



# Supporting **young adults** living with **pulmonary arterial hypertension** **(PAH)** in the best practice management of their disease

A report developed by Actelion's Global Advocacy function  
in collaboration with the international steering group

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# Executive summary

Young adults living with pulmonary arterial hypertension (PAH) face a specific set of challenges; choosing a career, leaving the parental home, dating and understanding the potential impact of PAH on starting a family of one's own, are just some of the considerations confronting young people living with the condition.

Despite these issues, patient associations report that young adults are underrepresented in their groups. This suggests that they may have alternative ways to connect with other young patients, if they seek to understand other patients' experiences at all.

While there is an increasing volume of literature highlighting the burden of living with PAH generally, there is less available on the impact of the condition on young adults specifically, beyond the physical symptoms. In order to better understand the information and communication needs of young adults living with PAH, in 2016, Actelion held a series of one-to-one interviews with patients aged 18-30 from Europe and the US. In November 2016, Actelion brought together a 'virtual' steering group meeting of five young adults from five different countries, to reflect on the insights gathered in the one-to-one interviews and further discuss the experience of being a young person living with PAH and how their wider needs could be better met.

This report documents the discussions held and proposed recommendations for how the multidisciplinary team, comprising specialist physicians, specialist nurses, allied health professionals, social workers and patient groups, can best engage with and support young adults living with PAH in the management of their condition.

**The recommendations for action included in this report are as follows:**

- 1. Information and education provision around the practical aspects of living with PAH as a young adult must be improved to support patients and enable them to become more active in their own care**
- 2. The psychological needs of people living with PAH of all ages should be better recognized by the multidisciplinary team, including the offer of emotional support provided by a psychologist and/or patient group**
- 3. Patient groups should consider the different channels and ways young people with PAH access and exchange information to demonstrate value and tailor their offering to younger audiences**
- 4. Multidisciplinary team members should discuss the individual life circumstances and priorities of each patient, to identify motivational goals and desired outcomes to support and enable patient empowerment and self-management**

See page 12 for suggestions of practical ways these recommendations may be implemented.

Actelion is committed to supporting the PAH community and dedicated to improving PAH patient care. This report was initiated and funded by Actelion Pharmaceuticals Ltd as part of this commitment to support patients in living with PH 'as part of their life'.

# Acknowledgement: International steering group

Actelion would like to acknowledge the international steering group formed of young adults living with PAH who contributed to the development of this report. Through taking time to participate in interviews and attend advisory board meetings, they have shared important insights into the distinctive challenges faced by younger individuals living with the disease thereby improving understanding of their particular needs.

This report was developed by Actelion's Global Advocacy function in collaboration with the international steering group.

# Foreword

As someone who has lived with PAH their whole life, through childhood, adolescence and adulthood, I understand how lonely it can be to stand separate from other people your age that cannot understand your condition or why you cannot run alongside them.

When I was a child, my parents and even my local doctors knew very little about the disease. As I became a young adult, I realized how important it was for me to learn everything I could about my condition and become an expert in PAH in my own right, to be able to play an active role in my care and decisions about how I should be treated.

It can be easy to feel like a victim, asking yourself 'why has this happened to me?', but I appreciate now that I am a fighter. In discovering my own strength, I have become more aware of the need to unlock this potential in others, particularly young adults with PAH, who are just beginning their journey.

In September 2015, I was fortunate to be able to attend PHA Europe's annual meeting, bringing together patient group representatives from across Europe and in this case, me. It was the first time I had ever met another patient with PAH and the experience totally changed my life. Following the meeting I founded PH Serbia and have made it my mission to connect with and support other patients, sharing advice accumulated over a lifetime of living with the disease. I empathize with each new person diagnosed, particularly young people who are trying to navigate the various challenges that the adult world presents, with the addition of an invisible, yet serious disease that very few other people have ever heard of.

Young adults are the people who will have to live with this disease for the longest time, so it is essential that doctors, nurses, social workers, families, peers and patient groups, acknowledge the particular challenges they face and support them to approach all aspects of PAH management and its wider impact with a positive mind-set and the information they need to live rich, full lives. I was delighted to have been part of the conversations with other inspirational young adults that informed the development of this report and hope that these insights may help healthcare professionals and patient groups alike, better meet the needs of this special group of people living with PAH.

