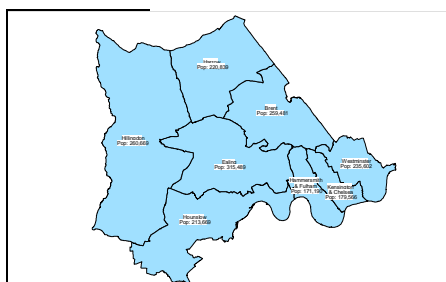


Managed Haemoglobinopathy Clinical Network



Newsletter No4 April

2003

Meet the members of the Steering Group

- **Chair:** Dr Zach de Beer Director Public Health Brent PCT
- **Secretary:** Dr Mabel Alli, Network Co-ordinator,
- **Haematologist**
Dr M. Layton / Dr I. Dokal
- **User representatives**
Mr Patrick Ojeer (parent SCD patient), Hammersmith
Mrs Malkhani (parent Thallaesaemia patient), Harrow
- **Counsellor**
Ms Jean Griffiths (Richford Gate HC, Hammermith & Fulham PCT)
- **A&E Department**
representative to be advised
- **Social Services**
representative to be advised
- **Children's Services**
Mr Frank O'riel, Dep Director Children & Maternity services, Ealing PCT
- **NHS Haemoglobinopathy Screening Program (London)**
- **Health Visitor**
- **Register**
Prof Sally Davies,
- **Specialist Commissioning**
Mr David Kemsley, sector lead Hillingdon PCT
- **The Chair of the two local groups**
Prof Elizabeth Anionwu, Group A
Dr Jo Howard, Group B



DrJo Howard and Mr Patrick Ojeer captured at the last protocol group meeting.



Back row: Tania Dasgupta, Mabel Alli
Front row: Emma Quarshie and Jean Griffiths at the recent Expert Patients Programme (EPP) launch held on Friday 2nd of May in Brent PCT

What you decide at the July 2nd Annual Conference will make a vital difference to our Network

Venue for this event is Wembley Centre for Health and Care,
Boardroom
116 Chaplin Road, Wembley HA0 4UZ.
9:00am to 12 noon.

Please complete the registration form we have sent to you and return it today. You can also phone in your registration or fax it to: Mecheal Wickam

Tel 020 8795 6780 / 6748
Fax 020 8795 6751

With your active participation on **July 2nd** we can move faster towards seamless care across borough boundaries. This will make a huge difference to many thousands of patients and their families struggling to live with sickle cell and thalassaemia.

The Network is seriously underfunded

Last year individual PCTs did not allocate money for expanding the register and community counselling services. Therefore in 2003/2004 we are hoping to go for joint commissioning, and in particular specialist centres (1 per sector in London).

Your contribution to the open consultation on **July 2nd** for a London-wide perspective on Haemoglobinopathy services from screening to clinical care, could bring the funding we need closer.

This newsletter aims to facilitate communications between members of the network. Four issues are produced annually in July, October, January and April. Please send short articles to Dr Mabel Alli Network co-ordinator.
Tel 020 8795 6749
Fax 020 8795 6751
Email mabel.alli@brentpct.nhs.uk

❖ STEERING GROUP TERMS OF REFERENCE

- The steering group shall meet at least twice a year.
- It shall approve the network 3-yr delivery plan 2003-6 as the network stems from the workplan
- It shall review the work undertaken by the network manager and the management team on an annual basis
- It shall approve the establishment of themes and project groups for a timely achievement of network objectives
- It shall recommend strategy (is) for the way forward to stakeholders every year
- It shall set priorities working with the two local haemoglobinopathy groups in a systematic way.
- It shall report to individual Trusts & PCTs for commissioning needs, and from 03/04 joint specialist commissioning.
- It shall report to the NWLHA board for linkage with similar networks in other sectors of London and with the public health networks.
- It shall ensure that the core elements of the network are in place which include:
 - clear management arrangements as stipulated above
 - supporting primary care in their role, starting with GP training about pathways for referral purposes
 - defined service configuration and evidence-based patient pathways to ensure seamless care are received by patients
 - patient expectations defined as part of care pathway resulting in improved patient satisfaction
- It shall facilitate the driving of a London consortium for commissioning specialised elements of the haemoglobinopathy service, in particular Specialist Centres (1 per sector)