

Development of a Web Site for a regional Familial Hypercholesterolaemia (FH) Patient Support Group

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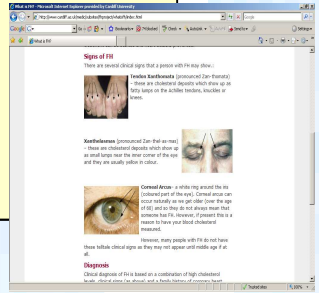
www.FHwales.co.uk

1) Introduction

- An FH cascade testing pilot project commenced in 2005 with the aim of improving the identification and management of those affected in South Wales.
- The need for a patient support group was identified as the pilot progressed. This support group was named the FH Family Forum
- A web site was then developed to support this group.

3) Site for Patients

- The web site has been primarily developed for individuals and families with FH.
- It is an educational resource about FH - diagnosis, inheritance, cascade testing etc.
- Some examples of topics that have been suggested by members of the FH support group and will be added in the future are:
 - Advances in medication
 - Lifestyle & diet advice
 - Q&A
 - Personal stories



6) Development

- The web site has been developed using the content management software Rhythmyx.
- It is hosted by Cardiff University and is a sub site of the School of Medicine web site.
- The content has been based on suggestions from health professionals, and individuals and families affected by FH.
- There is a feedback form on the site which invites suggestions for further content.
- The web site is continually being developed and additional content added.

2) FH Family Forum

- This patient support group has been successfully running since 2006.

Aims of the Group

- To provide a network for individuals and their families
- To develop and promote services for FH
- To provide a forum for sharing advances in this area.

Meetings

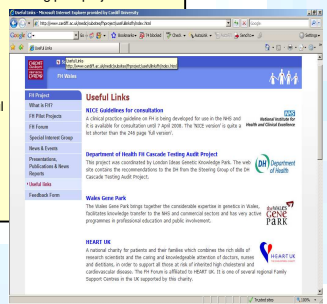
- The meetings are quarterly and the venues have rotated around Cardiff, Neath Port Talbot, Barry and Newport. The aim of rotating the venues is to broaden accessibility from other localities. There are plans to hold a meeting in North Wales in 2008.
- The web site promotes and advertises these meetings and allows members to download the newsletters of past and future events.



Members of FH Support Group

4) Site for Health Professionals

- The site also contains resources and information for health professionals.
- Information about the FH cascade testing pilot projects in Wales and England.
- Presentations, publications and news reports related to the Welsh FH Project.
- Links to other relevant and useful web sites

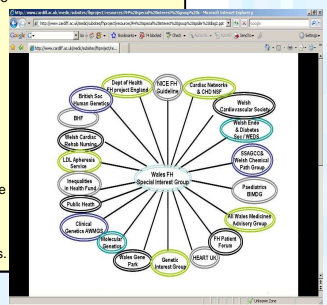


7) Online Forum

- There are plans to develop an online forum, which will allow people to communicate by posting messages onto a secure message board.
- This will enable individuals to give and receive support and to share information.

5) Support the FH Special Interest Group

- This is a group of health professionals from various backgrounds who have a special interest in developing and promoting a clinical service for FH. It is part of the Cardiac Reference Group for Wales.
- The support group maintains close links with the FH Special Interest Group so that families can hear of new initiatives and can also feed back to the professionals.
- The web site is one way in which families can give feedback to professionals. For example, there was a link to the draft NICE guidelines (during the 2 month consultation period) and an invitation to submit comments.



8) Summary

- The patient forum site has been successful in:
 - Supporting families with FH
 - Educating health professionals
 - Being a focus for publicity.

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