

Time to **Talk**



Best practice case study

Hellenic Pulmonary Hypertension

Spotlight on Greece

Roundtable discussion and press conference to promote the use of the Patient and Carer Dialogue Tools by patients, carers and their healthcare teams

Findings from the International Patient and Carer Survey (IPCS) highlight the often overlooked **emotional impact** of pulmonary arterial hypertension (PAH) on both patients and carers. In response to these findings, PHA Europe, in conjunction with a steering committee of PAH experts and patient organization representatives developed the **Patient and Carer Dialogue Tools**. The aim of these tools is to encourage patients and carers to keep a record of their feelings to support more open discussions with their friends, families and healthcare teams. These Dialogue Tools have been translated into 15 different languages and made available to local patient organizations across Europe. In this case study, Ioanna Alysandratou, President of Hellenic Pulmonary Hypertension (HPH) talks about the success of the translated Dialogue Tools in Greece and explains how conducting a press conference and roundtable event supported their use and promoted discussion about the emotional impact of PAH.

In order to reach the 1,500 people living with secondary pulmonary hypertension (PH) and the further 500 people living with idiopathic PH in Greece, as well as healthcare professionals, HPH organized a variety of activities aimed at increasing the knowledge of the Patient and Carer Dialogue Tools, including:

- Supporting conversations around the emotional impact of PAH between patients and healthcare professionals
- Raising awareness of the emotional impact of PAH among healthcare professionals and the general public
- Bringing together and educating healthcare professionals on the use of the Dialogue Tools

Supporting conversations around the emotional impact of PAH

In Greece, healthcare professionals can be unused to talking about the emotional challenges of PAH, with consultations typically focusing on the physical symptoms. Therefore, HPH recognise that more needs to be done to **highlight the everyday challenges** that patients and carers face and to encourage patients, carers and healthcare professionals to talk

about these issues in consultations. In order to support these conversations, 500 copies of the Patient and Carer Dialogue Tools were distributed to five specialist hospitals in Greece (three in Athens and two in Thessaloniki).

Raising awareness of the emotional impact of PAH

Following the distribution of the Dialogue Tools among healthcare professionals, HPH held a press conference in December 2013 at the PH unit of Attikon University Hospital of Athens. The aim of the press conference was to educate journalists on the **importance of the Patient and Carer Dialogue Tools** and demonstrate their value for facilitating **focused discussion** around the emotional and social challenges faced by those living with PAH and their carers. Ioanna Alysandratou was one of the members of the panel and was joined by two PH specialists: Professor Apostolos Armaganidis and Associate Professor Stylianos Orfanos, who spoke about the Dialogue Tools and answered journalists' questions. The press conference achieved **media coverage** in specialist publications and online outlets, allowing the discussions to reach and educate a wide audience.



HPH was awarded the 'Remarkable initiative' award for translating the Dialogue Tools and the success of the press conference

Due to the **success of the press conference**, as well as HPH's **achievement** translating and distributing the Dialogue Tools HPH received the 'Remarkable initiative' award at the Patients in Power conference, an annual conference that brings together all rare and chronic disease patient groups. The award itself also succeeded in attracting **media attention** for HPH's awareness raising activities

Bringing together and educating healthcare professionals

Building on the success of the press conference, HPH participated in a roundtable meeting to discuss the Patient and Carer Dialogue Tools. The roundtable meeting, held in March 2014, was planned to coincide with the elections for the Greek board of directors of the Institute for the Study of PH. This meant that HPH was able to ensure higher attendance of PH specialists already in Athens for the elections, as well as generate greater media interest. The roundtable meeting was very popular and was attended by more than 50 healthcare professionals and 10 patient group representatives.

The roundtable event had three main aims:

- To provide a **practical overview** of the Patient and Carer Dialogue Tools and to demonstrate how they can be used and filled in
- To remind healthcare professionals about the **importance of using the Dialogue Tools** with patients and carers
- To **encourage regular use of the Dialogue Tools** by patients and carers through the provision of a one-page summary



More than 50 healthcare professionals and 10 patient group representatives attended the roundtable event

The practical overview of the Dialogue Tools allowed healthcare professions to familiarize themselves with the Tools and to understand their benefit for patients and carers. Furthermore, by reminding both audiences (healthcare professionals and patient group representatives) about the importance of the Dialogue Tools, this increased the likelihood that they would be discussed and used with patients and carers.

In order to further encourage regular use of the Dialogue Tools, HPH also created a one-page summary which offers a quick reference to these Tools, condensing them into a simple and easy-to-use guide. A similar version of this summary can be found on the Time to Talk pages of the PHA Europe website.

Looking ahead

By conducting the press conference, roundtable event and developing the one-page summary of the Dialogue Tools, healthcare professionals now have a better knowledge of how they can be successfully used with patients. The next goal for HPH is to support a pan-European patient conference to explain the importance of keeping a diary of the emotional and physical impact of PAH to help to facilitate conversations with healthcare professionals.



Top tips for encouraging the use of the Patient and Carer Dialogue Tools in your own country from **Ioanna Alysandratou, President of HPH**

“ The press conference and roundtable event provided an unparalleled opportunity for us to reach a wide audience of healthcare professionals, patients, carers and the media to educate them around the benefits of regular use of the Patient and Carer Dialogue Tools. By sharing the Tools, we hope to encourage more conversation around the emotional, social and physical impact of PAH on the lives of patients and their carers ”

Convey the importance of the dialogue tools

- Reaching patients to educate, inform and support them is the main objective of any patient organization, therefore consider providing training on the Patient and Carer Dialogue Tools to both patients and healthcare professionals to increase the likelihood that they will be used to support conversations around the impact of PAH

Involve healthcare professionals

- It is really important that healthcare professionals support and understand how to use the Patient and Carer Dialogue Tools
- Consider arranging a meeting with leading PH specialists to educate them on how to use the Dialogue Tools so that they feel confident using them with their patients

Offer a summary

- The Patient and Carer Dialogue Tools are extensive and can be time consuming for patients and carers to fill in on a regular basis. By offering a summary, it makes them more accessible and easier to pick up and follow
- For a summary, please see the Time to Talk Patient and Carer section of the PHA Europe website

Conduct a variety of events

- In order to reach and educate a wide variety of audiences, including healthcare professionals, patients and the general public, plan a range of different events to target different groups

Make use of related events

- In order to maximize the number of people at your event, think about whether there are any other related events happening at the same time. Consider coinciding with the event to draw more attention

Further information

For more information about how to create your own meeting and for a draft agenda, please see the Time to Talk **member resources section** of the PHA Europe website.