The impact of pulmonary arterial hypertension (PAH) on the lives of patients and caregivers: results from a U.S. study.
The impact of pulmonary arterial hypertension (PAH) on the lives of patients and caregivers: results from a US study.

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PHA contracted with Harris Interactive for this work.
The impact of pulmonary arterial hypertension (PAH) on the lives of patients and caregivers: results from a U.S. study.

This survey included both patients and caregivers with the purpose of providing new insights into the wider impact on PAH patients and caregivers beyond the clinical definition of the physical burden of the disease, which until now, has not been extensively researched. It explored three main areas:
1. physical and practical impact of PAH
2. emotional and social impact and
3. information needs; to better understand PAH patients’ and caregivers’ experience living with the disease and to inform research and provision of more comprehensive care in the future.

The findings reveal not only the major limitations that PAH imposes on the ability of patients to carry out everyday activities, however small, but also the financial impact due to limitations on the ability of patients and caregivers to work, and last, but not least, the social isolation the disease causes, especially among family and friends.

The U.S. survey was modeled after a similar study completed in the European Union within the past year which was developed by the steering committee of PAH specialists and representatives of patients’ organizations and modified by U.S. staff.

WHAT IS PAH?

Pulmonary arterial hypertension (PAH) is a progressive disease caused by narrowing and tightening (constriction) of the pulmonary arteries, which connect the right side of the heart to the lungs. By definition, PAH is characterized by an increase in mean pulmonary arterial pressure (PAP) to at least 25 mm Hg at rest, and a mean pulmonary capillary wedge pressure (PCWP) of ≤15 mm Hg.1,2

As PAH develops, blood flow through the pulmonary arteries is restricted, and the right side of the heart becomes enlarged due to the increased strain of pumping blood through the lungs. It is this strain on the heart and the decrease in blood to the left heart and systemic circulation through the lungs that leads to the common symptoms of PAH, such as breathlessness, fatigue, weakness, angina, syncope, and abdominal distension.2

Although there is no cure, treatment is aimed at improving symptoms, exercise tolerance, long-term outcome and quality of life. Until the mid-1980s there were limited treatment options for patients, and PAH was associated with poor prognosis.

Illustration 1

WHAT CAUSES PAH?

One of the more common forms of PAH is idiopathic PAH (IPAH), which is sporadic disease in which there is neither a family history of PAH nor an identified risk factor.4 Heritable PAH (HPAH) accounts for at least 6% of cases of PAH3 and mutations in the bone morphogenetic protein receptor 2 (BMPR2) have been identified in the majority of cases.6 PAH can also be caused by the use of certain anorexigens, such as fenfluramine.2,7 However, the incidence of drug-induced PAH related to fenfluramine is decreasing as this agent is no longer available.

PAH can also be associated with a number of other conditions (associated PAH, APAH), which together account for most other cases. These conditions include: connective tissue disease; HIV infection; portal hypertension congenital heart disease; schistosomiasis and sickle cell disease.

WHAT IS THE IMPACT OF PAH ON PATIENTS?

Changes to the pulmonary vasculature lead to the typical symptoms of PAH, which include: breathlessness (dyspnea), particularly during physical activity; fatigue; dizziness; syncope, also on physical activity; peripheral edema; chest pain, again particularly during physical activity.2,7 These symptoms can severely impair patients’ ability to carry out normal daily activities.

As the disease progresses, some patients may experience constant dyspnea and fatigue so that even simple tasks, such as getting dressed and walking short distances, become difficult.

Although PAH is a rare disease, with an overall estimated prevalence of 15-50 cases per million,7 the prevalence of PAH is substantially higher in certain at-risk groups including patients with human immunodeficiency virus (HIV) infection and those with systemic sclerosis.
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WHAT IS THE IMPACT OF PAH ON PATIENTS?

The clinical severity of PAH is classified using a system that grades PAH severity according to the functional status of the patient, linking symptoms with activity limitations. It allows clinicians to quickly assess disease progression and prognosis, as well as the need for specific treatment regimens, irrespective of the underlying etiology of PAH (Table 1).

Table 1. WHO functional classification of pulmonary hypertension

<table>
<thead>
<tr>
<th>FUNCTIONAL CLASS</th>
<th>SYMPTOMATIC PROFILE</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Patients with pulmonary hypertension but without resulting limitation of physical activity. Ordinary physical activity does not cause dyspnea or fatigue, chest pain, or near syncope.</td>
</tr>
<tr>
<td>II</td>
<td>Patients with pulmonary hypertension resulting in slight limitation of physical activity. They are comfortable at rest. Ordinary physical activity causes undue dyspnea or fatigue, chest pain, or near syncope.</td>
</tr>
<tr>
<td>III</td>
<td>Patients with pulmonary hypertension resulting in marked limitation of physical activity. They are uncomfortable at rest. Less than ordinary activity causes undue dyspnea or fatigue, chest pain, or near syncope.</td>
</tr>
<tr>
<td>IV</td>
<td>Patients with pulmonary hypertension with inability to carry out any physical activity without symptoms. These patients manifest signs of right heart failure. Dyspnea and/or fatigue may even be present at rest. Discomfort is increased by any physical activity.</td>
</tr>
</tbody>
</table>

PAH currently tends to be evaluated based on a physical definition of clinical symptoms including clinical evaluation, exercise tests, biochemical markers and echocardiographic and hemodynamic assessments. For example, exercise capacity is measured using the six-minute walk test (the distance that a patient can walk in six minutes on level ground to distinguish from a treadmill walking test). However, PAH has much broader impact than suggested by the current definition of clinical symptoms, but there has been relatively limited previous research into this.

IMPACT OF PAH ON CAREGIVERS

The limitations imposed by PAH mean that patients often need help from a caregiver, with partners and family members taking on this role. Becoming a caregiver can have a major effect on a person's life, often reducing their opportunities for working and taking part in other activities. However, the needs of caregivers of PAH patients are often overlooked, and they are not even mentioned in the European or U.S. guidelines on pulmonary hypertension. This is in contrast to other long-term serious conditions such as cardiovascular disease and Alzheimer’s disease where written guidelines acknowledge the role of caregivers, and they are offered help and support.

METHODOLOGY

This quantitative research was fielded in August 2012, gathering opinions from patients and caregivers within the U.S. with all participants completing the survey online. Participants were recruited from various online PHA sites such as Facebook, leader listservs, general listservs and message boards. A portion of participants also participated from Harris Interactive partner panels. A total of 79 patients completed the survey (average age 53 years; 90% female; 3% FC I, 23% FC II, 10% FC III, 4% FC IV). A total of 76 caregivers completed the survey (average age 47 years; 78% female; 1% FC I, 8% FC II, 22% FC III, 4% FC IV).

Table 2. Background information on PAH: patients self-reported awareness, understanding & relevance of FC

BACKGROUND

Pulmonary arterial hypertension (PAH) is a rare condition, but one which has a major impact on morbidity and mortality, and ultimately, there is no cure. There has previously been relatively limited research into the broader impact of PAH on the lives of patients and caregivers beyond the current definition of clinical symptoms, so originally an international self-reported survey using market research methodologies was carried out to explore this. A multidisciplinary steering committee of PAH specialists, including respiratory physicians, internists, rheumatologists, PAH specialist nurses and patient group representatives, led the development of the survey content and analysis of results to ensure medical and practical relevance. After the completion of the international survey, a replica of the survey was completed within the U.S.

Sponsorship: This survey and report have been developed under the auspices of a steering committee of PAH specialists and representatives of PAH patients’ organizations and is supported by Actelion Pharmaceuticals Ltd. The market research agencies involved in the surveys were commissioned by PHA, with grant support from Actelion.
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**STEPS PATIENTS AND CAREGIVERS ARE TAKING TO MANAGE PAH**

A majority of both patients and caregivers who participated in the surveys currently belong to a patient association/support group, with over 90% belonging to PHA.

- Patients join support groups to hear about/meet other patients and to gain a greater understanding of the condition.
- Three quarters of patients who receive emotional support from a psychologist are active in a support group and 83% joined a support group because they wanted to know all about the condition.
- Patients receiving emotional support from nurses are more likely to join a support group to hear about/meet other patients (75%) as well as learn more about the condition (92%). Nurses are great advocates for support groups and aiding patients to join.
- Over three quarters of caregivers (9 out of 10 parent caregivers) joined a support group to hear about/meet other patients/caregivers.

Belonging to a support group helps assist PAH patients with feelings they might encounter. Data show patients who currently belong to a support group are less likely to feel worried or be embarrassed, less likely to have low self-esteem or be afraid to leave home and have an increased desire to socialize compared to those patients who do not belong to a support group.

Patients not belonging to a support group and not having emotional support show an increase lack in desire to socialize.

Patients need an outlet to discuss their feelings and are finding it easy with their spouse/partner, in addition to external contacts such as family doctor/GP, specialists involved in the management of PAH, nurses, other PAH patients and members of patient association/support groups.

