

**WEBINAR: Patient groups are only set up to support the over 30s**  
*Episode 1 – Thursday 14 December 2017*

**DISCUSSION SUMMARY**

**Overview**

On Thursday 14 December 2017, Actelion hosted the first webinar episode in the 'PAHuman Self-Management series', provocatively titled '*Patient groups are only set up to support the over 30s*'. Patient group representatives were invited to participate in the one-hour webinar to discuss how they could better tailor their offering to young people living with PAH. Insights from the recently developed '*Supporting young adults living with PAH in the best practice management of their disease*' report were presented by Four Health Communications. Guest speaker, Danijela Pešić, founder and president of PHA Serbia, presented on how patient groups can unlock the 'fighting' spirit of and engage young people living with PAH in their activities.

There were three primary learning objectives of the session:

- To increase understanding of the specific needs of young adults living with PAH
- To share insights as to why there is a reluctance among this demographic to join traditional patient groups
- To suggest how patient groups can tailor their offering to better attract and serve young adult members

**Discussion summary and key learnings**

***Understanding specific needs of young people living with PAH is necessary to engage them***

- Patient groups need to cater to the needs of young people living with PAH as there are certain topics that need to be explored more so for this group than for those with more life experience at the time of diagnosis. Topics include:
    - Choosing a career that suits their long-term needs and developing the necessary skills to support them
    - Coming to terms with the fact that pregnancy is a life-threatening condition for young women with PAH
    - Talking about 'embarrassing' topics, such as intimacy and becoming sexually active
    - Achieving and maintaining a level of independence
  - It is important for patient groups to work with multidisciplinary healthcare teams to ensure they are referring young adults with PAH to them for emotional support for those with psychological needs
  - The psychological needs of people living with PAH needs to be better recognized by patient groups (as well as the multidisciplinary healthcare team) and offering emotional support should be prioritized
  - Other reasons for reluctance to join an association also need to be considered and addressed, such as:
    - 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
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- 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 and perhaps they would rather not focus on PAH as a dominant aspect of their lives
- In the digital age that younger adults have grown up as 'digital natives' – 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

### ***Invoking a greater cause to increase engagement***

- Creating a greater cause for people to become involved in is key to improve engagement levels. For example, if young people are invited to join an association as a 'patient', this may act as a deterrent based on negative connotations. However, if a person is engaged as someone with a level of expertise or as someone who is able to share personal experiences for the benefit of others, this creates a sense of purpose for the individual and transforms the role into something positive

### ***Maximizing the use of social media/digital channels***

- The role of social media in engaging young adults cannot be ignored and it is of increasing importance for patient associations to recognize the value in communicating their offering through digital channels
- 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
- PH Serbia has also set up a website and Facebook page where they discuss an initiative called 'Inspired by HOPE'; they avoid talking directly about the disease or exclusively providing specific PAH-related information. Topics such as sport are covered and celebrities/sportspeople who support the group are encouraged to engage with the platforms. This often attracts a wider audience as it creates a more interesting platform and PAH discussion is often generated organically by the page members. Having other high-profile social media pages/accounts engage and share content helps broaden the audience and ultimately young adult engagement
- A simple tip can be for organisations to set up their own Facebook page or WhatsApp group to attract and engage with young adults locally
- Another example shared that has proven successful in Greece has been to set up a closed online forum, which also offers Skype sessions with healthcare professionals. A closed Facebook group has also been set up in France, however, has seen success by opening this up to all ages and not specifically for young adults

### ***The importance of role models and celebrity/sportsperson endorsement***

- Exposing young adults to positive role models as part of a patient association's offering can be extremely valuable to demonstrate to young adults that a future living with PAH can be promising, goals can be achieved and they can be contributing members of society
- Having a role model who is able to communicate these messages not only to the individuals themselves but to their families can boost morale and help improve their overall quality of life
- Working with celebrities and high-profile sportspeople to shine a light on PAH can also be a way to improve general disease awareness and engagement with young adults. In Europe, PHA Europe Italy and PH Serbia has had exceptional success in attracting young members through its engagement with young, high-profile athletes who support the cause
  - ***PH Serbia tip:*** take small steps – approach an accessible spokesperson first and aim to broaden this support network with more high-profile personalities over time

***Other practical ways patient groups can engage and support young adults living with PAH:***

- Offer an employment skills workshop
- Hold a young adult networking event
- Establish a peer support programme
- Offer education for parents
- Organise volunteer work experience opportunities within the patient group
- Develop and offer new materials written specifically for young adults on relevant issues