**Danijela Pešić**

Writer, PAH patient and founder of PH Serbia  
[www.phserbia.rs/](http://www.phserbia.rs/)

# Living with PAH as a young adult today: where are we now?

## 1. Young adults living with PAH are underrepresented in patient associations

Patient associations play an important role in supporting the wider needs of their members, through the provision of tailored information and education, advice on social support and benefits available to those living with PAH, and opportunities to hear from or meet with other people living with the condition. The age demographic of local patient associations varies from group to group, however, it is generally accepted that under-30s are underrepresented, given the prevalence of those diagnosed with PAH at a young age.

A cross-section of young adults, some of them active participants of patient associations themselves, can provide important insights into why 18–30 year olds are often reluctant to join such a group.

It can be intimidating to join an association where the majority of its members are older than the individual. Some may fear being confronted with a negative vision of their potential future if they encounter older adults at a more progressed stage of the disease. For busy young adults with active social lives, there is the perception that being a member of an association is an unnecessary drain on their time. Moreover, they would rather not focus on PAH as a dominant aspect of their lives. Ultimately, in the digital age that younger adults have grown up in, there are alternative forums online where they can access information about PAH and other health matters quickly, in a secure, potentially anonymous, space that they feel comfortable in.

Understanding these reasons can help patient associations better communicate their value to young adults living with PAH through the digital channels that young adults favor. One way that the US Pulmonary Hypertension Association, PHA, has successfully achieved this is through the development of an online community exclusively for young adults, *Generation Hope*.<sup>1</sup> In Europe, PH Serbia has had exceptional success in attracting young members through its founder's fighting mentality and engagement with young, high-profile athletes for the cause (see pages 10 and 11 for further information on these initiatives).

## INTIMIDATING

Older demographic

Don't want to focus on the disease when older

Maybe

Information available online

Don't want to focus on the disease when older

Don't understand the benefits

FEAR OF VERY ILL PEOPLE

Too busy

## 2. The rise of the 'blogger': a dynamic outlet for young adults to share experiences

Documenting one's experience as a form of therapy, by writing down and analyzing one's feelings in a diary for example, has long been accepted as beneficial for a person's overall wellness.<sup>2</sup> Over the past decade, the rise in internet 'blogging' has provided a new platform for people to record their own experiences and importantly, share them with others.

Of the young adults interviewed, the majority found writing to be a source of comfort and a way to positively reflect upon living with PAH. Through developing their own blogs or reading those of others, young people living with PAH are able to share personal experiences and interact with each other without the need to be part of a formal patient group or physically meet other patients.

While the choice to blog or publish one's story is a very personal one, it can be encouraged as a positive outlet by multidisciplinary team members to ultimately improve self-management. Successful examples can be found from bloggers living with other long-term conditions. In the case of a patient with type 1 diabetes, upon being challenged by their specialist physician to begin documenting their experience, the patient became much more active in their disease management, leading to the stabilization of their diabetes as well as the sharing of their experience to help educate others.<sup>3</sup> Positive, young role models in the PAH community are important to inspire others to become active self-managers.

## 3. Patient empowerment requires individualized goals and a positive mind-set

For anyone living with a chronic disease, it is helpful to retain a positive mind-set to adjust to the challenges posed by long-term illness and support overall wellbeing.<sup>4</sup> Depending on the individual, this can be a lesser or greater task and it can be expected that one's mind-set will fluctuate over time.

A sense of 'empowerment' is often linked to a positive mind-set, as a psychological state of feeling in control over one's disease, treatment management and health outcomes.<sup>5</sup> The goals of patient empowerment are personal to the individual and as such, multidisciplinary team members should proactively discuss and encourage young people to set their own goals, according to their particular circumstances and life priorities.<sup>5</sup>

Young adults look to their healthcare team to offer guidance as to what activities they can safely undertake. Communication about any risk should use clear and simple language to avoid misinterpretation, while healthcare professionals should also be cognizant to offer positive advice on what their patient can do or how to adapt an activity to suit their condition, thereby empowering them.

The young adults interviewed commented that being told 'no, someone with PAH should not do that' by their healthcare team with no further information provided on how to mitigate risk was extremely demotivating and unreflective of the advances made in the management of PAH over the past decade. Some physicians may be very cautious in their recommendations to any patient, regardless of age or ability, while others may simply not tailor their guidance to the individual before them.

A number of potential practical solutions to engage young people living with PAH in their own care are included in this report. Other tools, such as "information prescriptions", written care plans, patient "passports" and self-management courses, described in a special report on a holistic approach to PAH care, can be employed to deliver high-quality, tailored information, education and support to the PAH patient.<sup>6,7</sup>

“ Feeling empowered is so important; you must find what works best for you

You don't want to only be told the bad things that can happen; you need to be told the good along with the bad ”



associations or social workers can advise on workplace rights and benefits, as well as the pros and cons of disclosing one's condition to their employers, a topic that many young adults living with PAH do not feel confident about. Clinicians should be proactive in referring their patients to patient associations and/or social workers to offer support in these areas.