- 6 out of 10 patients state they receive emotional support from PAH specialists and/or family. Around half get this support from a caregiver, friend, a family doctor/GP or patient organization.
- Those patients who do not currently belong to any type of support group find it easier to discuss their feelings with a spouse/partner or family doctor/GP and receive emotional support from family, caregiver, PAH specialist or nurse.

Patients are receiving the proper tools, education and support from support groups on how to better manage and adapt to new attitudes and behaviors such as seeking information about PAH, talking more openly about the disease with others, preparing for change, getting rest and being flexible.

On average, caregivers who belong to a support group tend to have fewer negative thoughts or feelings than those who do not belong to a support group. Caregivers are less likely to feel:

- That their relative asks for more help than he or she needs
- Feel angry when in the presence of their relative
- Feel their relative is over dependent on them
- Feel strained when they are around their relative
- Feel that they do not have as much privacy as they would like because of their relative

Caregivers who are parents find themselves needing to be organized all the time 71% and involved in the administration of medication 71%.

Both patients and caregivers are satisfied with the information they receive from physicians involved in the management of PAH, family doctor/GP, nurse and other patients with PAH.

**SUMMARY AND CONCLUSIONS**

Patient organizations/support groups have significantly assisted both patients and caregivers with the management, education and tools to move forward with living with PAH. Patients and caregivers are finding the necessary means with the tremendous amount of data PHA has to offer.

Support groups help aid patients and caregivers in learning and adapting to new attitudes, behaviors and feelings, however patients continue to feel frustrated and caregivers continue to feel exhausted whether they belong to a support group or not.

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<table>
<thead>
<tr>
<th>Feelings when you are taking care of another person</th>
<th>Belong to support group (n=45)</th>
<th>Do not belong to support group (n=31)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel that my relative asks for more help than he or she needs</td>
<td>9%</td>
<td>32%</td>
</tr>
<tr>
<td>I feel angry when I am around my relative</td>
<td>9%</td>
<td>19%</td>
</tr>
<tr>
<td>I feel my relative is over dependent on me</td>
<td>7%</td>
<td>29%</td>
</tr>
<tr>
<td>I feel strained when I am around my relative</td>
<td>11%</td>
<td>26%</td>
</tr>
<tr>
<td>I feel that I do not have as much privacy as I would like because of my relative</td>
<td>13%</td>
<td>39%</td>
</tr>
</tbody>
</table>

**HOW CAN PHA HELP?**

- Frustration and exhaustion are feelings that will be continuous with the progression of PAH. PHA can assist by expanding their efforts specifically addressing these topics through their website, increasing blogs, forums, testimonials or support from nurses and Physicians involved in the management of PAH.

Patients belonging to support groups do not find it easy to discuss their feelings with people outside of their group.

How can PHA increase the desire to socialize and expand the comfort to be able to talk openly with others outside of the support group?

- While having a support group is essential in the aid to fight this disease, it can also in turn be harmful knowing that the only other outlet is online chatting via website or Facebook.

- Allow PHA specialists, nurses and doctors to be aware of and promote in-person support meetings and the value of having support outside of an actual support group. While the support group is essential for educational information and is a safe place to reside, patients need to be able to trust and openly discuss their feelings with different outlets.

<table>
<thead>
<tr>
<th>Feelings in the last month among patients</th>
<th>Belong to support group (n=55)</th>
<th>Do not belong to support group (n=24)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling worried</td>
<td>31%</td>
<td>42%</td>
</tr>
<tr>
<td>No desire to socialize</td>
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<td>38%</td>
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<tr>
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</tr>
</tbody>
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**HOW CAN PHA HELP?**

Additional information about financial consequences is being requested by both patients and caregivers and should be distributed at the time of diagnosis.

Have educational packets available at the time of diagnosis that can be distributed to patients and caregivers with topics including financial consequences, information about the condition, shift in roles, depression/anxiety, possible consequences on sexual relationships, specialists, treatment, follow-ups, testimonials, and support groups.

Patients and caregivers are satisfied with the information they receive from physicians involved in the management of PAH, followed by support groups and other patients. Allow these physicians to promote necessary and invaluable sources to use during this time of transition and for support in the future.

Slightly more caregivers who belong to a support group (compared to those caregivers who are not participants to a support group), are likely to feel isolated or excluded for reasons including the disease not being visible or a lack of understanding by society.

**HOW CAN PHA DECREASE THIS FEELING?**

How can we educate society and increase the awareness of PAH? Might there be an opportunity for educational pamphlets to be available for caregivers to have and hand out to those they are surrounded with? Are there known celebrities dealing with PAH that can promote this disease and the effects it has not only on patients but the caregivers as well? The use of TV and Internet ads would help to increase this awareness.

Overall, a total of N=79 Patients and N=76 Caregivers participated in the survey.

## 1.0 KEY RESULTS:

### PHYSICAL AND PRACTICAL IMPACT ON PATIENTS

**On a scale from 1 to 10, how would you describe the impact of your PAH on your daily life?**

PAH has a significant impact on the lives of patients and has significantly impacted over half of patients with about one third stating a very significant impact, selecting a 10 on the 10 point scale.

![Chart 1.1. Impact of PAH on patients' daily lives](chart)

**Patients find numerous restrictions with physical activities due to PAH symptoms. The most common physical symptoms patients often or very often experienced in the last month are fatigue (66%), breathlessness (61%) and little energy (57%). Poor appetite, chest pain and dizziness are physical symptoms patients experienced less often when compared to other physical symptoms.**

Your ability to perform or carry out the following activities compared to your ability prior to your diagnosis:

- **Physical activities**: Nine out of ten patients experience difficulty when participating in sports activities/exercise and 8 out of 10 report difficulty when climbing a flight of stairs.
- **Social activities**: Social activities with a physical component are more difficult to manage such as employment/work (92%) and traveling (83%). Having a telephone conversation or being visited by friends are managed without difficulty after the diagnosis of PAH.
- **Daily life**: Domestic work or household chores (83%) and running errands (78%) are managed with minimal difficulty with over half of patients able to carry on with daily activities such as getting dressed, cooking and taking a shower without difficulty just as they did prior to the diagnosis.
- **Relationship**: Difficulty being intimate with a spouse or partner is reported by three quarters of patients. Over half of patients report fulfilling the role of spouse or partner to be difficult.

## 1.1 IMPACT ON INTIMACY WITH SPOUSE/PARTNER

Three-quarters of patients find it difficult being intimate with a spouse or partner, and 20% were most concerned with their intimacy with a spouse or partner when asked which activities they are most concerned or frustrated with regarding the impact PAH has had on the ability to perform them.

What caused your loss in libido/interest in sex since your diagnosis?

There doesn’t seem to be exactly one reason as to why patients have experienced loss of libido or interest in sex since the diagnosis of PAH. Over one-fifth of patients claim the lack of interest is due to low self-esteem/negative body image, due to the presence of one or more serious diseases or conditions in addition to PAH or have just lost interest since having PAH. Several other reasons include patients not physically being able to be intimate due to PAH, fear of getting more ill and fear of pregnancy.

## 1.2 IMPACT ON EMPLOYMENT/WORK

One of three activities patients find concerning regarding the impact of PAH has had on the ability to perform them is employment/work; 20% of patients report the decrease in ability to work is concerning.

Overall, 52% of patients have at least partially stopped working. 12% of patients found themselves changing their occupation or having their working conditions change. 64% of patients who had to stop or change their working conditions found it to have a negative impact on their emotional well-being while 13% found the change to be positive.

### Chart 1.3

<table>
<thead>
<tr>
<th>Cause of Loss of Libido/Interest in Sex Since Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>10% Working conditions found to have a negative impact</td>
</tr>
<tr>
<td>20% Due to the presence of one or more serious diseases</td>
</tr>
<tr>
<td>26% Slight loss of interest since having PAH</td>
</tr>
<tr>
<td>36% I am physically not able due to PAH</td>
</tr>
<tr>
<td>54% I am afraid of getting worse</td>
</tr>
<tr>
<td>5% I am afraid of pregnancy</td>
</tr>
<tr>
<td>61% Other</td>
</tr>
</tbody>
</table>

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**DID THIS CHANGE HAVE AN IMPACT ON THE OVERALL INCOME OF YOUR HOUSEHOLD?**

The decrease in ability to work or having working conditions change severely affected 9 out of 10 patients and had an impact on the overall income of their household. 13% reported a decrease by 76% or more, 33% reported a decrease by 26%-50% and 20% reported a decrease in their household income by 25% or less.

**SUMMARY OF PHYSICAL AND PRACTICAL IMPACT ON PATIENTS**

Research on PAH as a whole has taught us that PAH is a rare condition which has a major impact on those lives affected by the diagnosis. This research reiterates the severity of this disease and the impact patients are faced with on a daily basis when living with PAH. Not only are daily and physical activities affected, but relationships are affected with the loss of intimacy and overall quality of life within a household due to unemployment and the impact of a decreased or completely removed income.

**2.0 KEY RESULTS: EMOTIONAL AND SOCIAL IMPACT ON PAH PATIENTS**

An overwhelming majority of patients feel that the overall public awareness of PAH is very low or non-existent, in turn affecting their well-being.

