

# REASONS TO JOIN PULMONARY HYPERTENSION PATIENT ASSOCIATIONS – DO NOT FORGET THE CAREGIVERS!

Eva Otter<sup>1</sup>, Roberto Badagliacca<sup>2</sup>, Regina Steringer-Mascherbauer<sup>3</sup>, Khodr Tello<sup>4</sup>, Gerald Fischer<sup>1</sup>, Ralf Lenhard<sup>5</sup>, Martina Neubauer<sup>6</sup>, Hall Skara<sup>1</sup> and Carmine Dario Vizza<sup>2</sup>

<sup>1</sup> PHA Europe, Vienna, Austria <sup>2</sup> Department of Cardiovascular and Respiratory Sciences, Sapienza University of Rome, Rome, Italy <sup>3</sup> Department of Cardiology, Ordensklinikum Linz GmbH Elisabethinen, Linz, Austria <sup>4</sup> Department of Internal Medicine, Justus-Liebig-Universität Gießen, Germany <sup>5</sup> OrphaCare GmbH, Vienna, Austria <sup>6</sup> AOP Orphan Pharmaceuticals GmbH, Vienna, Austria

## Aim:

To **better understand the needs and hurdles of Pulmonary Hypertension (PH) patients and their caregivers**, a multinational survey was performed in 2023.

## Background:

This evaluation focuses on the impact of the disease on their daily life as well as on awareness of patient associations and motivational factors to join these.

## Objectives:

- Understand the **typical patients with Pulmonary Hypertension (PH) seeking support** at patient associations.
- Understand the **role of caregivers and patient associations** in supporting PH patients and their interactions.
- Identify the **unmet needs of PH patients, caregivers and patient associations** and the key areas in which they need support.
- Investigate the **information and educational support most needed** by and helpful for PH patients and caregivers (topics being requested or sought).
- Clarify the **most appropriate channels for distribution and/or access to information** (GP, specialists, nursing support, websites, etc., ...).

## Methods:

Patient associations from 9 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.

### A multi-country two phases research

#### Phase I: Qualitative interviews

- 13 qualitative interviews with presidents and board members of PH patient associations in Europe.
- Get a first understanding of the main motivations and barriers in interacting with a PH patient association.

#### Phase II: Quantitative online survey

- Feedback and answers directly from patients and caregivers.
- Deep-dive into actions and activities held at local associations.
- Highlight areas of interest for patients and caregivers at patient associations.

**619 patients and caregivers responded to the survey!**



### Background & demographics

#### Country of residence

Countries									
Patient associations (N)	1	2	1	3	1	1	1	1	1
Patients (N)	103	70	80	73	56	43	50	35	17
Caregivers (N)	14	18	7	7	11	22	6	6	1
Total respondents (N)	117	88	87	80	67	65	56	41	18

### Symptoms & diagnosis

#### Most common symptoms

#### Patient response

TOP 3	Fatigue, exertion	89%
	Dyspnoea, shortness of breath	83%
	Palpitations, irregular heartbeat	61%
	Weight gain due to water retention	48%
	Pressure in the chest	46%
	Signs of depression	43%
	Blue lips	40%
	Nausea	33%
	Syncope	31%
	No symptoms	20%

Time between onset of symptoms and diagnosis was ~ 35 months.



### DAILY CHALLENGES

#### Main daily challenges related to the disease

Patients and caregivers face multiple daily challenges.

Both groups **feel mentally exhausted** or **suffer psychological distress**.



N = 527

#### Main challenges faced by patients

Mental or psychological exhaustion or distress	46%
Lack of understanding and/or support from others	45%
Non-acceptance of the diagnosis	22%
Lack of information about the disease and treatment	21%
Lack of medical facilities to go to for treatment, check-ups	20%
Lack of information about which specialists to go to	15%
No daily challenges	25%



N = 92

#### Main challenges faced by caregivers

It is hard for me to accept the diagnosis of the patient	38%
I am mentally or psychologically exhausted or in distress	36%
I have difficulties coping with my daily activities	30%
I lack information about the disease and treatment	25%
My role or responsibilities towards the patient are unclear	12%
No daily challenges	17%

Responses are not mutually exclusive. Respondents were able to select multiple responses.