Patient associations can also build the confidence of young adults living with PAH, through supporting them to see and communicate what additional value they bring to employers because of the transferable skills developed and honed by living with a long-term condition. These may include; a positive mind-set and high level of self-motivation, organizational skills (through having to liaise with multiple healthcare team members and manage complex treatment regimens); a mature outlook on life and 'big-picture'-thinking.

#### 5. Young women living with PAH require education and support to come to terms with the fact that pregnancy is a life-threatening condition for mother and child

Whatever age a young female is diagnosed with PAH, whether pre- or during their child-bearing years, it can be extremely difficult to process and accept the fact that pregnancy is a life-threatening risk posed to mother and unborn child<sup>11</sup> and they should never become pregnant. Even for those who have already had a child, the prospect that they may not naturally conceive or carry another child can be devastating.

It is important that PAH specialists recognize that their patients' views may change over time as they come to terms with the information or their relationship status and life situation changes. It is therefore beneficial to check in with the patient at appropriate touch points, emphasize the associated risks of pregnancy and offer counseling support as needed, through psychologists and connecting to other patients who have been through a similar experience.

There are a range of resources, specially designed for young adults by patient associations, to help people consider and navigate the adoption process.<sup>12</sup> It is important that young people are exposed to stories from patients living with PAH around their experiences of adoption and other alternatives to carrying a child to instil a positive mind-set for the future. Equally, young people would benefit from hearing from others the energy levels required to be a parent, to inform their decision.

#### 4. It is important for young adults to choose a career that suits their needs and develop the necessary skills to support them

According to an international survey of people living with PAH and their carers, 85% of patients reported their work was affected by PAH, with nearly half (45%) saying they were unable to work anymore or needed help to do so.<sup>8</sup> For young adults, many of whom have had no work experience before their diagnosis, employment is a major cause of frustration and concern for the future.

It is therefore important for young adults living with PAH to choose a career that suits their current needs, while being cognizant of potential future needs if their disease progresses. Specialist physicians and nurses are well placed to advise their young patients on the levels of daily activity that are most appropriate for them, while avoiding language that can be perceived as 'telling' the patient what they 'cannot do', which can be demotivating. This is particularly important as employment has a proven positive effect on mental health and overall wellbeing.<sup>9</sup>

Advances in technology mean that there are many jobs that can be done remotely, allowing employees to work from home and more flexible hours. This can alleviate emotional and physical stress for people living with PAH, for example by avoiding demanding commutes to and from work and providing flexibility to attend hospital appointments as needed. Digital advances have also opened up new career options in themselves, with computer programming or 'coding' being among the most desired skills across multiple industries.<sup>10</sup> Cumulatively, this means that young adults living with PAH need not feel as if their work or earning potential is limited, but it is advisable to train in jobs that suit a relatively sedentary and possibly home-based work environment.

Patient associations can offer young adults practical and inspirational examples of the different types of employment of their members. Importantly, patient

#### 6. Intimacy can be an embarrassing topic for young adults to raise with multidisciplinary team members, but is an important area to acknowledge

For young adults just entering sexual maturity and age of consent, as it is important that clinicians inform them of the risk of pregnancy and the importance of contraception, it is also important that they invite them to ask any questions that they have about intimacy and the impact of PAH on sexual relationships.

Young adults (as well as people of all ages) may be uncomfortable speaking with their doctor or nurse about intimacy. If embarrassment is a barrier to open conversation, clinicians should be confident to refer their patients to patient groups for further information, as they may be more likely to discuss such issues with a peer. Many patient groups have developed resources that address intimacy and relationships and young adults with PAH should be reassured that they can determine what level of activity is right for them by listening to their body and sharing how they feel with their partner.

#### 7. Multidisciplinary teams can support young adults living with PAH in achieving and maintaining a level of independence

'Coming of age' or a young person's transition from being a child to being an adult is defined in a variety of ways by different cultures and in different countries. However, many share a common theme of growing independence from others. Some young people living with PAH may feel they need to depend upon family and friends more than they'd like to, due to the variability of the condition and this can be a cause of tension.

While accepting when one needs support is a valuable life lesson, regardless of health status, the young adults interviewed reported how important it is feel that they are in control of their PAH.

Independency can be difficult when living in the parental home, particularly if the parent has assumed a dominant carer role for a child diagnosed at a young age. Multidisciplinary team members, such as specialist nurses, psychologists and patient groups can play a role in recognizing these potential tensions and providing reassurance to both the patient and the family/carers as to what the young adult with PAH can be expected to do independently and safely.

