to the medical burden, this condition has a serious social aspect, which is why such an event in Bulgaria in which people can participate, demonstrate their commitment to patients and provide emotional support, is as important as the performance of treatment”

Top tips for a roundtable event

- **Invite a variety of stakeholders**
 - When planning a roundtable event, try to include representatives from different disciplines, such as government and health service officials and PAH specialists for a more diverse and engaging discussion
 - Having distinguished stakeholders at your roundtable can also attract media attention
- **Invite journalists to your event**
 - Identify journalists who cover health stories and develop a media list of people you would like to target
 - Share an outline agenda and offer the opportunity to interview key speakers
 - Ensure your speakers are happy to talk to journalists and ask them to prepare some “key messages” that they think are important for journalists to report
- **Leave time at the end of the meeting for open discussion**
 - It is important for attendees to have the chance to ask questions and discuss the issues that have been raised at the meeting, therefore an open discussion session is advised at the end of the event

Top tips for a press conference

- **Make your event newsworthy**
 - Include quotations from local patients and healthcare professionals
 - Include local facts and figures – including the IPCS findings to back up anecdotal examples
 - Ensure you have patients willing to share their own experiences with journalists
- **Invite as many journalists as possible**
 - Journalists are busy people and therefore cannot always dedicate the time to attend press conferences, therefore send an invite out to a wider list of people than you necessarily expect at your event
- **Develop a press release**
 - To summarize your discussions, develop a press release to be provided at the event and issue it directly after the press conference to your media list. A sample press release can be found on the Member section of the PHA Europe website

Further information

For more information about how to conduct your own roundtable meeting or press conference, including preparing a press release, please see the Time to Talk **member resources** section of the PHA Europe website.