

Best practice case study

PHA Norway

Spotlight on Norway

Annual patient and carer conference provides a supportive setting to discuss the International Patient and Carer Survey findings and share experiences of living with pulmonary arterial hypertension

The results of the International Patient and Carer Survey (IPCS) show that over half of patients living with pulmonary arterial hypertension (PAH) and one-third of their carers feel isolated. One of the main reasons for this is a lack of awareness of the condition amongst the general public.

There are only 100-150 people in Norway living with PAH and the survey highlighted a need to bring patients and their carers together to share their experiences and to build a support network to help address the social and emotional impact of living with the condition. In this case study, Hall Skaara, President of PHA Norway explains how an initiative to bring patients and carers together has been a great success and has helped participants to learn more about living with PAH and to build a support network.



Patients and carers gather at the conference in Oslo

Building a support network for patients and carers

In order to bring PAH patients and their carers together from across the country, Pulmonary Hypertension Association (PHA) Norway introduced an annual Patient and Carer Conference in 2011.

The objectives of the annual conference are to:

- Educate patients and carers about the management of PAH
- Support patients and carers to share their experiences and seek support from PHA Norway
- Create a united community and support network for patients and carers

It was really reassuring to hear that the IPCS findings showed other patients struggle with the same issues as I do
Patient

Educating patients and carers

In June 2013, 30 patients and carers attended the conference. This was held at a rehabilitation centre just outside of Oslo, a central and accessible location for the attendees who are geographically spread across Norway.

Over the course of two days, attendees were exposed to a wide variety of activities and presentations on topics such as **nutrition, insurance, exercise and medication**, including a presentation from Norway's **leading pulmonary hypertension specialist**, Dr Arne Andreassen.

For those who were newly diagnosed in particular, the opportunity to have their **medical questions answered** by Dr Andreassen was greatly valued. Attendees were also able to learn from the questions asked by others, which they may not have discussed with their own doctor or nurse.

Through hearing about **PHA Norway's services and resources**, which address the needs of both patients and their carers, attendees were able to identify any education needs of their own and request the relevant materials.



Attendees relax in between sessions

Sharing personal experiences

The conference provided a much needed opportunity to **present and discuss the IPCS findings**, which formed a central part of the meeting. Through discussing the survey, patients and carers were encouraged to talk openly about the **emotional impact** that PAH has on their daily lives and how the survey findings relate to their own experiences. Copies of the survey were made available to take away and read in full.

In addition to discussing the survey findings themselves, the meeting also provided a platform to explore the **Patient and Carer Dialogue Tools**. Patients and carers were divided into two separate groups to use each respective Dialogue Tool as a basis for discussion about the impact of PAH on the patient as well as for the carer. Both groups really valued the opportunity to share their experiences with others who faced similar challenges and by splitting into smaller groups it created an **intimate setting** and allowed patient and carers to talk freely and **discuss private issues** that they may not have felt comfortable talking about with their relative/friend. The IPCS findings show that carers often feel neglected and overlooked, therefore this event provided an important opportunity to discuss the impact of caring for someone with PAH with other carers who could relate to the issues and provide guidance. Through using the Dialogue Tools to facilitate discussions, patients and carers felt **empowered to have important conversations**, such as conversations about intimate issues, at home.

It was great to meet other carers as PH is a disease that affects the entire family. I really appreciated the chance to speak to other carers who could relate to my situation
Carer

Creating a united community

An important objective of the conference is to strengthen the group's **sense of community** and create a **support network** beyond the scope of the meeting. To facilitate this, the meeting included an open session on the first day to allow attendees to introduce themselves and explain their connection to PAH with the group.

Entertainment, including a performance by local musicians, was organized in the evening to allow attendees to relax and get to know one another before the main meeting. Attendees reported that they really enjoyed the social aspects of the meeting and appreciated being able to talk to others in a similar situation to their own, either as a patient managing their condition or as a carer supporting someone living with PAH.

Some PAH patients at the meeting had **never met anyone living with the same condition** as them before and welcomed the opportunity to learn from each another. Following the meeting, attendees have kept in **close contact** with one another, meeting outside the annual conference to provide **support and friendship to each other**.

Looking ahead

The last day of the meeting included an evaluation session where attendees could discuss what they enjoyed most and any areas for improvement. Feedback demonstrated the **success of the meeting** and patients and carers noted that using the Dialogue Tools to aid discussions around the emotional impact of PAH was particularly valuable.

In 2014, PHA Norway invited representatives of the newly established Danish patient organization to join their conference, with a view to supporting them to set up their own conference in future years. By working together and sharing best practice, the organizations hope to **strengthen their relationships** as part of the **wider PAH community** and provide further support to their members.

This was the first time I had met another PAH patient face-to-face! Fantastic!
Patient



Evening entertainment for attendees



Top tips for conducting your own patient and carer conference from **Hall Skaara, President, PHA Norway**

“ The Patient and Carer Dialogue Tools were really useful for discussion as they enabled both groups to talk openly about the impact that PAH has on their daily life. Patients and carers spoke about a wide range of issues, including the physical and emotional burden that PAH can have. In Norway, these tools are sent out to all newly diagnosed patients as part of the PHA Norway welcome pack to encourage patients and carers to have these important conversations with their family, friends and healthcare professionals ”

Include carers

- Ensure patients and carers both have the opportunity to participate, learn and connect with others to help address isolation

Hold your meeting in a central and accessible location

- Travelling can be difficult for people with PAH so choosing a convenient location and a venue with accessible facilities will help – the rehabilitation centre we use in Oslo is a great example of this

Plan varied content for the meeting

- PAH is a multi-faceted disease, with a varied physical, emotional and social impact
- Include talks on a number of different topics, from medical management to insurance, to address a broad spectrum of information needs
- However, do not be too ambitious with the agenda as patients attending the meeting can become tired

Include a presentation from a healthcare professional

- There are often questions regarding the medical management of PAH, therefore it is important that there is someone present who is qualified to answer these questions – our patients reported they found the session with Norway's leading PH specialist particularly valuable

Include breaks in between sessions

- Sessions can be tiring therefore it is important that regular breaks are included to allow attendees to relax and prepare for the next session
- Having a break in between sessions also allows for any particularly engaging discussions to overrun if needed and also allows for attendees to socialize with one another

Hold discussions in smaller groups

- Dividing into groups provides a more intimate setting for patients and carers to talk about their challenges and personal experiences

Include a social element

- It is important that attendees feel comfortable talking with one another at the meeting, therefore consider a social event, such as a meal the night before, for attendees to get to know one another better
- This will also help patients and carers to begin building a support network that they can maintain after the conference – our patients and carers speak regularly and meet up whenever they can outside of our annual meeting

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.