#### 8. Patients require specialist care to support their mental health needs

Prevailing stigma surrounding mental health issues mean that some patients are reluctant to raise their needs in conversation with their healthcare team. Probing questions in regular appointments are useful in uncovering underlying emotional or mental health issues that may be unlikely to surface in regular conversation otherwise.

These particular challenges are not unique to younger adults with PAH. In a recent study of health-related quality of life among young, middle, and older adults with PAH, mental health symptoms were comparable across the three age groups<sup>13</sup> and as per the latest international guidelines for the diagnosis and treatment of pulmonary hypertension, appropriate psychological support should be offered to all patients.<sup>14</sup>

#### 9. Patients require advice on how to manage treatment side-effects

In addition to the physical symptoms of the disease itself, the physical side-effects of some treatments to control PAH can impact an individual's day-to-day life in a variety of ways such as absence from school or work, or missing out on social occasions. It is important that young adults feel confident in how to manage their conditions, advised by a healthcare professional, with additional practical support provided by a patient group or patient mentor as necessary.

“ The brain is an organ just like the heart and lungs, it needs specialist care too ”

# Case study 1:

**Generation Hope:** a dedicated online group for young people living with PAH to air their feelings



Recognizing the different needs of young adults living with the condition, PHA (US patient association) established Generation Hope in 2010, an email group for college students, young professionals and other 20- and 30-somethings living with PAH. The group is marketed as 'a safe space to vent, socialize and chat about life as a young adult with PH'. Since 2010, it has helped numerous young people to think positively about living with PAH and support others experiencing shared successes and challenges.

In addition to their email group, Generation Hope offers a mentor scheme, connecting young adults living with PAH with other knowledgeable young patients who can provide advice and ongoing, one-on-one support. Young adults can browse potential mentor profiles to choose people of similar age, gender and interests to speak to.

To find out more, visit [www.phassociation.org](http://www.phassociation.org).

# Case study 2:

**PH Serbia:** appealing to a new generation of young adult PAH advocates



Acknowledging the work being done in other parts of Europe to unite patients, provide peer-to-peer support and raise awareness of PAH, Danijela Pešić founded PH Serbia in late 2015. With few PH specialists in Serbia and a scarcity of information on PAH written in the local language, there was a need for a patient organization to bring together the patient and clinical communities and provide a platform to exchange information.

Within just 18 months, the organization attracted 180 members (of an estimated 300 people living with PH in Serbia), a high proportion of which were young adults. The group's success in appealing to a younger demographic than typical patient organizations can be attributed to four main factors:

1. Danijela, the founder, has lived with PAH all her life and therefore has personal experience of the specific issues facing young adults and is an approachable, young woman with an inspirational story and a positive, 'fighter's' mentality
2. In line with Danijela's personal attitude toward her condition, PH Serbia's strategy to attract members and wider publicity is explicitly to avoid sad stories about living with the disease that inspire fear and pity and instead position PAH patients as 'fighters' to inspire people of all ages living with the disease that they can live full lives
3. PH Serbia identified sportspeople who push themselves to their physical extreme (to the point of breathlessness, exhaustion and pain) as those that could be particularly sympathetic to the symptoms of PAH and continues to successfully rally high-profile young athletes to walk, run, swim or play for the cause
4. The group's social media channels, predominantly its Facebook page, which has more than 500 followers at the time of writing, are instrumental in allowing young adults to connect, share and read information in Serbian, as well as promote disease-awareness campaigns

To find out more, visit <https://www.facebook.com/plucnahipertenzija/>.

# Recommendations

The recommendations for action included in this report are as follows:

- Information and education provision around the practical aspects of living with PAH as a young adult must be improved to support patients and enable them to become more active in their own care
- The psychological needs of people living with PAH of all ages should be better recognized by the multidisciplinary team, including the offer of emotional support provided by a psychologist and/or patient group
- Patient groups should consider the different channels and ways young people with PAH access and exchange information to demonstrate value and tailor their offering to younger audiences
- Multidisciplinary team members should discuss the individual life circumstances and priorities of each patient, to identify motivational goals and desired outcomes to support and enable patient empowerment and self-management

In order to support the implementation of these wider recommendations, the following suggestions for activities, initiatives and materials have been included in this report.