**Chart 1.5 Impact on well being**

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>32%</td>
<td>68%</td>
<td></td>
</tr>
</tbody>
</table>

**HOW OFTEN DID YOU EXPERIENCE THE FOLLOWING FEELINGS?**

Patients very often/often experience a vast array of feelings when living with PAH, including frustration (35%), worry (34%), feeling misunderstood (25%), loneliness (23%), having no desire to socialize (22%) and feeling isolated (22%). Seven out of ten patients, who feel isolated, attribute it to the fact that this disease is not “visible” and 50% of patients attribute it to a lack of understanding of the disease by friends/colleagues. 52% feel that the lack of understanding by friends/colleagues had a significant impact on the friendship.

Being fearful at night or during the day, feeling numb, afraid to leave home and hopeless are emotions that were rarely experienced among patients in the last month.

Patients feel comfortable seeking emotional support from a specialist, nurse or their family doctor/GP and are likely to find it easy to discuss their condition with them.

Frustration and exhaustion are feelings that will be continuous with the progression of PAH.

**IN WHICH PLACE OR SPACE ARE YOU GENERALLY MOST COMFORTABLE LIVING WITH PAH?**

Patients feel most comfortable discussing their feelings in a patient organization meeting or on the internet, but find support from their friends, family doctor/GP, a nurse and spiritual/religious organizations.

**How often have you found yourself adopting any of the following attitudes/behaviors relative to living with PAH?**

Living with PAH requires attitudes and behaviors to change to be able to handle and manage this condition. Often times, patients find themselves needing to become flexible (61%), having a positive attitude (71%), getting rest (66%), maintaining healthy relationships (63%), maintaining a healthy lifestyle (61%) in addition to a multitude of other coping mechanisms.

**SUMMARY OF EMOTIONAL AND SOCIAL IMPACT ON PAH PATIENTS**

Patients need an outlet to discuss their feelings and are finding it easy with their spouse/partner, in addition to external contacts such as family doctor/GP, specialists involved in the management of PAH, nurses, other PAH patients and members of patient association/support groups.

**3.0 KEY RESULTS: PATIENTS’ INFORMATION NEEDS**

Patients join a support group to hear about/meet other patients and to gain a greater understanding of the condition. Belonging to a support group helps assist with feelings patients dealing with PAH might encounter. Data shows patients who currently belong to a support group are less likely to feel worried or embarrassed, less likely to have low self-esteem, afraid to leave home and have an increased desire to socialize compared to those patients who do not belong to a support group.

**Chart 1.6 Coping Mechanisms Among Patients**

<table>
<thead>
<tr>
<th>Coping Mechanisms</th>
<th>Very Often/Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seeking information about PAH</td>
<td>77%</td>
</tr>
<tr>
<td>Positive attitude</td>
<td>71%</td>
</tr>
<tr>
<td>Getting rest</td>
<td>66%</td>
</tr>
<tr>
<td>Maintaining healthy relationships</td>
<td>63%</td>
</tr>
<tr>
<td>Maintaining a healthy lifestyle</td>
<td>61%</td>
</tr>
<tr>
<td>Being flexible</td>
<td>61%</td>
</tr>
</tbody>
</table>

**Chart 1.7**

<table>
<thead>
<tr>
<th>Feelings in the last month among patients</th>
<th>Belong to support group (n=55)</th>
<th>Do not belong to support group (n=25)</th>
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</thead>
<tbody>
<tr>
<td>Feeling worried</td>
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<td>17%</td>
</tr>
</tbody>
</table>

**What type of information on PAH do you feel you need or you wish you received?**
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Half of patients feel they need additional information or wish they received information about treatment options/drugs used for PAH therapy (59%), general information about the disease such as symptoms or prognosis (57%) and tips for travel (51%).

### WHEN IS THE MOST USEFUL TIME TO BE GIVEN INFORMATION?

Information about the disease itself is considered the most suitable for 8 out of 10 patients at the actual time of the PAH diagnosis. Specialists/doctors involved in PAH care and treatment options are also seen as the most useful to know at the time of diagnosis among the majority of patients. Financial information, patient stories and travel information can wait until up to 1 month after diagnosis for a majority of patients.

While the majority of patients reference physicians involved in the management of PAH as an information source, 4 out of 10 patients are more likely to seek out information on the Internet and/or from other patients. Just under one third of patients seek out additional information from their family doctor/GP or nurse.

In terms of online support to gain information, Facebook is the most commonly consulted website for PAH information, with WebMD and PHAssociation used by at least a quarter of U.S. patients.

### SUMMARY OF PATIENTS’ INFORMATION NEEDS

Patients are highly satisfied with their physician and patient associations/support groups as a source of information about PAH. Patient organizations have significantly assisted patients with the management, education and tools to move forward with PAH.

### 1.0 KEY RESULTS: PHYSICAL AND PRACTICAL IMPACT ON CAREGIVERS

On a scale of 1 to 10, how would you assess the impact of your relative’s PAH on your daily life and their daily life?

PAH not only affects the patient diagnosed with the disease, but also the dedicated caregiver. 62% of caregivers report the overall impact of their relative’s PAH on their daily lives as very significant, selecting the top 3 box on a 10 point scale. Three-quarters of caregivers say their patients live are affected by the impact of PAH.

### Chart 2.1

<table>
<thead>
<tr>
<th>Impact of Relative’s PAH on Your Quality of Life</th>
<th>Impact of PAH on Your Relative’s Daily Life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very significant impact</td>
<td>Top 3 (8-10)</td>
</tr>
<tr>
<td>6-7</td>
<td>6-1</td>
</tr>
<tr>
<td>4-5</td>
<td>3-3</td>
</tr>
<tr>
<td>2-1</td>
<td>1-1</td>
</tr>
<tr>
<td>No impact at all</td>
<td>0-0</td>
</tr>
</tbody>
</table>

**CHART 2.2**

<table>
<thead>
<tr>
<th>Changes Your Relative’s PAH Has Had on Your Life Among Caregivers</th>
<th>Yes (%)</th>
<th>No (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am more involved in the household chores</td>
<td>62%</td>
<td>38%</td>
</tr>
<tr>
<td>I feel more exhausted more frequently (due to extra responsibilities)</td>
<td>61%</td>
<td>39%</td>
</tr>
<tr>
<td>I have to schedule family life around his/her needs</td>
<td>57%</td>
<td>43%</td>
</tr>
<tr>
<td>I need to be organized all the time (extra planning)</td>
<td>55%</td>
<td>45%</td>
</tr>
<tr>
<td>I am involved in administration of PAH medication</td>
<td>54%</td>
<td>46%</td>
</tr>
<tr>
<td>I am more involved in tasks my relative used to manage</td>
<td>51%</td>
<td>49%</td>
</tr>
<tr>
<td>I take on planning of his/her daily life</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>I have made changes to my work (e.g. work from home, charged responsibilities)</td>
<td>29%</td>
<td>71%</td>
</tr>
<tr>
<td>I am more involved in taking care of our children or of PAH</td>
<td>17%</td>
<td>83%</td>
</tr>
<tr>
<td>I have given up work</td>
<td>13%</td>
<td>87%</td>
</tr>
<tr>
<td>I have chosen to work part time</td>
<td>13%</td>
<td>87%</td>
</tr>
<tr>
<td>I found a different job to fit in taking care of my relative</td>
<td>13%</td>
<td>87%</td>
</tr>
<tr>
<td>Other</td>
<td>4%</td>
<td>96%</td>
</tr>
</tbody>
</table>

**SUMMARY OF PHYSICAL AND PRACTICAL IMPACT ON CAREGIVERS**

Caregivers’ lives are drastically changed once they become a caregiver from increased responsibility to having less time for themselves and/or their family. To say that it takes a special and dedicated person to become a caregiver to a patient who is living with PAH would be an understatement.

### 2.0 KEY RESULTS: EMOTIONAL AND SOCIAL IMPACT ON CAREGIVERS

While caregivers openly admit that taking care of a relative with PAH has significantly impacted their life in some fashion, that doesn’t go without any positives with the experience.

To what extent do you agree with the following statements?

**OVERALL, HOW DO YOU AGREE WITH THE FOLLOWING STATEMENTS?**

- Caregivers agree (strongly agree/agree) that their role has not only benefited their relative (91%), but also has brought new meaning to their lives (72%), made them realize they can do things they never thought they were capable of (71%) and brought out a better person (67%).
- Over half of caregivers (54%) agree that they find fulfillment in being a caregiver.

### Chart 2.3

**FEEL ISOLATED/EXCLUDED AS A RESULT OF TAKING CARE OF SOMEONE WITH PAH?**

<table>
<thead>
<tr>
<th>Feel isolated/excluded</th>
<th>Yes (%)</th>
<th>No (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>51%</td>
<td>49%</td>
</tr>
</tbody>
</table>

It is likely that caregivers will experience a range of feelings when taking care of their relative. Caregivers often feel afraid about what the future holds for their relative (64%), feel stressed between caring for their relative and trying to meet other responsibilities for the caregivers family or work (45%) and feel their health has suffered because they are caring for their relative (21%).

