

All Wales FH Family Forum

- for individuals and families with inherited high cholesterol.

Spring 2013

Welcome to the newsletter of the All Wales Familial Hypercholesterolaemia (FH) Family Forum. We have lots to update you on since our last issue.

Who are we?

The All Wales FH Family Forum is a group of patients and their families who are affected by FH. We were involved in successfully lobbying the Welsh Government (formerly Welsh Assembly Government) to fund the All Wales FH Cascade Testing Service. We are very proud to have been instrumental in developing this service in Wales.

What do we do?

We are increasingly being asked to tell our FH stories to key health campaigners elsewhere, particularly in England, where there is enthusiasm to implement a service based on the Welsh model.

In relation to this, members of the FH Family Forum have organised stories for the Guardian Newspaper, Specialist Cardiac Journals and on BBC Television (Wales Today).

You can read the full Guardian story at:

<http://www.guardian.co.uk/society/2013/jan/22/blood-screening-heart-attacks>

The FH Family Forum needs you

The FH Family Forum was set up to make it easy for families affected by FH to support each other. However, membership of the group has not grown as the service has developed. We need your help to make the FH Family Forum beneficial for families with FH and to help grow awareness of the FH Testing Service across Wales.

We want everyone in Wales to know that the All Wales FH Cascade Testing Service exists and how to access it.

Currently we only have one organised arm of the FH Family Forum which is based in Cardiff. Although there are lots of FH patients in and around Cardiff we realise that there are lots of people with FH all across Wales. We would therefore like to extend the FH Family Forum beyond the Cardiff area by encouraging people with FH in other areas of Wales to form FH Forum Hubs.

FH Sponsored Walks

In our last newsletter we told you about our plans to work with British Heart Foundation (BHF) –Cymru to organise a sponsored walk in North Wales so that families with FH could meet to enjoy a day out together.

The first walk took place in North Wales on 7th October 2012. Thirty families took on the four mile hike in the area around Moel Famau and were rewarded with bright sunshine and clear views of the surrounding countryside.

Blood screening that is preventing heart attacks – but not in England

NHS in Wales, Scotland and Northern Ireland is tracking down and treating people with inherited condition

Denis Campbell, health correspondent
The Guardian, Tuesday 22 January 2013 19:26 GMT

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Suzanne Sheppard, who has familial hypercholesterolaemia. Her son, Cameron, has a 50/50 chance of developing the condition. He will be tested when he is 10.

FH Sponsored walk Moel Famau



This year we are again working with BHF-Cymru to organise more walks.

June 2013 - FH Walking Month

South – Sun 9th Machen

West – Sat 15th Pembrey

North – Sat 22nd Aber Falls (Conwy)

We've chosen walks which showcase beautiful Welsh scenery and can be enjoyed by families. Each walk is about 4 miles long. To register, contact your local FH Specialist Nurse or email us and we will send the registration forms.

The purpose of the walks is so that families with FH can have a fun day out, meet each other, meet FH health professionals and become more involved with the FH Family Forum. Please also bring family and friends (they do not need to have FH to come!)

We would like to be able to organise FH Family Forum activities across Wales so that information and events are accessible to all families with FH.

If you would like to be more involved with the FH Family Forum or have an idea for an FH event in your area, please contact us (see contacts box).

FH Wales logo

We are proud to be able to share with you the new logo for the All Wales FH Cascade Testing Service. The FH Family Forum will be adopting the new logo on our communications and we will be flying the FH flag by having new banners printed to show off at our sponsored walks this year.



FH Wales nominated for awards

Lessons learned from the All Wales FH Cascade Testing Service have informed UK Wide guidelines for clinical practice such as those produced by the National Institute for Clinical Excellence (NICE). In addition, the All Wales FH Testing Service has recently been shortlisted for NHS Care Integration and NHS Wales Awards. The winners will be announced in the summer.

The FH Patient Forum does not have access to your contact details. Please email or phone us with your details so we can keep you updated on our activities.

Email us:

fhwales@gmail.com

Phone us via:

FH Office: 029 20744021

On the web via:

www.FHwales.co.uk

Please note that the 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.