



# ERS CONGRESS | 2024

7-11 September | Vienna, Austria

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## **Reasons to join pulmonary hypertension patient associations – do not forget the caregivers!**

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**Background:** To better understand the needs and hurdles of pulmonary hypertension patients and their caregivers a multinational survey was performed in 2023. This evaluation focuses on the impact of the disease on their daily life as well as on awareness about patient organizations and motivational factors to join these. A publication of complete survey results is under preparation.

**Methods:** Patient organizations from nine European countries (Germany, Italy, Austria, Spain, Sweden, Poland, Hungary, Czech Republic, Slovakia) invited their members to complete the online survey, as the overall target was to collect 230 surveys.

**Results:** 619 surveys were completed (527 patients, 92 caregivers). For this analysis 523 surveys of members of patient associations (454 patients, 69 caregivers) were evaluated. For both patients and caregivers, main sources of awareness about patient organizations were the internet (40 and 47%) and recommendation by a health care professional (35 and 25%). On motivational factors to join patient organization participants were asked to rank these from 1 to 7. Not surprisingly for patients the by far predominant motivation was to find support and information about their disease (1.9), while in contrast psychological support was ranked highest by caregivers (1.9). Motivational factors ranked second and third were support in the daily treatment management (3.0/2.7) and the interaction with other patients and caregivers (3.0/3.2). Country specific differences will be presented in detail.

**Conclusion:** Our results indicate that patient associations should offer tailored support programs for caregivers to attract this target group which is critical in the management of PH.

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