### DIFFICULTIES

#### Other impact of the disease on daily life

Both **patients and caregivers** agree they **experience difficulties in their daily activities, in leisure activities and hobbies** as well as **travelling issues**. Additionally, caregivers report a **lack of psychological support!**



N = 527

#### Other difficulties faced by patients

Difficulties in daily life activities*	70%
Difficulties in leisure activities & hobbies	61%
Traveling issues	45%
Changes regarding professional life	36%
Lack of support in social issues**	28%
Lack of psychological care	25%
Lack of knowledge or training about the level of care needed because of the disease	18%
Lack of medical care and support from Healthcare Professionals***	14%
Challenges in engaging with other patients	6%
No other difficulties	9%

e.g. walking, climbing stairs, shopping... \*\*social security, retirement policies, disability applications... \*\*\*e.g. doctor, nurse, specialist...



N = 92

#### Other difficulties faced by caregivers

Difficulties in leisure activities & hobbies	54%
Difficulties in daily life activities*	46%
Traveling issues	40%
Lack of psychological care	38%
Lack of support in social issues**	35%
Lack of knowledge or training about the level of care needed because of the disease	29%
Changes regarding professional life	27%
Challenges in handling the patient	23%
Lack of medical care and support from Healthcare Professionals***	22%
No other difficulties	12%



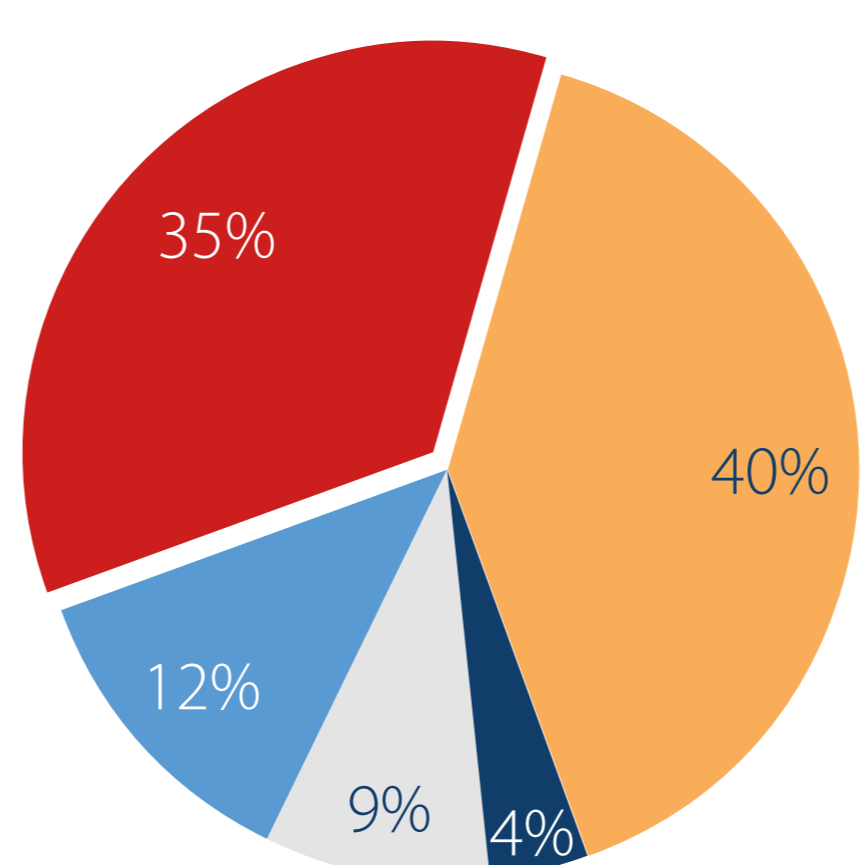
### CHANNELS

#### Awareness of patient associations

Most patients and caregivers discovered their patient association on the Internet. Only one third of the patients became aware when being recommended by an HCP.



