

All Wales FH Family Forum

- for individuals and families with inherited high cholesterol.

Summer 2012

Welcome to the newsletter of the All Wales FH Family Forum. This issue is being sent to you by the All Wales FH Genetic Cascade Testing Service. It is a while since we produced a newsletter and we thought it was time to update you on some of the many things that have happened since our last edition.

The All Wales FH Genetic Cascade Testing Service is funded in partnership between the Welsh Government and the British Heart Foundation (BHF). It was officially launched at the Senedd in December 2010 after successful lobbying by the All Wales FH Family Forum.

The service has now been available across Wales for approximately a year and a half. During that time the reach and range of the service has grown. A specific FH genetic diagnosis has been made in 415 individuals. The clinical care of these families and others with high cholesterol has been optimised to help individuals stay healthy and prevent heart attacks.

The All Wales FH Family Forum is a group of patients and their families who are interested in promoting awareness of FH and support for people with the condition. We have previously put on a number of talks relevant to living with FH and are keen to increase the range of our activities so that we raise awareness of FH, to develop the service further and to secure services for the future. FH is present in about 1 in 500 people. We estimate that there are still more than five thousand of people with FH in Wales who are not getting the right diagnosis and treatment.

We would like more people from across the whole of Wales to join in Forum activities to raise the profile of this important condition.



Plans for Sponsored Walks

We are currently working with the British Heart Foundation and Cardiff University to plan some sponsored walks to raise the profile of FH across Wales.



We aim to organise a series of walks over the next year so that people affected by FH can take part in raising awareness of the condition and in fundraising activities.

Our first walk will take place in North Wales on the 7th October and will be open to anyone who wants to participate. Contact us if you are interested in taking part. Our contact details are at the end of this newsletter.

“Saving Lives, Saving Families” Report. Wales FH Service Highlighted in House of Commons Reception.

The Wales FH service was represented at a reception at the



reception at the House of Commons in February to launch the report from Heart UK “Saving Lives, Saving Families”. Members of Parliament were lobbied to improve services for FH across the UK. Mrs Suzanne Sheppard from the Wales FH family forum and Dr

Ian McDowell, chair of the Wales FH steering group attended. The Wales FH service was quoted as an example of good clinical practice in the UK. For more details see this link.

<http://heartuk.org.uk/latest-news/article/heart-uk-urges-nhs-to-make-improvements>

FH Team Win Award

For the third consecutive year the work of the All Wales FH Genetic Cascade Testing team has been recognised at the annual Heart UK conference. Kate Haralambos won the Young Investigator's Award for her work on developing scoring criteria for genetic testing in FH. The score is used to guide whether lipid clinic patients with a clinical diagnosis of FH are suitable for genetic testing. Kate reported that

'It is a useful tool to help predict the likelihood of identifying a FH-causing genetic variant.'



Kate Haralambos (left) receiving her award

This means that genetic testing is being offered to those families that are most likely to benefit from it.

Facebook



To keep up with the times we have recently created a facebook page. At the moment there is not much on it, but we would be happy for FH patients and family members to use the page to post about their experiences of FH, ask questions about FH or share information. Our facebook name is derived from the usual abbreviation of Familial Hypercholesterolaemia which many of us use when we are discussing the condition - FH for short

Involving People

Involving People / Cynnwys Pobl are a public engagement network funded by the National Institute of Social and Health Research (NISCHR).

Members of the All Wales FH Family Forum have recently been involved in consultations which were facilitated by the Involving People network. The first activity included reviewing written materials for use in an FH Research Study to be undertaken by researchers at Cardiff University. The second involved a consultation on the content and delivery of questionnaires which will be used to evaluate the All Wales FH Genetic Cascade Testing Service in the coming months.

From time to time we will be letting you know about activities carried out through Involving People which are relevant to FH. If you'd like to know more about the work of Involving People their web site can be found here:

<http://www.wales.nhs.uk/sites3/home.cfm?orgid=1023>

Cynnwys Pobl Involving People

Keeping you up to date with FH Family Forum activities.

This newsletter was sent to you by the All Wales FH Cascade Testing Service.

In future the FH Family forum would like to correspond with you directly. To receive information from us electronically, please email us at our gmail address below putting the word 'newsletter' as the subject. Alternatively, please ring the FH Service and ask that your postal address be added to the Forum's mailing list. To stop receiving the newsletter you can email us or contact the FH Service at any time. Please note that email addresses will only be used for sending information about Forum activities and will not be used for discussing issues relating to individual patient care.

Our contact details

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💻 www.wales.nhs.uk/FHService

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