



Grŵp Cydlynu Rhwydwaith y Galon
Cardiac Networks Co-ordinating Group

Feedback on the first South Wales FH Patient Forum evening.

The first Patient Forum for individuals and families affected by inherited high cholesterol (Familial Hypercholesterolaemia or FH) was held on the evening of Wednesday the 13th of September, 2006 at the University Hospital in Cardiff. The evening was very well attended by people across south east Wales who wanted the opportunity to find out more about FH, to meet others and to take part in a discussion and ask questions to healthcare professionals who are involved in FH.

The evening was chaired by Dr Ian McDowell, Consultant at the lipid clinic at the UHW in Cardiff and consisted of a series of brief talks including:

Dr Alan Rees, Consultant, Lipid Clinic, UHW; presented an overview of FH as a condition, how it is inherited and the various methods to manage the condition through medication and healthy living such as taking exercise and a healthy diet.

Dr Stephanie Matthews, Consultant, Lipid Clinic, Llandough; discussed the importance of passing on the message of healthy living to children and young people with FH. She also showed a short film promoting these factors to a younger audience and invited audience members with an interest in taking part to review the film to get in touch with the group.

Mr Phil Rowlands, Heart UK Expert Patient; talked about his work as a volunteer 'expert patient' with the cholesterol charity Heart UK and how he works with the charity to help them in raising awareness of the dangers of high cholesterol.

Ms Cathy Radcliffe, Communications officer, Heart UK; talked about their plans to establish specialist centres across the UK. Here, families could learn about how to manage their cholesterol levels with specialists, Heart UK workers and other families.

Miss Buddug Williams, Genetic Interest Group; described the work the FH team will be involved in over the next few months to promote the need for an NHS service for people with FH across Wales.

Future plans

Feedback received from the Forum high-lighted several areas of interest. As a group, we will now take these forward as part of our work to maintain and build on the enthusiasm between individuals, patient groups and medical professionals. This will improve the information, support and healthcare provision for individuals and families with FH in Wales. Here are the details of some of our plans:

- **Provision of information.**

After the success of the first Patient Forum, other evenings will be scheduled in the future. These will have different topics such as the latest information on medication, lifestyle choices such as exercising and diet & nutrition. Please see the attached flyer for further information.

- **Establishing a local voluntary group.**

In partnership with Heart UK, a local group will be formed. Patients and families often find information sharing from others in similar positions very useful and valuable. If you are interested in finding out more, please get in touch.

- **Achieving a cascade screening and management service for FH in Wales.**

Currently, there is no service for adults and children with FH in Wales. We will work with the Government to help them recognise the clear need for such a valuable and important health service. Over the next few months we will be lobbying the Government and the National Assembly on this issue. We will let you know about our work and will give you the chance to take part, should you wish.

- **Raising awareness about FH amongst children and young people.**

Following from Dr Matthews' film to help young people learn about FH, she and her team will be reviewing the rest of the film. They are now looking for parents and young people to help them with the reviewing process. If you or your family members would be interested in helping us with this work, please contact us.

The next Patient Forum evening will be held on the 28th of November 2006, at the Wales Heart Research Institute, University Hospital of Wales. The topic for the evening will be about diet and food and there will be an opportunity for questions and discussion. Further details are enclosed. We look forward to seeing you there!

If you would like more information or have any comments about the FH Patient forum, the children and young people's education film, or our future plans, please contact us at the following address:

June Williams, Unit 31, The Medicentre, University Hospital of Wales,
Heath Park, Cardiff, CF14 4UJ.

Tel: 02920 682140.

Email: williamsjk1@Cardiff.ac.uk