N = 454



#### First source of awareness among patients (% of respondents)

- I found its existence on the Internet
- The patient association was recommended by a Healthcare Professional
- I found its existence through a brochure, leaflet addressed to patients with the disease
- It was recommended by another patient
- It was recommended by a caregiver (family, relative...)



### CHANNELS

N = 454

#### Awareness of patient associations per country

Total									
On the Internet	65%	29%	23%	52%	23%	40%	27%	23%	24%
Recommended by HCP	13%	32%	51%	35%	50%	22%	73%	49%	58%
Brochure, leaflet	4%	23%	18%	3%	17%	4%	0%	19%	18%
Recommended by another patient	16%	8%	7%	7%	6%	30%	0%	6%	0%
Recommended by caregiver	2%	8%	1%	3%	4%	4%	0%	3%	0%

Respondents who mention being a member of a patient association



### MOTIVATIONS

#### Main motivations to become a member

Patients were mainly motivated to join their association for **additional support and information about their disease and treatment**.

Caregivers' main driver was to receive their **own psychological support**.

Both wanted to **engage and exchange** with other patients and/or caregivers.



TOTAL sample

	Support and information about their disease*	Help and support for daily management of their treatment	Ability to engage and exchange with other patients/ caregivers	Psychological support	Social issues**	Recommendation from caregiver of doctor
Patients N=454	#1 1.9	#2 3.0	#3 3.0	#4 3.9	#5 4.7	#6 4.8
Caregivers N=69	#4 3.6	#2 2.7	#3 3.2	#1 1.9	#6 5.0	#5 4.7

\*Symptoms, evolution of the disease, treatment; \*\*social security, retirement policies, disability applications... Respondents who mention being a member of a patient association, average ranking – 1-7



### NEED FOR SUPPORT

#### Current unmet needs – for patients

Across countries, a majority of patients agree they need **help and support** mainly for receiving **tips to improve their Quality of Life**.

Most needed										
TOP 3	Tips for Quality of Life	61%	70%	54%	61%	59%	74%	50%	51%	59%
	Exercise advice	53%	68%	46%	51%	56%	54%	51%	44%	29%
	Nutrition advice	45%	48%	34%	35%	63%	48%	56%	40%	34%
	Advice in case of social issues*	36%	48%	31%	29%	44%	30%	44%	36%	23%
	Tips for rehabilitation	36%	35%	9%	34%	44%	38%	51%	38%	49%
Least needed										

\*social security, retirement policies, disability applications...

#### Current unmet needs – for caregivers

A large majority of caregivers in **Germany, Poland and Hungary** need help and support mainly for receiving **tips to improve their Quality of Life**.

In **Austria, Spain, Poland and Hungary** they mainly expressed the **need for psychological support**.

Most needed									
TOP 3	Tips for Quality of Life	57%	86%	50%	43%	14%	36%	68%	50%
	Exercise advice	50%	71%	44%	29%	29%	36%	55%	67%
	Psychological support	49%	36%	44%	57%	57%	18%	64%	67%
	Nutrition advice	41%	43%	39%	14%	43%	36%	50%	50%
	Tips for rehabilitation	38%	36%	22%	71%	14%	9%	55%	33%
Least needed									

0-33 % = low need 34-66% = medium need 67-100% = high need

Slovakia was not considered in the country split (N=1 caregiver). Responses are not mutually exclusive. Respondents were able to select multiple responses.

## Conclusions:

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 Pulmonary Hypertension.

**Strengthen profile-specific initiatives and topics for a better impact on both patients and caregivers:**

- Patients and caregivers still have distinct expectations** when interacting with a patient association.
- Strong psychological support** is expected from **caregivers**. **Patients** would typically look for information and **advice to live with their disease**.
- Therefore, it remains key to create **profile-specific initiatives** to allow both patients and caregivers to participate in activities they are **primarily looking for**.