

# PHA-UK aim to raise awareness of lethal disease that can kill before being diagnosed during first ever PH awareness week

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First ever Pulmonary Hypertension awareness week launched

PHA-UK aim to improve awareness and diagnosis of disease that takes 2 years for correct diagnosis

Monday 4th April sees the launch of the first ever PH Awareness Week in the UK. The week, run by the PHA-UK (Pulmonary Hypertension Association UK), the patient charity for PH sufferers, aims to raise awareness of the condition amongst sufferers, healthcare professionals and the general public to aid faster diagnosis and to make more people aware of the specialist PH treatment centres.

PH is manageable with drug therapy if diagnosed early enough. However, the time taken from onset of symptoms to a correct diagnosis is 2 years<sup>(1)</sup> with new research from PHA-UK showing that more than 1 in 5 current PH patients have had to wait significantly longer than 2 years to be correctly diagnosed. Given that the longer it takes for the diagnosis to be made, the less likely treatment is to be successful; this situation is far from ideal. Indeed, if not treated, approximately half of PH patients die within two years.

The research also showed that before being correctly diagnosed, almost three quarters of sufferers had to see more than three doctors and more than a quarter had to see more than five<sup>(2)</sup>! Due to its similarities to the more common asthma, PH is often mistakenly diagnosed by health professionals.

Iain Armstrong, chairman of the PHA-UK, says, "The lack of awareness is very frustrating. If sufferers had the opportunity to be referred to one of the specialist centres earlier in their disease progression we would have the ability to greatly improve their quality of life living with the disease. Unfortunately some sufferers are just not getting the appropriate care soon enough and as a result there are limitations for the patients in both the treatments and the outcomes."

PH is a disease in which the blood pressure in the arteries in the lungs elevates putting pressure on the heart and reducing the amount of oxygen that is able to reach the tissues of the body causing breathlessness and exhaustion. This can significantly impact the sufferer's ability to lead a normal life. It can often lead to heart failure and can be a standalone condition or associated with other diseases. Although there is no cure, there are effective treatments that can help sufferers if they are diagnosed early in the disease progression. PH is a disease that affects people of all ages (including young children). It is twice as common in women than men and the commonest age at presentation is 40 - 50 years old.

Unfortunately, knowledge of PH amongst the general public is very low. When compared with other less common diseases such as non-Hodgkin's lymphoma, Huntington's disease and CJD (where 74%, 85%, and 95% of people have heard of the diseases respectively, only 55% had heard of PH).

While there are currently approximately 4,000 diagnosed PH sufferers in the UK, the lack of awareness and frequent misdiagnosis make the actual number of sufferers harder to estimate but by far higher.

Dr Simon Gibbs, Consultant Cardiologist at Hammersmith Hospital NHS Trust says "PH is a complex disease that shares similar symptoms with other heart and lung diseases such as asthma and heart failure. It can be associated with connective tissue diseases such as scleroderma. The patients are frequently misdiagnosed as having asthma and they can try a number of medications for this which are often ineffective. As a result there is a long delay in the time taken to obtain the correct diagnosis and they often arrive at specialist centres very breathless indeed. Also we are noticing that even when some patients are being diagnosed they are being referred to transplant units for a heart lung transplant when often the specialist drug treatments would be far more beneficial and offer a better prognosis."

Iain Armstrong, continues, "PH is a very complex disease, requiring expert treatment, best provided by the specialist centres.

PHA-UK is committed to improving diagnosis, treatment, and outcome for PH sufferers and this awareness week is one of many projects we are undertaking to facilitate this process. Once we have improved recognition and diagnosis of PH, more patients will be properly managed and the outlook for sufferers could be significantly improved."

For more information visit [www.pha-uk.com](http://www.pha-uk.com).

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Notes to editors:

For media enquiries, interviews with PHA-UK spokespeople, KOLs or case studies please contact:  
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PH specialist centres

There are seven specialist PH centres in the UK:

Western Infirmary, Glasgow  
Freeman Hospital, Newcastle  
Royal Hallamshire, Sheffield  
Papworth Hospital, Cambridgeshire  
Great Ormond Street Hospital, London  
Hammersmith Hospital, London  
Royal Brompton Hospital, London  
Royal Free Hospital, London

Contact details for all of the specialist centres are available from [www.pha-uk.com](http://www.pha-uk.com).

References:

- 1 Peacock A, 2003, Treatment of Pulmonary Hypertension. *BMJ*, 326:835-836
- 2 PHA-UK IMPACT survey 2004
- 3 Black C, 2005. Pulmonary arterial hypertension: are we doing enough to identify systemic sclerosis

patients at high risk of this rare condition? Rheumatology. 44:141-142

4 TNS Consumer research 2005