



Best practice case study

HTAPFrance

Spotlight on France

Calendar of meetings for patients, carers and healthcare professionals provides education, support and encourages sense of community

Recommendations resulting from the International Patient and Carer Survey (IPCS) outline that in order to meet the needs of patients with pulmonary arterial hypertension (PAH), a **multidisciplinary approach** to their care should be adopted and provided. This means involving physicians and nurses, as well as psychologists, patient organizations and carers to support patients' physical and emotional needs. France's PAH organization, HTAPFrance recognises this approach and regularly organizes events for patients, carers and healthcare professionals to **promote education and offer guidance**. In this case study, Mélanie Gallant-Dewavrin, Director of HTAPFrance talks about the numerous activities HTAPFrance has organized recently and its future plans to extend further support to the PAH community.

Reaching out to patients, carers and healthcare professionals

In order to support the estimated 3,000 patients in France living with pulmonary hypertension (PH), including PAH, as well as their carers and healthcare teams, HTAPFrance organizes regular events with the aim to:

- **Support patients and carers to share** their experiences
- **Bring healthcare professionals together** to discuss best practice management of PAH
- **Create a united community of patients, carers and healthcare professionals**

These meetings also present a great opportunity to discuss the IPCS findings and present the patient and carer dialogue tools to patients, carers and healthcare professionals.

Focus on patients and carers

Every three years, HTAPFrance holds a patient congress to provide education and support to patients and their carers. In 2013, the two-day patient conference was held in Lyon and **attended by more than 200 people** from across France (and abroad) who heard from a variety of different expert speakers on topics addressing the management of PAH, including the social and emotional impact of PAH.

Four presentations were held at any one time, allowing patients and carers to **tailor their own schedule** by picking the sessions that would benefit them most. This included sessions specifically aimed at newly diagnosed patients and those directed at carers.



More than 200 people attended the patient congress in Lyon

In response to the IPCS findings, which highlighted that the emotional impact of PAH is often overlooked, patients and carers appreciated the opportunity to **talk to a psychologist** over the course of the conference. These sessions encouraged attendees to speak freely and to ask questions which they may not feel able to talk about with a physician. Patients and carers were also given the opportunity to share their experiences of how PAH can impact on intimacy. To support patients in their conversations outside of the meeting, patients and carers were given copies of the dialogue tool, which includes information about intimacy. During the course of the two days, over 300 copies of the dialogue tool were given out.



Christophe Pison, a leading pulmonologist, gives the closing speech at the congress

Bringing healthcare professionals together

HTAPFrance recognizes the importance of **bringing healthcare professionals together to share expertise, knowledge and experiences of managing PAH**. In 2014, HTAPFrance held a workshop with representatives from expert centres across France, including physicians, nurses, psychologists and patients to discuss topics such as pregnancy with PAH, how to treat emergencies and how to manage catheter-related infections for patients on prostacyclins.

The workshop provided a unique opportunity to explore the similarities and differences between expert centres across France and to learn from one another's experiences. By inviting psychologists and a small number of patients, the group benefited from hearing about the **emotional impact of PAH, beyond the physical symptoms**. To support conversations with patients and carers about the emotional impact of PAH, attendees were given copies of the dialogue tool as a practical resource. For those who were unable to make this workshop, HTAPFrance has arranged one-to-one visits in order to introduce healthcare professionals to the dialogue tools and discuss the IPCS findings.



Marc Humbert, Professor of Respiratory Medicine at the South Paris University gives the opening session

HTAPFrance representatives are also invited to talk at nurse meetings. Nurses are often the daily contact for patients in hospital therefore these meetings provide an opportunity to educate and inform nurses about incorporating emotional issues into PAH care management.

Creating a united community

HTAPFrance develops a **biannual magazine**, CapVers, which provides updates and interviews to keep members up-to-date about the activities that have been going on and new resources available to them. In addition to traditional channels, **HTAPFrance is also active on both Facebook and Twitter** to ensure that their online members can always be informed of their activities. Using social media and engaging with patients and carers in this way means members can more easily communicate with each other outside of meetings.

Looking ahead, HTAPFrance hope to set up café catch-ups in Paris and elsewhere in France to enable patients and carers to meet up regularly to share experiences and build a **supportive community**. Choosing an informal setting, such as a café, aims to encourage patients to talk openly about the emotional impact that PAH has on their daily lives and share experiences with one another.



Top tips for conducting your own meetings from **Mélanie Gallant-Dewavrin,** **Director of HTAPFrance**

“ The patient congress enables patients and carers from all over France (as well as from other countries), to come together to share experiences and learn from expert speakers. It also provides a great opportunity for patients and carers to discuss important issues in PAH with other patients and carers who best understand the emotional impact of living with PAH and its daily challenges ”

Planning is key

- Particularly for larger events, begin planning your meeting as far in advance as possible
- To support this, try to have one or two people who are involved in the organization from the beginning, so they can be easily established as the main contacts for speakers, attendees and suppliers for greater continuity

Identify meeting topics and sessions before contacting speakers

- Once you have decided what topics you would like to cover at your meeting, approach specialists within that field
- Their availability may dictate when you can hold your event – once they have confirmed, book a venue which has room capacity for the amount of people you hope to draw
- Approach speakers as far in advance as possible to ensure that if they cannot attend, you have time to find alternatives – If a speaker is unable to attend, ask them to recommend anyone else, they may be better placed to share this information

Include an evaluation session

- An evaluation session allows you to see what worked well and what could be improved, this is really helpful if you are hoping to conduct future meetings
- A questionnaire can be a good way for attendees to provide feedback confidentially

Be mindful of sensitive issues

- While some attendees may be happy to talk about sensitive issues in a group, others may not want to, therefore smaller groups are recommended

- It can be helpful to split groups into patients and carers as different issues may affect each group

Include healthcare professionals in the meeting

- Patients and carers will appreciate the opportunity to ask questions that they may not have had time to ask in a typical consultation
- Having healthcare professionals at the meeting also allows patients to receive medical attention if they need it

Keep in contact with members between meetings

- Social media can be used a great tool for keeping in contact with your members between meetings and to raise awareness of upcoming meetings

Choose an appropriate venue

- It is very important to choose a suitable venue for your meeting which can comfortably accommodate your attendees, with wheelchair access throughout the building
- Contact your venue in advance to talk through any requirements you have and to make sure that they are comfortable with any medical equipment you may need to have on the premises

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.