



Hyperlipidaemia Education &
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London Cardiac & Stroke Networks

Implementing the NICE Familial Hypercholesterolaemia Guideline in England

Supported by: The London Cardiac and Stroke Networks

Date: 9.30am – 4pm, Monday 25 January 2010

Venue: The Great Hall, BMA House, Tavistock Square, London WC1H 9JP

HEART UK - The Cholesterol Charity - would like to invite you to a stakeholder conference to advance the implementation of NICE's 2008 clinical guideline for the 'Identification and management of familial hypercholesterolaemia'.

The estimated prevalence of familial hypercholesterolaemia (FH) is 1 in 500, suggesting 120,000 individuals are affected in the UK. FH is hugely under-diagnosed - a 2008 survey of lipid clinics indicates that 15,000 cases are known at most. The disorder has an autosomal dominant mode of inheritance, with children and siblings of a person with FH having a 50% chance of inheriting the condition. Although NICE published a clinical guideline for the 'Identification and management of FH' in 2008, little has been done to realise its recommendations. HEART UK is campaigning for the guideline to be implemented across England.

Conference presentations will cover the practical implementation of cascade testing and the preparation of commissioning bids, showcasing examples from across the UK. HEART UK will also use the conference to launch its FH Toolkit, aimed at providing a step-by-step guide to commissioning local FH services with the involvement of relevant partners. For more details, please see agenda below.

Target audience: commissioners, lipidologists, geneticists, diabetologists, paediatricians, general practitioners, cardiologists, nurses, genetic counsellors, patients, public health officials and planners, PCTs, SHAs.

Place are strictly limited!

Please RSVP by email to Jodie Dray: jd@heartuk.org.uk

When replying, please state your title, name, occupation and organisation.

Or for more information, contact Slade Carter sc@heartuk.org.uk; Tel. 07879 684 111

We hope you will be able to join us. Please feel free to pass this invitation on to colleagues who may also wish to attend.

Yours sincerely,

Michael Livingston
Director, HEART UK

HEART UK gratefully acknowledges the support of Pfizer, MSD and Genzyme towards the FH Guideline Implementation Team project.



Implementing the NICE Familial Hypercholesterolaemia Guideline in England BMA House, London, 25 January 2010

Chair: Professor John Betteridge, Professor of Endocrinology and Metabolism, University College London Medical School

9.15 – 10.00: Registrations, refreshments

Session one: Introduction to FH

10.00 – 10.10: Welcome - Professor Roger Boyle, National Clinical Director for Heart Disease and Stroke

10.10 – 10.30: Key elements of the NICE FH guideline and HEART UK FHGIT activities - Dr Jonathan Morrell, Chairman HEART UK FH GIT, GP and hospital practitioner in cardiology, Hastings

10.30 – 11.00: FH guidelines in practice: cost analysis of cascade testing and findings from DH pilot and RCP audit – Professor Steve Humphries, BHF Professor of Cardiovascular Genetics at University College London

11.00 – 11.15: Introduction to the HEART UK FH Toolkit – Dr Jonathan Morrell and Dr Dermot Neely, Lead Consultant for the Lipid & Metabolic Outpatient Clinic, Royal Victoria Infirmary, Newcastle

11.15 – 11.40: Refreshments

Session two: Patient pathways

11.40 – 12.00: The Wales FH cascade testing initiative – Dr Ian McDowell, Dept of Medical Biochemistry and Immunology, University Hospital of Wales

12:00 – 12:20: Developing FH patient pathways in Scotland – Dr Bill Simpson, Consultant Chemical Pathologist, Clinical Biochemistry Laboratory, NHS Grampian

12.20 – 12.40: The patient experience: cascade testing in action – Mr John Moore and Dr Devi Nair, Consultant and Honorary Senior Lecturer in Clinical Biochemistry, Royal Free Hospital

12.40 – 1.40: Lunch and networking

Session three: Commissioning

1.40 – 2.00: Working collaboratively to commission FH services in the North West – Dr Ian Ellis, Consultant Clinical Geneticist, Dept of Clinical Genetics, Alder Hey Children's Hospital, Liverpool

2.00 – 2.20: Developing FH services across Yorkshire and The Humber – Ged Oliver, West Yorkshire Cardiovascular Network

2.20 - 2.40: Developing FH services in South West and South East London – Dr Anthony Wierzbicki, Consultant in Chemical Pathology/Metabolic Medicine, Guy's and St Thomas' Hospital

2.40 – 3.45: Facilitated workshop – Identifying and developing optimal local care pathways and commissioning FH services in your region

3.45 – 4.00: Conclusions and ways forward

4.00 Close