Do you feel isolated/excluded at times as a result of caring for someone with PAH?

Half of caregivers report feeling isolated or excluded as a result of taking care of someone with PAH. The impact of feeling isolated or excluded has affected the daily lives for about one third of caregivers and attributed reasons for these feelings are the lack of understanding of the disease by family, friends and society and the lack of visibility of the disease. However, 83% of caregivers feel they have made a significant contribution to their relative’s quality of life (selecting 8-10 on a 10 point scale).

**SUMMARY OF EMOTIONAL AND SOCIAL IMPACT ON CAREGIVERS**

Caregivers have endured several changes to their own daily lives since caring for their relative with PAH along with dealing with increased responsibilities or feelings of isolation. However, caregivers have in turn gained positive experience/feelings for doing such a tremendous task and feel like they have significantly contributed to their relative's life.
The impact of pulmonary arterial hypertension (PAH) on the lives of patients and caregivers: results from a U.S. study.

### 3.0 KEY RESULTS: CAREGIVERS INFORMATIONAL NEEDS

What type of information on PAH do you feel you need or wish you received?

- Dealing with such a rare and serious disease will always leave room for additional information whether you are the patient dealing with the diagnosis or caregiver taking care of a relative living with PAH.  In the grand scheme, half of caregivers wish they had received information on treatment options, administrative consequences of the disease, general information of the disease, travel tips and information on depression and anxiety.

### SUMMARY OF CAREGIVERS INFORMATION NEEDS

Caregivers, as do patients, wish they had received information about PAH at the onset of diagnosis or soon thereafter. Obtaining proper and meaningful information would aide in the planning of the future for their relative and how best to care for them. Caregivers trust patient associations and treating physicians for such reputable information.

### WHEN IS THE MOST USEFUL TIME FOR YOU TO BE GIVEN THE FOLLOWING INFORMATION?

- The majority of caregivers feel the most suitable time to be given information pertaining to PAH would be at the time of diagnosis, particularly information regarding the disease, information about specialists and doctors and treatment options. A fair amount of caregivers feel that information about roles shifting, financial consequences, emotional consequences, support for children, and preferred time to be given information would aide in the planning of the future for their relative and how best to care for them.

### WHERE ARE YOU LIKELY TO GO AND LOOK FOR INFORMATION ABOUT PAH?

When searching for information on PAH, one needs to ensure they are not only receiving reputable and accurate information to guide in the process of treatment and caring for their relative, but useful and meaningful information as well. Eight out of ten caregivers feel that the physician involved with their relatives PAH are reputable sources of information, along with 62% feeling that patient associations/support groups are also common sources for reputable information. Overall, caregivers find more satisfaction with physicians, support groups or other patients compared to external sources such as websites, blogs and/or forums.

### APPENDIX: U.S. VS E.U. SIGNIFICANT DIFFERENCES

#### E.U. METHODOLOGY

The European phase was conducted in 2011 through early 2012. A total of 455 PAH patients (n=326) and caregivers (n=129) from given European countries (France, Germany, Italy, Spain and the UK) replied to questionnaires asking about four main areas: the physical and practical impact of PAH; the emotional impact; the social impact; and the impact on sexual relationships. A total of 455 PAH patients and 15 caregivers to provide information needs and provision. The quantitative data was informed by qualitative interviews with 25 PAH patient membership, Healthcare professionals (Physicians/nurses managing PAH patients) or though the Harris Interactive patient panel.

#### IMPACT ON DAILY LIFE

In the last month how often have you experienced the following?

- **Lack of concentration**
  - U.S. (79)
  - E.U. (201)
  - U.S. (79)
  - E.U. (203)

- **Dizziness**
  - U.S. (79)
  - E.U. (203)

- **Thinking more slowly than usual**
  - U.S. (79)
  - E.U. (205)

- **Fidgety/restless**
  - U.S. (79)
  - E.U. (206)

- **Talking more slowly than usual**
  - U.S. (79)
  - E.U. (201)

- **Chest pain**
  - U.S. (79)
  - E.U. (275)

- **Over-eating**
  - U.S. (79)
  - E.U. (279)

- **Poor appetite**
  - U.S. (79)
  - E.U. (203)

#### SIGNIFICANT PATIENT COMPARISONS: U.S. vs. E.U.

<table>
<thead>
<tr>
<th>Experience in the Last Month</th>
<th>U.S.</th>
<th>E.U.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>11%</td>
<td>11%</td>
</tr>
<tr>
<td>Breathing</td>
<td>16%</td>
<td>61%</td>
</tr>
<tr>
<td>Loss of libido / risk of death</td>
<td>15%</td>
<td>71%</td>
</tr>
<tr>
<td>Sleep disorders</td>
<td>43%</td>
<td>43%</td>
</tr>
<tr>
<td>Little energy</td>
<td>6%</td>
<td>57%</td>
</tr>
<tr>
<td>Stress</td>
<td>16%</td>
<td>12%</td>
</tr>
<tr>
<td>Difficulty remembering</td>
<td>15%</td>
<td>22%</td>
</tr>
<tr>
<td>Depression</td>
<td>16%</td>
<td>13%</td>
</tr>
</tbody>
</table>
The impact of pulmonary arterial hypertension (PAH) on the lives of patients and caregivers: results from a U.S. study.

Please indicate your ability to perform or carry out the following activities compared to your ability prior to your diagnosis.

### Ability to Perform or Carry Out the Following Activities Compared to Your Ability Prior to Your Diagnosis (2/4)

<table>
<thead>
<tr>
<th>Activity</th>
<th>U.S. (79)</th>
<th>EU (241)</th>
<th>Difficulty Net</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment / work</td>
<td>16%</td>
<td>29%</td>
<td>85%</td>
</tr>
<tr>
<td>Traveling / going on holiday</td>
<td>16%</td>
<td>23%</td>
<td>87%</td>
</tr>
<tr>
<td>Playing with my children or grandchildren / helping them do their homework</td>
<td>28%</td>
<td>33%</td>
<td>73%</td>
</tr>
<tr>
<td>Activities such as going to movies, museum, etc.</td>
<td>30%</td>
<td>35%</td>
<td>63%</td>
</tr>
<tr>
<td>Visiting relatives / friends</td>
<td>38%</td>
<td>44%</td>
<td>31%</td>
</tr>
<tr>
<td>Being visited by friends / relatives</td>
<td>63%</td>
<td>72%</td>
<td>4%</td>
</tr>
<tr>
<td>Having a telephone conversation</td>
<td>81%</td>
<td>81%</td>
<td>15%</td>
</tr>
</tbody>
</table>

### Social Opportunities

Ability to Perform or Carry Out the Following Activities Compared to Your Ability Prior to Your Diagnosis (3/4)

<table>
<thead>
<tr>
<th>Activity</th>
<th>U.S. (79)</th>
<th>EU (241)</th>
<th>Difficulty Net</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dealing with domestic work / household chores</td>
<td>16%</td>
<td>44%</td>
<td>83%</td>
</tr>
<tr>
<td>Going on errands e.g. shopping for food</td>
<td>23%</td>
<td>56%</td>
<td>78%</td>
</tr>
<tr>
<td>Taking a shower</td>
<td>5%</td>
<td>32%</td>
<td>49%</td>
</tr>
<tr>
<td>Cooking</td>
<td>57%</td>
<td>39%</td>
<td>39%</td>
</tr>
<tr>
<td>Getting dressed</td>
<td>62%</td>
<td>67%</td>
<td>33%</td>
</tr>
</tbody>
</table>

### Activities of daily life

Frustration or Concern With the Ability to Perform or Carry Out the Following Activities Compared to Your Ability Prior to Your Diagnosis

<table>
<thead>
<tr>
<th>Activity</th>
<th>U.S. (79)</th>
<th>EU (241)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sport activity / doing exercise</td>
<td>16%</td>
<td>19%</td>
</tr>
<tr>
<td>Being fully intimate with my spouse / partner</td>
<td>34%</td>
<td>40%</td>
</tr>
<tr>
<td>Employment / work</td>
<td>23%</td>
<td>38%</td>
</tr>
<tr>
<td>Going on errands e.g. shopping for food</td>
<td>23%</td>
<td>38%</td>
</tr>
<tr>
<td>Taking on the role of spouse / partner within my couple</td>
<td>4%</td>
<td>13%</td>
</tr>
<tr>
<td>Traveling / going on holiday</td>
<td>28%</td>
<td>44%</td>
</tr>
<tr>
<td>Visiting relatives / friends</td>
<td>23%</td>
<td>38%</td>
</tr>
<tr>
<td>Taking a shower</td>
<td>51%</td>
<td>72%</td>
</tr>
<tr>
<td>Getting dressed</td>
<td>11%</td>
<td>14%</td>
</tr>
</tbody>
</table>

For which three activities are you most concerned or frustrated regarding the impact PAH had on your ability to perform them?
Did this change in your working activity have an impact on the overall income of your household?

