

NHS GENETICS EDUCATION CENTRE

UPDATE

Winter 2009/10



Our plans for supporting genetics education in 2010

I am delighted to highlight some of our plans for 2010, following a full review of the Centre's strategy over the last few months.

We are:

- developing a web-based tool to record family history information which will be useful in education and clinical service
- undertaking a major piece of work with the UK Genetic Testing Network to provide resources for health professionals ordering genetic tests
- developing courses to support educators in updating their knowledge of genetics, particularly as applied to clinical practice in the NHS
- setting up a programme to identify and develop the use of learning technology in genetics education
- continually adding to the teaching and learning resources on our website
- identifying the knowledge, skills and attitudes which are likely to be required in practice by health professionals related to "common complex disorders".

We value your feedback and comments on any of our current and proposed programmes. Please contact us on enquiries@geneticseducation.nhs.uk

Professor Peter Farndon, Director

Bridging the Gaps: Making genetics teaching clinically relevant Tuesday 21st September 2010 The 3rd NHS National Genetics Education and Development Centre conference

We are pleased to announce that the Centre's third conference will be held on Tuesday 21st September 2010 at the International Convention Centre, Birmingham. More details about the day will be available via our website soon. In the meantime please make a note of this date and keep watching the website for further details.

Have you read our Familial Hypercholesterolaemia factsheet? We also have many more, read on...

In this edition you will find a copy of the '*Familial Hypercholesterolaemia Scenario 1*' factsheet. This factsheet shows a trigger event in a consultation and how a Primary Care professional could use the NICE guidelines to assess the risk based on a family history.

The factsheet can be used as a teaching scenario. The family history information is given to students and they then assess the risk using the NICE guidelines. You can also use the factsheet as an information sheet to be handed out in a teaching session.

All of our factsheets are free to download and copy for use in non-commercial education purposes for healthcare staff. If you liked '*Scenario 1*' you might find '*Familial Hypercholesterolaemia Scenario 2*' useful! You will find this and many more on our website at www.geneticseducation.nhs.uk/about-us/resources.aspx

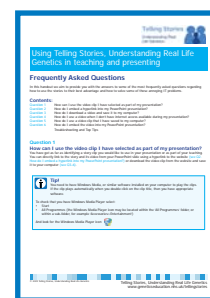
Telling Stories: New and improved!

New URL launch for 2010 www.tellingstories.nhs.uk

Telling Stories, our website containing real life patient stories about genetics, has been re-launched. But don't worry about not being able to find us as the original URL will direct you to the new site straight away.

'Frequently Asked Questions' guide now available online

This handy guide provides information and guidance on using the audio and video clips from the stories. You can find out how to use clips in presentations,



embed hyperlinks, download and save videos and solve problems with internet access during a presentation. The guide is available to view online or download as a PDF.

Expert commentaries available on Telling Stories

Professionals with expertise across healthcare practice have provided commentaries on aspects of the stories. The commentaries provide additional perspectives to supplement the stories for teaching and learning. Look out for the new owl icon which identifies the stories with commentaries.



Your points of view

If you are a regular or new visitor to the Telling Stories website, we would like to hear your views about what you think of the site. It will only take a few minutes to complete our new online questionnaire on the home page.

Helping GPs, GP trainers and trainees at the Royal College of General Practitioners 2009 conference



November 2009 saw the National Genetics Education and Development Centre attending the RCGP annual conference in Glasgow. Over the course of the 2 ½ day event our stand saw 300 GPs, GP trainers and trainees, a number of whom were familiar with the Centre's work. These GPs provided us with positive feedback about our website and resources, which many of the trainers had already used in teaching sessions. Special praise was given to the wonderful work of the Genetics Education Facilitators who helped many a GP trainer navigate the RCGP curriculum statement '*Genetics in Primary Care*'.

From the GP trainees and trainers, who were new to the work of the Centre, there was one overall message we received: *the genetics part of the RCGP curriculum is one of the hardest to cover*. GP trainers told us that they don't have confidence in their own knowledge and expertise to teach genetics effectively. The GP trainees, on the other hand, didn't know where to go to find credible and relevant information to complete the genetics component of their e-Portfolio.

We responded to these concerns in two ways:

1. At the conference we provided the contact details of the 8 Genetics Education Facilitators, located throughout the UK, who can help facilitate training sessions in genetics. Since doing that we have had a number of requests to run training courses for GP trainees covering the RCGP curriculum statement '*Genetics in Primary Care*'.
2. Coming soon to our website will be a dedicated page for GP trainees. This page will have links to all the Centre's resources which tie in with the RCGP curriculum, as well as links to other relevant websites. This page will be launched in March 2010
www.geneticseducation.nhs.uk/learning-genetics/AIT

After a successful 2009 conference, we are hoping to run a genetics workshop within the conference programme at the 2010 conference in Harrogate. For further information about any points raised in this article please contact Michelle Bishop (michelle.bishop@geneticseducation.nhs.uk) or Rob Newton (robert.newton@geneticseducation.nhs.uk).

