

WEBINAR: Managing my career and my PH

Episode 9 - Thursday 3 October 2019

DISCUSSION SUMMARY

Overview

On Thursday 3 October 2019, Actelion hosted a webinar entitled 'Managing my career and my PH'. Steve Van Wormer, co-founder of patient advocacy group, phaware (US-based) and father of a son living with pulmonary hypertension (PH), was the guest speaker. Steve discussed how to choose and manage a career after receiving a PH diagnosis, sharing practical advice and inspirational stories from the PH community about how to lead a fulfilling and satisfying career whilst living with PH.

The primary objectives of the webinar were:

- To discuss the impact of PH on people's career decisions and how to adapt to achieve career satisfaction, whilst ensuring best practice management of PH is upheld
- To share and discuss best practice approaches to help support conversations with existing or potential employers, to enable those living with PH to pursue career aspirations whilst managing their health
- To identify sources of further information on how to manage a career whilst living with PH

Discussion summary and key learnings

The HCP perspective – living with PH and pursuing a career

- Steve Van Wormer presented insights shared by his HCP network, which highlighted that many patients who have stable PH are able to work regular hours, especially in sedentary jobs that do not put pressure on the body, particularly the heart and lungs
 - It was recommended that gentle exercise can be beneficial during the working day, especially when working in a sedentary job. It is important that people living with PH get up periodically and walk around and/or undertake gentle exercise
 - Some jobs, especially those that are physically demanding e.g. a career involving aerobic exercise, heavy lifting or long hours, may be more difficult to perform if living with PH. Talk to your employer to see how your job role can be adapted e.g. potential to work from home
 - Shortness of breath, as well as fatigue, can be one of the biggest barriers when it comes to choosing a suitable career. Talk to your doctor about recognizing your limitations and consider this when thinking about your options to enter or move within the workforce
 - As with all activities, pace yourself and listen to your body – if you need to rest or take time out, build this into your working day
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The patient perspective - advice when planning a career while living with PH

- Having a career can be important for personal development, mental health, social interaction and financial independence. One person living with PH explained: 'Going back to work was probably one of the best decisions I have made. I'm much happier and content with my life now. Getting out of the house and working helps me achieve that'. Another person who lives with PH, added: 'I think it's important to keep moving and stay social and keeping busy is most important. It takes your mind off PH'
- Applying for a job can take some time, it was recommended that while looking for a job you should set small goals to help keep a sense of progression and fulfilment throughout the application process. If you are in a job, setting goals can also help with career satisfaction. A person living with PH explained: 'As a PAH patient, you can have 'good' and 'bad' days. What I've noticed is that working and having goals, helps to keep me going'
- If you are finding it difficult to decide on a suitable career or would like to know more about your options, speak to a career counsellor or contact people who work in a field you are interested in. You may be able to shadow them or speak to them about their experiences
- Networking with like-minded people can raise awareness of the range of jobs that are available and how to manage living with PH whilst starting or maintaining a career. Patient organizations or online communities are a good way to meet and discuss career options with peers and/or others living with PH

Things to consider when looking for a career while living with PH

- Job modifications may be required in certain instances to help manage symptoms, including fatigue or shortness of breath:
 - When looking for work, prioritize jobs that do **not require physical strength but utilize other skills** e.g. intellectual skills, communication skills, something you are qualified in and/or passionate about. A person who lives with PH explained: 'Often, PH denies you of your full physical strength and many quit their jobs. Consider replacing physical work with intellectual work. The mind is sometimes the most important organ that keeps us alive'
 - If you enjoy the field you work in, or have a **particular field you are interested in**, think of associated careers that may be less physically demanding. A person living with PH explained that they wanted to be a nurse after growing up around inspirational nurses. However they knew this would be too physically demanding for them so they became a cardiac sonographer, meaning they could still fulfil their passion for interacting with patients
 - It was recommended that those living with PH should **explore flexible ways of working** such as reduced hours or working from home. One person living with PH, enjoyed teaching but was struggling with the demands of the role, such as being on their feet all day and being around children prone to infections. They swapped the classroom for teaching English online to children in China
 - Career decisions can have an impact on your quality of life and happiness and it is important to try and do something that you will enjoy (or will enjoy some aspects of). A recommendation was to **consider a career related to your hobbies** as this is likely a natural avenue/interest area for you and will mean you are more likely to enjoy it. A person who lives with PH found a career in their hobby of photography. It allows them to take unpredictable time off to manage their healthcare needs whilst being personally fulfilling
 - Many people living with PH work in the healthcare field as they can **utilize their unique experience to provide valuable insights**. Consider how you can use your areas of knowledge and personal experiences in a career
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- If you are unable to find paid work or if you wish to supplement your career, you could join a voluntary group and or a local organization. For example, a person who lives with PH leads two Girl Scout troops in their spare time. These groups can provide many of the benefits of a fulfilling career and help to provide a sense of purpose

Advice on working while living with PH

- If you feel comfortable to do so, tell colleagues and your employer about your condition so that they can understand and be flexible to your needs. Speaking to and educating your employer about PH will enable them to be more equipped to support you if you were to become ill at work. Visit the PH Human Website (<https://www.ph-human.com/careers-and-hobbies>) for advice on this
- You may need to take regular breaks or rest during the working day. This may be another reason to talk to your employer so they can understand your condition and help you make adjustments at work. This could include flexible working hours and/or dedicated breaks throughout the day
- There are many people who can provide you with emotional support regarding PH and your career. You can speak to your medical team about the mental and physical impact of the condition and subsequent impact on your career choices. Patient support groups are another useful resource – by joining a patient group you can share experiences and learn from others living with PH
- Try not to rush into making important decisions about your career straight after a diagnosis. See if you can take some time out before giving up on a career to ensure you have looked at all the options

Conclusion

- Listen to your body and recognize your limitations and equally your opportunities
- Consider what will bring you happiness in terms of a career
- Find ways to adapt your plans to achieve a fulfilling career
- Speak to others to share experiences and gain emotional support

Appendix

For more inspirational patient stories regarding careers, visit the 'I'm aware that I'm rare' podcast, at phawarepodcast.libsyn.com

For more information on career planning, visit <https://phassociation.org/patients/living-with-ph/working-with-ph/>