**Impact on Professional Activity and Annual Income**

**Stop working since diagnosis (U.S. (79) / E.U. (307)**
- Yes, totally 47% / 37%
- Yes, partially 5% / 13%
- No, but I change my occupation 3% / 3%
- No, but my working conditions have changed 10% / 9%
- Not relevant 25% / 27%

**Impact of the change in my occupation**
- Very negative 29% / 27%
- Negative 35% / 36%
- Neutral 24% / 23%
- Positive 10% / 9%
- Very positive 2% / 4%

**Impact on overall income**
- Yes 90% / 73%
- No 10% / 27%

**Estimation of the impact on the income**
- Decreased by 76% or more 13% / 21%
- Decreased by 51-75% 33% / 19%
- Decreased by 26-50% or less 20% / 27%
- Increased by 25% or less 0% / 1%
- Increased by 26-50% 2% / 1%
- Increased by 51-75% 0% / 1%
- Increased by 76% or more 0% / 1%

**The impact of pulmonary arterial hypertension (PAH) on the lives of patients and caregivers: results from a U.S. study.**

**EMOTIONAL AND SOCIAL IMPACT**

**In the last month how often did you experience the following?**

<table>
<thead>
<tr>
<th>Feeling in the Last Month (1/3)</th>
<th>Very Often/ Often</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling frustrated</td>
<td>U.S. (79) / E.U. (307)</td>
<td>10% / 14%</td>
<td>13% / 29%</td>
<td>28% / 29%</td>
<td>20% / 16%</td>
<td>0% / 0%</td>
</tr>
<tr>
<td>Feeling worried</td>
<td>U.S. (79) / E.U. (307)</td>
<td>4% / 23%</td>
<td>16% / 29%</td>
<td>37% / 30%</td>
<td>15% / 16%</td>
<td>0% / 0%</td>
</tr>
<tr>
<td>Feeling misunderstood</td>
<td>U.S. (79) / E.U. (307)</td>
<td>10% / 20%</td>
<td>16% / 16%</td>
<td>37% / 30%</td>
<td>22% / 15%</td>
<td>10% / 30%</td>
</tr>
<tr>
<td>Feeling lonely</td>
<td>U.S. (79) / E.U. (307)</td>
<td>45% / 22%</td>
<td>22% / 30%</td>
<td>30% / 16%</td>
<td>16% / 16%</td>
<td>0% / 0%</td>
</tr>
<tr>
<td>Feeling isolated</td>
<td>U.S. (79) / E.U. (307)</td>
<td>47% / 27%</td>
<td>16% / 25%</td>
<td>29% / 15%</td>
<td>10% / 16%</td>
<td>0% / 0%</td>
</tr>
<tr>
<td>No desire to socialize</td>
<td>U.S. (79) / E.U. (307)</td>
<td>24% / 25%</td>
<td>21% / 32%</td>
<td>28% / 16%</td>
<td>10% / 16%</td>
<td>0% / 0%</td>
</tr>
</tbody>
</table>

**Emotional and social impact**

- In the last month how often did you experience the following?

**Stop working since diagnosis (U.S. (79) / E.U. (307)**
- Yes, totally 47% / 37%
- Yes, partially 5% / 13%
- No, but I change my occupation 3% / 3%
- No, but my working conditions have changed 10% / 9%
- Not relevant 25% / 27%

**Impact of the change in my occupation**
- Very negative 29% / 27%
- Negative 35% / 36%
- Neutral 24% / 23%
- Positive 10% / 9%
- Very positive 2% / 4%

**Impact on overall income**
- Yes 90% / 73%
- No 10% / 27%

**Estimation of the impact on the income**
- Decreased by 76% or more 13% / 21%
- Decreased by 51-75% 33% / 19%
- Decreased by 26-50% or less 20% / 27%
- Increased by 25% or less 0% / 1%
- Increased by 26-50% 2% / 1%
- Increased by 51-75% 0% / 1%
- Increased by 76% or more 0% / 1%
The impact of pulmonary arterial hypertension (PAH) on the lives of patients and caregivers: results from a U.S. study.

Feeling in the Last Month (3/3)

- **Hopeless**
  - U.S. (307) 13%
  - E.U. (311) 9%

- **Feeling angry**
  - U.S. (307) 24%
  - E.U. (309) 24%

- **Afraid to leave home**
  - U.S. (307) 24%
  - E.U. (309) 22%

- **Feeling numb**
  - U.S. (N/A) 56%
  - E.U. (N/A) 56%

- **Feeling afraid**
  - U.S. (306) 56%
  - E.U. (306) 56%

- **Feeling in the Last Month (3/3)**
  - 1 - Never
  - 2 - Rarely
  - 3 - Sometimes
  - 4 - Often
  - 5 - Very often

If you experienced a feeling of isolation at times after your diagnosis, what caused this?

- **Spouses and partners**
  - U.S. (309) 10%
  - E.U. (309) 10%

- **General practitioner**
  - U.S. (309) 10%
  - E.U. (309) 10%

- **Hospitals**
  - U.S. (309) 10%
  - E.U. (309) 10%

- **Other PAH patients**
  - U.S. (309) 10%
  - E.U. (309) 10%

- **Members of patient association/support group**
  - U.S. (309) 10%
  - E.U. (309) 10%

- **Specialists involved in the management of PAH**
  - U.S. (309) 10%
  - E.U. (309) 10%

- **Nurses**
  - U.S. (309) 10%
  - E.U. (309) 10%

- **Family doctor or general practitioner**
  - U.S. (309) 10%
  - E.U. (309) 10%

- **Other PAH patients**
  - U.S. (309) 10%
  - E.U. (309) 10%

- **Members of patient association/support group**
  - U.S. (309) 10%
  - E.U. (309) 10%

- **Spouses/partners**
  - U.S. (309) 10%
  - E.U. (309) 10%

- **General practitioner**
  - U.S. (309) 10%
  - E.U. (309) 10%

- **Hospitals**
  - U.S. (309) 10%
  - E.U. (309) 10%

- **Other PAH patients**
  - U.S. (309) 10%
  - E.U. (309) 10%

- **Members of patient association/support group**
  - U.S. (309) 10%
  - E.U. (309) 10%

Ease of Discussing Feelings (1/2)

- **Very easy**
  - U.S. (79) 21%
  - E.U. (79) 21%

- **Somewhat easy**
  - U.S. (79) 21%
  - E.U. (79) 21%

- **Neither easy nor difficult**
  - U.S. (79) 21%
  - E.U. (79) 21%

- **Somewhat difficult**
  - U.S. (79) 21%
  - E.U. (79) 21%

- **Very difficult**
  - U.S. (79) 21%
  - E.U. (79) 21%

- **Very easy**
  - U.S. (79) 21%
  - E.U. (79) 21%

Feeling of Shock When You Were First Told That You Had PAH

- **U.S.**
  - Extremely shocked 63%
  - Not shocked 17%

- **E.U.**
  - Extremely shocked 54%
  - Not shocked 21%

Feeling of Fear When You Were First Told That You Had PAH

- **U.S.**
  - Extremely afraid 56%
  - Not afraid 19%

- **E.U.**
  - Extremely afraid 56%
  - Not afraid 19%
The impact of pulmonary arterial hypertension (PAH) on the lives of patients and caregivers: results from a U.S. study.

In which place or space are you generally most comfortable discussing your feelings related to living with PAH?

Place most comfortable for discussing

<table>
<thead>
<tr>
<th></th>
<th>U.S.</th>
<th>E.U.</th>
</tr>
</thead>
<tbody>
<tr>
<td>At home</td>
<td>28%</td>
<td>28%</td>
</tr>
<tr>
<td>Patient organization meetings</td>
<td>13%</td>
<td>13%</td>
</tr>
<tr>
<td>No particular place</td>
<td>26%</td>
<td>26%</td>
</tr>
<tr>
<td>Other 4%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internet (blog, chat)</td>
<td>4%</td>
<td>4%</td>
</tr>
</tbody>
</table>

Who is providing you with emotional support around living with PAH?

Amount You Let The Person Know How You Are Feeling

<table>
<thead>
<tr>
<th></th>
<th>U.S.</th>
<th>E.U.</th>
</tr>
</thead>
<tbody>
<tr>
<td>I talk completely openly about feelings freely to this person</td>
<td>66%</td>
<td>62%</td>
</tr>
<tr>
<td>6-7</td>
<td>62%</td>
<td>58%</td>
</tr>
<tr>
<td>4-5</td>
<td>15%</td>
<td>16%</td>
</tr>
<tr>
<td>I do not talk about/show my feelings at all to this person</td>
<td>6%</td>
<td>6%</td>
</tr>
</tbody>
</table>

Av : 7.8  Sd : 2.4
Av : 7.5  Sd : 2.7

How often have you found yourself adopting any of the following attitudes/behaviors relative to living with PAH?