Evaluating new roles for cardiac nurses working with inherited cardiac conditions



The British Heart Foundation's Cardiac Genetic Nurse (CGN) Initiative aims to shape the development of improved models of service delivery, for patients and families at risk of inherited cardiac conditions (ICC). Nine nurses were appointed during 2008-09 (eight in England and one in Wales) and the Centre, along with colleagues at the University of Glamorgan, were commissioned by the BHF to evaluate the initiative.

We anticipate that this work will be very useful in informing the Centre's Nursing Professions Programme in its aim to support nurses working across the health service as they take on new roles and develop existing nursing positions to incorporate genetic based tasks (for example family history taking and risk assessment). More specifically, the outputs will be useful in providing information and guidance to Trusts across the country who may be looking to develop ICC services.

At the end of the three year project (Sept. 2011) we hope that we will be able to describe: *what an effective and sustainable cardiac genetics service looks like and, what the most effective way(s) are for the nursing role to be integrated into cardiac and genetics services*. This work is very timely as awareness around inherited cardiac conditions grows and the findings should sit well alongside the report from colleagues at the PHG Foundation (*Heart to Heart: Inherited Cardiovascular Conditions Services*) and the work of the Association for Inherited Cardiac Conditions.

A key component of our work so far has been in the development of an assessment tool, the BHF-CGN Maturity Matrix. It has been developed through consultation and contains a range of outcome based indicators that an ICC service would be expected to demonstrate. We anticipate that the sites may look very different at the end of three years compared to how they were initially conceived and so the Matrix will allow us to capture both continuity and change in the services over time.

As the project progresses, information about the evaluation will be added to the Centre's website www.geneticseducation.nhs.uk

Courses for Regional Genetics Centres

Please contact us for further information about our courses for staff from Regional Genetics Centres:

- Teaching Genetics: An interactive three day course providing a grounding in teaching genetics to health professionals
- Making the most of PowerPoint when Teaching Genetics

Contact

NHS National Genetics Education and Development Centre
Morris House
c/o Birmingham Women's NHS Foundation Trust
Edgbaston
Birmingham
B15 2TG

Tel: 0121 623 6987
Fax: 0121 623 6968
Email: enquiries@geneticseducation.nhs.uk

Familial Hypercholesterolaemia Scenario 1

Sophie Woods (date of birth 24.05.83) is new to your practice and has arranged an appointment to renew her prescription of the oral contraceptive pill. Before renewing the prescription you take Sophie's blood pressure which is 145/95. You ask if anyone else in the family has had high blood pressure or other signs of cardiovascular disease.

Sophie's family history

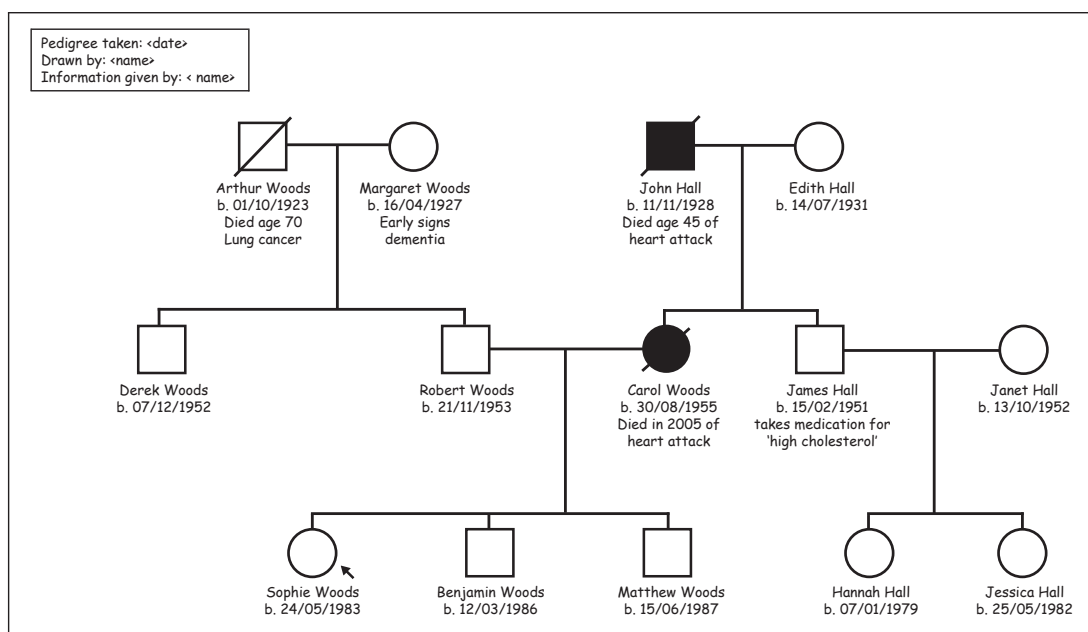


Fig. 1 Sophie's family tree

With two people on the same side of the family who have died from heart attacks at a younger than expected age (<50 years for a second degree relative, <60 years for a first degree relative) and another family member with high cholesterol, this family history is suggestive of FH.

Based on the NICE guidelines, you would test Sophie's cholesterol concentration.

- If the result was >7.5mmol/l, then you would need to inform Sophie that she had possible FH and discuss referral to a lipid clinic for confirmation of the diagnosis and the initiation of cascade testing in other family members.