## 1. Training for healthcare professionals on the specific needs of young adults with PAH

Young adults with PAH need to build open, trusting relationships with healthcare teams to enable them to confidently discuss their needs, including some intimate and often 'embarrassing' topics, such as becoming sexually active. Training on working collaboratively with patients, communicating with young patients specifically in a way that is engaging and easy for them to understand, and managing broader aspects of PAH for young adults including mental health, are just a few examples of training that could be provided internally by clinics to their staff, or by patient group representatives. In addition, education for parents and families about the disease and supporting young adults in managing their condition, provided by patient group representatives could be beneficial.

## 2. Using social media and live chat apps to engage young audiences in their care

The use of social media to discuss health matters has expanded exponentially in the last few years. Those interviewed expressed a preference to receive information online and many feel comfortable contacting their healthcare teams using live chat apps, such as WhatsApp, with queries between appointments. The multidisciplinary team and patient groups in particular can harness these new channels to provide education to young adults living with PAH. This could comprise regular Facebook and Twitter posts to address practical elements of living with PAH as a young adult, or planned 'Tweet chats' where a pre-defined topic is discussed 'live' on Twitter providing an immediate forum to connect all interested Twitter users. As a basic requirement, it is suggested that all patient groups set up their own Facebook page or 'group', given the popularity of the platform among young adults to share experiences and questions. Social media platforms also provide opportunities for young adults living with PAH to directly connect to one another and this can be encouraged by multidisciplinary team members.

## 3. Patient mentoring

Peer-to-peer mentoring coordinated by patient groups or through clinics to connect young adults living with PAH in their 20s and 30s with others of a similar age and background may be beneficial in providing patients with individualized support. Young, active self-managers are well placed to inspire other young adults on how to be involved in their care while balancing life goals and the specific demands of being a young adult. Equally, older adults living with PAH can serve as inspirational mentors for younger patients. Ideally such older mentors would have been diagnosed at a younger age and therefore gone through many shared challenges, to provide an experienced and reassuring perspective from someone now in their older years. It is, however, important that mentors are careful not to patronize young adults, ensuring they listen and coach rather than 'tell' the other young adult how best to manage their condition. Training for mentors on how to achieve this balance could be beneficial for both parties.

## 4. Tailored patient group materials for young people

Development of online materials aimed solely at young adults, such as a website with key resources and information on everyday activities, including sports and beauty would be engaging for younger patients. Some patient groups, such as PHA in the US, have already developed such resources on a variety of topics that affect young adults. These could be translated for use by other patient groups for local patients in their local language.

## 5. Networking events

Networking events aimed at younger patients would be valuable, to allow young adults to meet with patients of a similar age to share tips and support. Events may include 'fun' activities, such as music and social games for example, tailored to the interests of the target group, in addition to educational and practical content to encourage younger patients to attend. Patient groups, with experience of coordinating successful networking events for their members, are well placed to run such activities, either alone or in conjunction with specialist centers in their country.

## 6. Employment skills workshops

Practical workshops or informative resources on employment would be beneficial for young adults living with PAH. Workshops could be run by patient groups, coordinated by social workers on behalf of the multidisciplinary team with supporting online resources. Guidance could cover the following areas: how to disclose PAH to employers; employment skills; interview techniques; how to write a CV; information on key skills

and relevant careers that would suit a person living with PAH; how to communicate the positive skills learned through having a long-term condition that would be of advantage to a company employing someone with PAH. Partnering with experienced recruitment agencies or career counselors to deliver the training itself or to advise on the development of written resources, may support the content credibility.

## 7. Work experience within patient organizations

Patient organizations may also want to consider providing volunteer work experience opportunities for young adults living with the condition, who are both knowledgeable about PAH and the needs of the young adult population. Such opportunities are a great way to provide young adults with practical experience to boost their CV and to help them engage with the community. Patient groups with a largely online offering are more likely to be able to offer flexible, home-working voluntary experience compared to other companies without such a good understanding of the disease.

## 8. Showcasing young adults' careers and hobbies

Seeing the varied achievements and successes of other young adults living with PAH may serve as an inspiration to many. Patient groups or industry partners could support in the development of posters showcasing real young people with PAH and which careers or hobbies they have pursued, to be displayed in specialist clinics. Similarly, online blog posts or written booklets capturing the stories of young adults with PAH can highlight the importance of self-management in a way that is clearly evident to readers.

# Conclusion

The specific needs of young adults living with PAH should be considered in the delivery of tailored, high-quality information and holistic care by the multidisciplinary healthcare team, in collaboration with patient associations. As such, open, effective communication is needed between all stakeholders about the practical aspects of living with a serious, chronic disease as a young person. Successful communication should empower the patient to positively manage their disease and can be achieved through identifying and driving each individual's personal health and wider life goals.

# Disclosures

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