

Haemoglobinopathy News

Renewed and relaunched in 2005

Public Health Review influences organisational developments



A renewed **network board** was launched in September 2005. The picture above shows Dr Mark Layton a member of the board from the Hammersmith Hospital sharing a point with Dr Jo Howard board member from the Central Middlesex Hospital. The chair of the new network board is Ms Jean Bradlow, Director Public Health Harrow PCT.

Review Implementation Group (RIG)

A year on from the sector-wide review of Haemoglobinopathy Services in NW London (Dec 2004), a new network board takes over the Review Implementation Group (RIG) which was established in March 05 to oversee and co-ordinate implementation of the recommendations that came out of the service review. The chair of the RIG was Mr David Kemsley, lead specialist commissioner for NW London based in Hillingdon PCT.

Network structure and accountability

Since the review which was commissioned by Directors of Public Health between July and December 2004, the network has been subject to significant changes in its structure and accountability. The Chair of the Haemoglobinopathy Network Board is accountable to the Chief Executives of the acute Trusts, Primary Care Trusts and the Strategic Health Authority for the work of the Network and will report back to this community and to the Specialist Commissioning Board at regular intervals about progress in achieving the agreed objectives. The Network Chair will also, when necessary, bring specific proposals to the group of Chief Executives for agreement by the wider community.

The Review Implementation Group developed a work programme organised around the following network priorities:



1. Haemoglobinopathy Registry
2. Counselling Services
3. Role of Managed Clinical Network
4. Clinical Care Pathway/Standards
5. Specialist Centre(s)
6. Psychological Services
7. Local Authority (Education, Housing & Social Work)
8. Integration with the rest of London
9. Child Health and Community Services
10. Successful Completion and Implementation of Group Objectives



Picture of delegates discussing network priorities at a recent consultation



Local Multidisciplinary Team Sub-group agrees the agenda of the network

A local haemoglobinopathy group has met since 1995 under various names. Its main purpose is for sharing information about clinical practice, with a specific focus on the work of the Haemoglobinopathy specialist nurses in West London in order to facilitate optimal care of patients with Sickle Cell & Thalasemia in West London.

Professor Inderjeet Dokal, the chair of the local multidisciplinary team subgroup writes, "the current major issues in haemoglobinopathy services are access to genetic counselling, social work and the clinical register. Various other matters arise in relation to the care of the patients and communications between services."



Picture of Dr Asa'ah Nkohkwo, Director Sickle Cell Society, answering questions from patient representatives during an annual network conference.

A survey of patients' views conducted by the Sickle Cell Society in 2005 showed:

- Services are still dependent on which hospital a sufferer is treated at and the treatment is patchy.
- It is important to look for a standard approach when sufferers present at A&E, especially with regard to pain.

If you would like to make any comments on this newsletter, please contact Mabel Alli, Tel: 07974598122 or Email: communications@brentpct.nhs.uk

We're on the Web!

See us at:

www.haemoglobinopathy.org

ANNUAL NETWORK STUDY DAY 2006

This year's network day is on Wednesday 5th July 2006. Please

Adult Pain Protocol

If you are a patient, you can now print out your own copy by visiting our website: www.haemoglobinopathy.org

North West London Haemoglobinopathy Managed Clinical Network

Terms of Reference

The Haemoglobinopathy Network has the following key objectives –

- a) To ensure that haemoglobinopathy services develop to meet national standards, and are consistent and of high quality services across the sector, with clear routes to tertiary care.
- b) To establish support for a sector-wide approach to planning, commissioning and assessing the performance of haemoglobinopathy services and to develop robust mechanisms for involving the

public, patients and carers and local authorities

The network board meetings occur on the following dates in 2006: March 9th, June 6th, September 5th and December 5th at the Wembley Centre for Health & Care.

Please contact:

Rita.McCluskey@brentpct.nhs.uk for minutes and the agenda.

Back on track

The Haemoglobinopathy News is back!

This is the 1st publication since the service review of December 2004. We hope to produce 2 issues per year – summer edition in July, and winter edition in January.

Published by the network coordinator Dr Mabel Alli, this newsletter is provided to promote communications in the sector amongst participating acute trusts, PCTs and local councils.

A network management team supports the network coordinator. The members are:

- **Dr Judith Stanton**, Director Public Health Brent Teaching PCT
- **Ms Jean Bradlow**, Director Public Health Harrow PCT
- **Mr David Kemsley**, lead specialist commissioner Hillingdon PCT