Coping Mechanisms (1/4)

<table>
<thead>
<tr>
<th></th>
<th>U.S.</th>
<th>E.U.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seeking information about PAH</td>
<td>6%</td>
<td>9%</td>
</tr>
<tr>
<td>Positive attitude</td>
<td>28%</td>
<td>28%</td>
</tr>
<tr>
<td>Getting rest</td>
<td>24%</td>
<td>24%</td>
</tr>
<tr>
<td>Maintaining healthy relationships with friends and family</td>
<td>42%</td>
<td>42%</td>
</tr>
<tr>
<td>Maintaining a healthy lifestyle</td>
<td>15%</td>
<td>15%</td>
</tr>
</tbody>
</table>

Coping Mechanisms (3/4)

<table>
<thead>
<tr>
<th></th>
<th>U.S.</th>
<th>E.U.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talk more openly about my disease with others</td>
<td>16%</td>
<td>16%</td>
</tr>
<tr>
<td>Preparing for change</td>
<td>37%</td>
<td>37%</td>
</tr>
<tr>
<td>Seeking spiritual or religious support</td>
<td>13%</td>
<td>13%</td>
</tr>
<tr>
<td>Over-eating or under-eating</td>
<td>13%</td>
<td>13%</td>
</tr>
<tr>
<td>Withdrawal socially/ emotionally</td>
<td>30%</td>
<td>30%</td>
</tr>
</tbody>
</table>

Top 2 Box

- 1 - Never  2 - Rarely  3 - Sometimes  4 - Often  5 - Very often

The impact of pulmonary arterial hypertension (PAH) on the lives of patients and caregivers: results from a U.S. study.
The impact of pulmonary arterial hypertension (PAH) on the lives of patients and caregivers: results from a U.S. study.

Coping Mechanisms (4/4)

<table>
<thead>
<tr>
<th>Coping Mechanism</th>
<th>U.S. (79)</th>
<th>E.U. (294)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anger</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denial/rejecting diagnosis of PAH</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illicit drug use</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol use</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Top 2 Box

- U.S.
  - Anger: 24% 10%
  - Denial/rejecting diagnosis of PAH: 57% 24%
  - Illicit drug use: 92% 4%
  - Alcohol use: 67% 16%

- E.U.
  - Anger: 33% 20%
  - Denial/rejecting diagnosis of PAH: 66% 17%
  - Illicit drug use: 88% 1%
  - Alcohol use: 70% 15%

How would you describe overall public awareness of PAH?

Overall public awareness

- U.S.: Non existent 19% Very low 4% Low 19% High 4% Very high 1%
- E.U.: Non existent 35% Very low 4% Low 19% High 4% Very high 1%

Information on PAH You Feel You Need or Wish You Received

- Information about treatment options/drugs used for PAH therapy: U.S. 59% 66% E.U. 57% 61%
- Information about the disease (symptoms, prognosis): U.S. 57% 61% E.U. 57% 61%
- Information about travel (tips and tricks how to make traveling possible): U.S. 34% 31% E.U. 34% 31%
- Information about the financial consequences of the disease: U.S. 32% 30% E.U. 30% 33%
- Information about the administrative consequences of the disease: U.S. 4% 3% E.U. 4% 3%
- Information about depression, anxiety risk and other emotional consequences: U.S. 3% 3% E.U. 3% 3%
- Testimonials and patients stories: U.S. 25% 21% E.U. 25% 23%
- Information about the follow ups, including their schedules and purposes of these: U.S. 10% 6% E.U. 10% 6%
- Patient Associations contacts: U.S. 47% 37% E.U. 47% 37%
- Information about the specialists and doctors involved in PAH care: U.S. 27% 21% E.U. 27% 23%
- Information about possible consequences on sexual relationships: U.S. 25% 23% E.U. 25% 23%
- Other: U.S. 2% 1% E.U. 2% 1%

What type of information on PAH do you feel you need or wish you received?

Most Suitable Time to be Given Information (1/2)

- Information about the disease (symptoms, prognosis): U.S. (79) 87% 83% E.U. (308) 83% 84%
- Information about the specialists and doctors involved in PAH care: U.S. (79) 82% 74% E.U. (298) 7% 17%
- Information about treatment options/drugs used for PAH therapy: U.S. (79) 73% 80% E.U. (296) 80% 79%
- Information about depression, anxiety risk and other emotional consequences: U.S. (79) 54% 64% E.U. (248) 29% 29%
- Patient Associations contacts: U.S. (79) 50% 50% E.U. (260) 50% 50%
- Information about the follow ups, including their schedules and purposes of these: U.S. (79) 50% 50% E.U. (290) 50% 50%

- At the time of diagnosis
- 1 month after diagnosis
- 3 months after diagnosis
- 6 months after diagnosis
- 1 year or more after diagnosis
The impact of pulmonary arterial hypertension (PAH) on the lives of patients and caregivers: results from a U.S. study.

Most Suitable Time to be Given Information (2/2)

- Information about possible consequences on sexual relationships
  - U.S.: 51% at diagnosis, 25% 1 month after, 22% 3 months after, 1% 6 months after
  - E.U.: 40% at diagnosis, 25% 1 month after, 21% 3 months after, 7% 6 months after

- Information about the roles shifting within the family/couple
  - U.S.: 47% at diagnosis, 34% 1 month after, 13% 3 months after, 4% 6 months after
  - E.U.: 38% at diagnosis, 29% 1 month after, 19% 3 months after, 6% 6 months after

- Information about the administrative consequences of the disease
  - U.S.: 46% at diagnosis, 34% 1 month after, 13% 3 months after, 5% 6 months after
  - E.U.: 40% at diagnosis, 28% 1 month after, 16% 3 months after, 6% 6 months after

- Information about the financial consequences of the disease
  - U.S.: 44% at diagnosis, 31% 1 month after, 15% 3 months after, 7% 6 months after
  - E.U.: 39% at diagnosis, 26% 1 month after, 16% 3 months after, 7% 6 months after

- Testimonials and patient stories
  - U.S.: 52% at diagnosis, 34% 1 month after, 14% 3 months after, 4% 6 months after
  - E.U.: 42% at diagnosis, 25% 1 month after, 12% 3 months after, 4% 6 months after

- Information about travel (tips and tricks how to make traveling possible)
  - U.S.: 34% at diagnosis, 25% 1 month after, 24% 3 months after, 16% 6 months after
  - E.U.: 25% at diagnosis, 22% 1 month after, 25% 3 months after, 16% 6 months after

Where are you likely to go and look for information about PAH? Which of the following sources do you consider reputable/credible?

Information sources used

- Physicians involved in the management of your PAH: 84% U.S., 65% E.U.
- Patient associations/support groups: 65% U.S., 50% E.U.
- Other web sites: 49% U.S., 35% E.U.
- Other patients: 46% U.S., 30% E.U.
- Social network sites: 46% U.S., 31% E.U.
- Family doctor/general practitioner: 41% U.S., 29% E.U.
- A nurse: 50% U.S., 37% E.U.
- Other web sites: 21% U.S., 10% E.U.
- My pharmacist: 24% U.S., 11% E.U.
- Press that covers medical topics: 13% U.S., 7% E.U.
- Blogs/forums: 14% U.S., 9% E.U.
- My partner/spouse: 4% U.S., 6% E.U.
- People close to me/family/friends: 15% U.S., 11% E.U.

Reputable information sources

- Physicians involved in the management of your PAH: 94% U.S., 67% E.U.
- Patient associations/support groups: 67% U.S., 46% E.U.
- Family doctor/general practitioner: 46% U.S., 32% E.U.
- A nurse: 32% U.S., 20% E.U.
- Other patients: 24% U.S., 15% E.U.
- Other web sites: 24% U.S., 20% E.U.
- My pharmacist: 5% U.S., 3% E.U.
- Press that covers medical topics: 22% U.S., 12% E.U.
- Social network sites: 16% U.S., 10% E.U.
- Blogs/forums: 10% U.S., 7% E.U.
- My partner/spouse: 10% U.S., 5% E.U.
- People close to me/family/friends: 6% U.S., 5% E.U.

How often do you have contact with healthcare professionals involved in PAH management of your relative?

HCP contact frequency

- U.S.: At least once every 3 months 76%, Once a year 13%, Less than once a year 3%, Never 1%
- E.U.: At least once every 3 months 37%, Once a year 17%, Less than once a year 10%, Never 9%

IMPACT ON DAILY LIFE

Would you please indicate all the changes your relative’s PAH has had on YOUR daily life?

Changes Your Relative’s PAH Has Had on Your Life

- I am more likely to go on errands
- I am more involved in the household chores
- I feel exhausted more frequently (due to extra responsibilities)
- I have to schedule family life around his/her needs
- I need to be organized all the time (extra planning requirement)
- I am involved in administration of PAH medication
- I am more involved in tasks my relative used to manage
- I take on planning of his/her daily life
- I have made changes to my work (e.g. work from home, changed responsibilities)
- I am more involved in taking care of our child/children (if any)
- I have given up work
- I have chosen to work part time
- I found a different job to fit in taking care of my relative
- I am involved in administration of PAH medication
- I have made no changes as a consequence of my relative’s PAH

SIGNIFICANT CAREGIVER COMPARISONS

U.S. vs. E.U.

