

HHTIC London 2012 Research Newsletter

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We would like to thank all of you who have helped us with our recent research studies. Here, we give you a flavour of what is going on, and what will be happening next!

1) FLYING AND HHT

159 of you participated in our 2010 questionnaire study on Flying and HHT. This has now been published. The main message was that flight-related complications were surprisingly rare in people with hereditary haemorrhagic telangiectasia (HHT) and/or pulmonary arteriovenous malformations (PAVMs), despite low oxygen saturations and anaemia. **If any of you with HHT are finding doctors advising you that you should not fly, please check that they have read the article before finalising their advice to you.**

MASON AND SHOVLIN, THORAX 2012 JAN;67:80-1

2) BLOOD CLOTS AND HHT

People with HHT are known to be prone to bleeding, particularly from the nose. In the last year we have published two papers on HHT and blood clots in the deep veins or lungs. The big message for people with HHT is that they are at risk of blood clots, despite having a bleeding disorder: Normal clot prevention measures should be used at appropriate times, as in the general population. **If any of you with HHT are finding doctors advising you that you should not have blood thinning agents, please check that they have read the articles before finalising their advice to you.** *

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LIVESEY ET AL THORAX 2012: 67:328-33

3) LOW IRON LEVELS AND HHT

We already know that people who bleed need higher iron intake to balance their iron losses. The clotting study provided another reason to keep a close eye on iron levels, because people with HHT and lower blood iron levels were at higher risk of blood clots. If people had taken iron tablets to keep iron levels normal, their risks seemed normal. This did not mean low iron levels cause blood clots in HHT, they just seemed to make blood clots a little more likely. **More information for doctors can be found in this month's article** *LIVESEY ET AL THORAX 2012: 67:328-33*

A good way for you to think about this is by picturing a jigsaw - you need many pieces in place before you can see the picture. The more pieces that are already in place, the fewer additional pieces are needed to see the picture. By themselves, no one piece of the jigsaw can be considered to cause clots. For blood clots in HHT, having low iron levels seems to be one piece of the puzzle.

**4) DIET AND HHT**

Many of you participated in our 2011 Diet Study, either by Questionnaire, or by weighing your food. We have now completed acquiring the data and Medical Student Helen Finnamore is busy analysing the data. We hope to have results for you later in the year. We are also performing a dietary intervention study in volunteers which we will analyse later in the year.

5) EXERCISE AND PAVMs

Many of you have participated in our 2011-2012 PAVM Exercise Study coordinated by Medical Student Vatshalan Santhirapala. This involved people with PAVMs exercising on a stationary bicycle in the Exercise Physiology Suite. We think you will be very interested in the results, which again we hope to have for you later in the year.

NEW 2012 STUDY ON HHT AND OTHER MEDICAL CONDITIONS

As you know, we have conducted many research studies to look into different medical problems that people with HHT experience, in order to provide the HHT community with better advice about their lifestyle and health. We invite you to help us with our 2012 research, by filling out a short confidential survey on general health issues. We would like this to be filled in by people with HHT, and also by people who do not have HHT. It should take about 20-30 minutes to fill in. All questionnaires will be treated with the strictest of confidence. The responses will allow us to compare responses from people with HHT, and people without, to see if people with HHT are more or less likely to have certain common medical conditions.

For more information, see our website for the online survey

www.imperial.ac.uk/medicine/HHTsurvey2012.

If you do not have a home computer, your local library will be able to help. It is easier to fill the questionnaire in using a computer but if you would prefer us to send you the information sheet and questions by post, please could you reply using the tear off slip, and return to Dr Shovlin in the stamped addressed envelope.

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