

2015 Research Newsletter: Pulmonary AVMs and Hereditary Haemorrhagic Telangiectasia

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We would like to thank all of you who have helped us with our recent research studies. Here we provide information to summarise important new findings

For further information, and access to the papers, please see <https://www.imperial.ac.uk/people/c.shovlin/page/hht-and-pavms.html>

HEREDITARY HAEMORRHAGIC TELANGIECTASIA (HHT)

ANAEMIA, LOW IRON LEVELS AND NOSEBLEEDS

Our 2014 and 2016 HHT Newsletters explains how we showed that most people with HHT are anaemic simply because they do not get enough iron in to balance the iron they lost through their nosebleeds. Some people can find extra iron through their diet. Others with frequent nosebleeds, or other blood losses, may need iron supplements.

How much noses bleed [FINNAMORE ET AL PLOS ONE 2013 Oct 16;8\(10\):e76516](#)

Iron in your diet [FINNAMORE ET AL BJGP 2014 April 64 \(621\): 172 -173](#)

WHY DOES IT MATTER IF I HAVE LOW IRON LEVELS?

1) If you are anaemic, your heart has to work harder:

When people are very anaemic they feel tired, breathless and may need blood transfusions. This is because the blood contains less haemoglobin, and so less oxygen for the body. To compensate, your heart has to work harder as if you are exercising, even if you are just sitting quietly. It is similar to what the heart has to do if you have low oxygen levels due to pulmonary AVMs (see opposite), or large AVMs elsewhere in the body. To help explain these concepts, Dr Shovlin uses the example of a train delivering oxygen to the body. You can find the full description and explanations at www.theoxygentrain.net -images are shown opposite. Your doctors may wish to read:

HHT and the circulation: [SHOVLIN CL. FRONTIERS IN GENETICS 2015 Apr 9.6 \(101\)](#)
This explains how anaemia, low oxygen levels and AVMs in the body can all make the heart have to work harder. Of these, iron deficiency is usually the easiest to treat.

2) Low iron levels seem to increase your risk of blood clots (VTE)

In 2012, we showed that being short of iron seems to increase the risk of blood clots in HHT, apparently by making the blood a bit stickier.

Blood clots/ low iron in HHT [LIVESEY ET AL THORAX 2012 Apr;67\(4\):328-33](#)

3) Low iron levels also seem to increase the risk of strokes through pulmonary AVMs:

In 2014 we also showed that low iron levels were also linked to the risk of stroke in people with HHT and pulmonary AVMs in the lung.

Strokes and low iron in HHT [SHOVLIN ET AL, PLOS ONE 2014 FEB 19;9\(2\):e88812.](#)

We have always checked iron levels in clinic to make sure you had enough iron to make haemoglobin and help your heart- now there are just more reasons to do so.

PULMONARY ARTERIOVENOUS MALFORMATIONS (PAVMs)

LOW OXYGEN LEVELS:

In early 2014 we published three different studies that help explain why low oxygen levels are usually silent for people with pulmonary AVMs. One of these was the exercise study which many of you helped with. These studies showed that your body can set up different ways of compensating for low oxygen levels- your blood count (haemoglobin) goes up, and your heart will either beat faster or a bit more strongly. If this works as it should, you can exercise just as well as if you had normal oxygen levels. For some people though, there are reasons why their bodies cannot compensate as well. The most common problem is if you are short of iron:

[SANTHIRAPALA ET AL PLOS ONE 2014 Mar 17;9\(3\):e90777.](#)

This paper explains how the body can maintain the total oxygen content of blood

[HOWARD ET AL CHEST 2014 Sep;146\(3\):709-18.](#)

Using stationary bicycle tests, this study showed how the body can deliver the same amount of oxygen every heart beat

[SANTHIRAPALA ET AL THORAX 2014 Nov;69\(11\):1046-7](#)

This paper reminds us that the body is very good at making the heart beat faster to keep the body and brain supplied with oxygen.

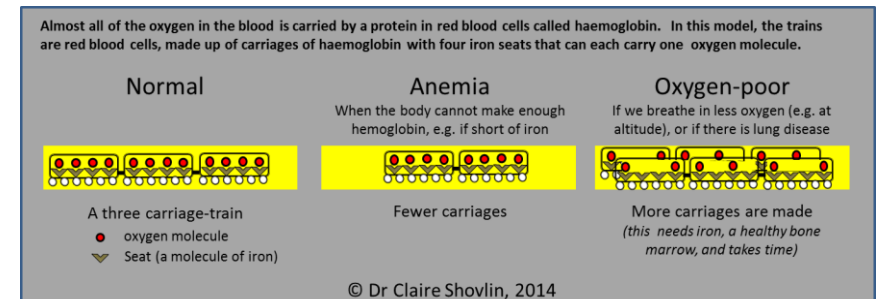
[YASUDA ET AL THORAX 2015 Jun;70\(6\):601-3.](#)

This 2015 paper provides a striking example of a very sporty young man, and summarises how this was possible despite really low oxygen levels due to PAVM.

[SHOVLIN, AM J RESP CRIT CARE MED 2014 DEC 1;190\(11\):1217-28](#)

This 2014 review article summarises all of the findings for doctors, and references:

THE OXYGEN TRAIN (from www.theoxygentrain.net)



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