At least once every 3 months
- U.S.: 56%
- E.U.: 38%
The impact of pulmonary arterial hypertension (PAH) on the lives of patients and caregivers: results from a U.S. study.

WHAT DO YOU EXPECT FROM THESE HEALTHCARE PROFESSIONALS?

**Expectations from HCP**

- Regular update of the health status of my relative and potential progression of PAH
- Detailed information of drugs used in PAH therapy
- Information which is not too technical and is easy for me to understand
- Detailed and theoretical information about the disease
- Practical information about PAH management (e.g. where to buy oxygen if needed, changes to house to improve accessibility)
- Active support in my role of caregiver (listening to what I need to say/how I feel)
- Contacts details for patient associations/support groups
- Tips and advice to improve my daily life
- Support to manage financial and administrative issues related to PAH

**EMOTIONAL AND SOCIAL IMPACT**

To what extent do you agree with the following statements?

<table>
<thead>
<tr>
<th>Agreement with Statements</th>
<th>Strongly agree</th>
<th>Very often</th>
<th>U.S. n=76</th>
<th>E.U. n=122</th>
</tr>
</thead>
<tbody>
<tr>
<td>By caring/supporting my relative positively contribute to his/her quality of life</td>
<td>91%</td>
<td>19%</td>
<td>95%</td>
<td>5%</td>
</tr>
<tr>
<td>Caring/supporting has given new meaning to my life</td>
<td>72%</td>
<td>28%</td>
<td>79%</td>
<td>11%</td>
</tr>
<tr>
<td>Caring/supporting has made me realize that I can do things I never thought I was capable of</td>
<td>86%</td>
<td>14%</td>
<td>79%</td>
<td>21%</td>
</tr>
<tr>
<td>Caring/supporting has brought out a better me</td>
<td>70%</td>
<td>30%</td>
<td>79%</td>
<td>21%</td>
</tr>
<tr>
<td>Caring/supporting has brought us closer together as a couple/family</td>
<td>61%</td>
<td>39%</td>
<td>65%</td>
<td>35%</td>
</tr>
<tr>
<td>I feel fulfilled being a caregiver</td>
<td>33%</td>
<td>67%</td>
<td>38%</td>
<td>62%</td>
</tr>
</tbody>
</table>

**Feelings When You Are Taking Care of Another Person**

The following statements reflect how people sometimes feel when they are taking care of another person. Please indicate how often, if ever, you feel that way.

**Feeling When You Are Taking Care of Another Person (1/2)**

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Very often</th>
<th>U.S. n=76</th>
<th>E.U. n=122</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel stressed between caring for my relative and trying to meet other responsibilities for my family or work</td>
<td>70%</td>
<td>30%</td>
<td>75%</td>
</tr>
<tr>
<td>I feel my relative asks for more help than he or she needs</td>
<td>77%</td>
<td>23%</td>
<td>80%</td>
</tr>
<tr>
<td>I feel that because of the time I spend with my relative, I do not have enough time for myself</td>
<td>79%</td>
<td>21%</td>
<td>80%</td>
</tr>
<tr>
<td>I feel that because of the time I spend with my relative, I do not have time to meet other responsibilities for my family or work</td>
<td>68%</td>
<td>32%</td>
<td>75%</td>
</tr>
<tr>
<td>I feel angry when I am around my relative</td>
<td>74%</td>
<td>26%</td>
<td>79%</td>
</tr>
<tr>
<td>I feel that my relative negatively affects my relationship with other family members or friends</td>
<td>68%</td>
<td>32%</td>
<td>75%</td>
</tr>
<tr>
<td>I feel uncertain about what to do for my relative</td>
<td>69%</td>
<td>31%</td>
<td>75%</td>
</tr>
<tr>
<td>I feel that my relative asks for more help than he or she needs</td>
<td>77%</td>
<td>23%</td>
<td>80%</td>
</tr>
<tr>
<td>I feel I could do a better job in caring for my relative</td>
<td>65%</td>
<td>35%</td>
<td>70%</td>
</tr>
<tr>
<td>I feel uncertain about what to do for my relative</td>
<td>69%</td>
<td>31%</td>
<td>75%</td>
</tr>
<tr>
<td>I feel I have lost control of my life since I began to care for my relative</td>
<td>64%</td>
<td>36%</td>
<td>70%</td>
</tr>
<tr>
<td>I feel that my relative asks for more help than he or she needs</td>
<td>77%</td>
<td>23%</td>
<td>80%</td>
</tr>
<tr>
<td>I feel that I have no choice but to look after my relative</td>
<td>43%</td>
<td>57%</td>
<td>49%</td>
</tr>
<tr>
<td>I feel I have lost control of my life since I began to care for my relative</td>
<td>64%</td>
<td>36%</td>
<td>70%</td>
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<tr>
<td>I feel I have no choice but to look after my relative</td>
<td>43%</td>
<td>57%</td>
<td>49%</td>
</tr>
</tbody>
</table>

**Feeling When You Are Taking Care of Another Person (2/2)**

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Very often</th>
<th>U.S. n=76</th>
<th>E.U. n=122</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel I do not have as much privacy as I would like because of my relative</td>
<td>63%</td>
<td>37%</td>
<td>67%</td>
</tr>
<tr>
<td>I feel I will be unable to take care of my relative much longer than I thought I would</td>
<td>70%</td>
<td>30%</td>
<td>73%</td>
</tr>
<tr>
<td>I wish I could just leave the care of my relative to someone else</td>
<td>68%</td>
<td>32%</td>
<td>75%</td>
</tr>
<tr>
<td>I feel about what to do for my relative</td>
<td>71%</td>
<td>29%</td>
<td>79%</td>
</tr>
<tr>
<td>I feel I should be doing more for my relative</td>
<td>64%</td>
<td>36%</td>
<td>70%</td>
</tr>
<tr>
<td>I feel I could do a better job in caring for my relative</td>
<td>65%</td>
<td>35%</td>
<td>69%</td>
</tr>
<tr>
<td>I feel I have no choice but to look after my relative</td>
<td>43%</td>
<td>57%</td>
<td>49%</td>
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<td>57%</td>
<td>49%</td>
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<td>49%</td>
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<tr>
<td>I feel I have no choice but to look after my relative</td>
<td>43%</td>
<td>57%</td>
<td>49%</td>
</tr>
</tbody>
</table>

**Notes:**
- 1 - Strongly disagree
- 2
- 3 - Neither agree nor disagree
- 4
- 5 - Strongly agree
- U.S. n=76
- E.U. n=122
The impact of pulmonary arterial hypertension (PAH) on the lives of patients and caregivers: results from a U.S. study.

**Feeling Isolated or Excluded**

U.S. 49% 51%

E.U. 30% 70%

Who, if anyone, do you tell about/have you made aware of your role as a caregiver?

**People You Tell About Being a Caregiver**

- Family members 83%
- Friends 80%
- Family doctor/general practitioner (GP) 62%
- PAH specialists or nurses 51%
- Colleagues 49%
- Neighbors 41%
- Nobody 16%

On a scale from 1 to 10, how would you rate how much you have positively contributed to the quality of life of your relative?

**How Much You Have Positively Contributed to Your Relative’s Quality of Life**

- Very significant contribution
  - Top 3 (8-10)
  - 6 - 7
  - 4 - 5
  - Bottom 3 (1-3)

U.S. 
- No contribution at all 3%
- Av: 8.5 Sd: 1.6

E.U.
- No contribution at all 3%
- Av: 7.3 Sd: 2.3

To what extent do you agree with the following statements? When I tell people I am a caregiver they...

**Impact of Caregiver Status Awareness**

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Better understand my situation
- U.S. (U) (72)
- E.U. (E) (96)
- 13% 19% 54% 10% 12%
- 4% 12% 27% 46% 12%

Are more empathic/compassionate with me
- U.S. (U) (72)
- E.U. (E) (96)
- 7% 22% 57% 10% 41%
- 5% 10% 28% 27% 41%

Change their perceptions of my situation
- U.S. (U) (72)
- E.U. (E) (85)
- 14% 31% 43% 10% 53%
- 10% 6% 32% 48% 50%

Change their perception of the person I support
- U.S. (U) (72)
- E.U. (E) (87)
- 17% 30% 29% 42% 50%
- 10% 6% 28% 42% 50%

No change in their understanding of my situation
- U.S. (U) (72)
- E.U. (E) (87)
- 15% 24% 36% 18% 25%
- 9% 19% 43% 24% 29%

On a scale from 1 to 10, how would you rate how much you have positively contributed to the quality of life of your relative?
Information Needs

What type of information on PAH do you feel you need or wish you received?

**Information Needs**

- Information about treatment options/drugs used for PAH therapy
- Information about the administrative consequences of the disease
- Information about the disease (symptoms, prognosis)
- Information about travel (tips and advice how to make travelling possible)
- Information about depression, anxiety risk and other emotional consequences
- Information about the financial consequences of the disease
- Information about the specialists and doctors involved in PAH care
- Information about the follow-ups, including their schedules and purposes of these
- Information about my new role of caregiver (practical consequences)
- Information about the roles shifting within the family/couple
- Testimonials and caregiver stories
- Patient association contacts
- Information about possible consequences on sexual relationships
- Information about support for children/education
- Other

**SUMMARY OF PATIENTS’ INFORMATION NEEDS**

Patients are highly satisfied with their physician and patient associations/support groups as a source of information about PAH. Patient organizations have significantly assisted patients with the management, education and tools to move forward with PAH.

---

The impact of pulmonary arterial hypertension (PAH) on the lives of patients and caregivers: results from a U.S. study.

Please indicate the most useful time for you to be given the following information.

### Most Suitable Time To Be Given Information (1/2)

<table>
<thead>
<tr>
<th>Information Provided</th>
<th>U.S. (%)</th>
<th>E.U. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information about the disease (symptoms, prognosis)</td>
<td>88%</td>
<td>9% 3%</td>
</tr>
<tr>
<td>Information about the specialists and doctors involved in PAH care</td>
<td>86%</td>
<td>78% 3%</td>
</tr>
<tr>
<td>Information about treatment options/drugs used for PAH therapy</td>
<td>72%</td>
<td>11% 8%</td>
</tr>
<tr>
<td>Patient association contacts</td>
<td>77%</td>
<td>8% 3%</td>
</tr>
<tr>
<td>Information about my new role of caregiver (practical consequences)</td>
<td>57%</td>
<td>14% 3%</td>
</tr>
<tr>
<td>Information about the follow-ups, including their schedules and purposes of these</td>
<td>52%</td>
<td>13% 6%</td>
</tr>
<tr>
<td>Information about the administrative consequences of the disease (disability claims, insurance coverage, travel grants for hospital appointments...)</td>
<td>51%</td>
<td>94% 6%</td>
</tr>
</tbody>
</table>

- **At the time of diagnosis**
- **6 months after diagnosis**
- **1 month after diagnosis**
- **3 months after diagnosis**
- **1 year or more after diagnosis**

### Most Suitable Time To Be Given Information (2/2)

<table>
<thead>
<tr>
<th>Information Provided</th>
<th>U.S. (%)</th>
<th>E.U. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information about depression, anxiety risk and other emotional consequences</td>
<td>50%</td>
<td>16% 4% 5%</td>
</tr>
<tr>
<td>Information about the financial consequences of the disease</td>
<td>43%</td>
<td>17% 8% 1%</td>
</tr>
<tr>
<td>Information about the roles shifting within the family/couple</td>
<td>44%</td>
<td>20% 9% 5%</td>
</tr>
<tr>
<td>Testimonials and caregiver stories</td>
<td>44%</td>
<td>15% 6% 9%</td>
</tr>
<tr>
<td>Information about support for children/education</td>
<td>34%</td>
<td>17% 3% 7%</td>
</tr>
<tr>
<td>Information about possible consequences on sexual relationships</td>
<td>36%</td>
<td>15% 6% 9%</td>
</tr>
<tr>
<td>Information about travel (tips and advice how to make travelling possible)</td>
<td>30%</td>
<td>12% 16%</td>
</tr>
</tbody>
</table>

- **At the time of diagnosis**
- **6 months after diagnosis**
- **1 month after diagnosis**
- **3 months after diagnosis**
- **1 year or more after diagnosis**
The impact of pulmonary arterial hypertension (PAH) on the lives of patients and caregivers: results from a U.S. study.

**Sources of Information About PAH**

Where are you likely to go and look for information about PAH? Which of the following sources do you consider reputable/credible?

<table>
<thead>
<tr>
<th>Sources of Information About PAH</th>
<th>U.S.</th>
<th>E.U.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physicians involved in the management of your relative’s PAH</td>
<td>83%</td>
<td>90%</td>
</tr>
<tr>
<td>Patient associations/support groups</td>
<td>62%</td>
<td>73%</td>
</tr>
<tr>
<td>Other websites</td>
<td>26%</td>
<td>47%</td>
</tr>
<tr>
<td>Family doctor or General Practitioner/my relative’s General Practitioner</td>
<td>25%</td>
<td>33%</td>
</tr>
<tr>
<td>Social network sites</td>
<td>17%</td>
<td>33%</td>
</tr>
<tr>
<td>Other patients</td>
<td>17%</td>
<td>22%</td>
</tr>
<tr>
<td>A nurse</td>
<td>18%</td>
<td>29%</td>
</tr>
<tr>
<td>Blogs/forums</td>
<td>0%</td>
<td>22%</td>
</tr>
<tr>
<td>My pharmacist</td>
<td>11%</td>
<td>22%</td>
</tr>
<tr>
<td>Press that covers medical topics</td>
<td>20%</td>
<td>22%</td>
</tr>
<tr>
<td>People close to me/family/friends</td>
<td>11%</td>
<td>15%</td>
</tr>
</tbody>
</table>

**Satisfaction With the Sources of Information (1/2)**

Please indicate your level of satisfaction with each of the following sources of information about PAH.

- **Physicians involved in the management of your relative’s PAH**
- **Patient associations/support groups**
- **A nurse**
- **Family doctor or General Practitioner/my relative’s General Practitioner**
- **Other patients**
- **Social network sites**
- **Other websites**
- **My pharmacist**
- **Blogs/forums**
- **Press that covers medical topics**
- **People close to me/family/friends**

**Withholding of Information**

Have you ever avoided sharing information you have found/received about PAH with your relative?

- **At diagnosis**
- **Currently**

**Have you ever avoided sharing information you have found/received about PAH with your relative?**

- **Yes, to protect him/her from the seriousness of PAH**
- **Yes, for other reasons**
- **Yes, because I felt uncomfortable understanding the information**
- **Yes, because I felt uncomfortable expressing it**
- **Yes, because he/she was in a denial (rejecting diagnosis of PAH) phase**
- **Yes, because I did not want to add his/her feelings of guilt**
- **No, I have never filtered any information**

**Withholding of Information**

- **Yes, to protect him/her from the seriousness of PAH**
- **Yes, for other reasons**
- **Yes, because I felt uncomfortable understanding the information**
- **Yes, because I felt uncomfortable expressing it**
- **Yes, because he/she was in a denial (rejecting diagnosis of PAH) phase**
- **Yes, because I did not want to add his/her feelings of guilt**
- **No, I have never filtered any information**
The impact of pulmonary arterial hypertension (PAH) on the lives of patients and caregivers: results from a U.S. study.

Notable differences between E.U./U.S. findings:

Patients:
- U.S. patients are significantly more likely than E.U. patients to want to receive information about the financial consequences of their disease, and E.U. patients are significantly more likely to want information about the specialists and doctors involved in the care.
- Significantly more U.S. patients find support from their friends, patient organizations, family doctor/GP, a nurse and spiritual or religious organizations when compared to E.U. patients. Four out of ten E.U. patients report their family as the most effective support, while under one quarter of U.S. patients report their family as the most effective.
- The majority of U.S. patients adopt a flexible attitude (61%) and maintain a positive self image (51%) as a result of living with PAH. More than a third of patients talk more openly about the disease with others, 39% of U.S. patients prepare for change and 33% of U.S. patients seek spiritual or religious support.

Caregivers:
- Overall, caregivers find more satisfaction with physicians, support group or other patients than external sources such as websites, blog, forums, etc.
- 80% of E.U. caregivers are significantly more satisfied with press that covers medical topics and 69% are significantly more satisfied with people close to them or family when compared to U.S. caregivers.
- Caregivers face increased responsibilities due to their relative’s PAH. Running errands, more involvement in household chores and feeling more exhausted are just a handful of the changes caregivers experience.
- U.S. caregivers report a significantly higher amount of responsibility compared to E.U. caregivers.
- On average, healthcare professionals managing relative’s PAH are contacted by caregivers at least once every three months.
- U.S. caregivers are significantly more likely to make contact with a healthcare professional at least once every three months (76%), compared to those in the E.U. (56%).
- 8 out of 10 U.S. caregivers expect to receive detailed information on drugs used for PAH with regular updates on the health status of their relative from healthcare professionals.
- U.S. caregivers are more likely than E.U. caregivers to report that their relative’s PAH has had a more significant impact on their life.
- The majority of U.S. caregivers report more involvement with household chores and errands, medication administration as well as higher levels of exhaustion and organization.
- Half of U.S. caregivers report feeling isolated or excluded as a result of taking care of someone with PAH, compared to one third of caregivers in the E.U.
- The impact from feeling isolated or excluded has affected the daily lives for about one third of caregivers.
- One third of caregivers report feeling isolated or excluded as a result of taking care of someone with PAH.
- Half of U.S. caregivers report feeling isolated or excluded as a result of taking care of someone with PAH.
- The impact from feeling isolated or excluded has affected the daily lives for about one third of caregivers.
- Lack of understanding of the disease by family, friends and society and the lack of visibility of the disease are reasons why caregivers feel isolated in the U.S.

KEY REFERENCES
6. Morrell NW. Genetics of pulmonary arterial hypertension: do the molecular findings have translational value? F1000 Biol Rep 2010;2.pii:22