

Haemoglobinopathy News



Issue 6
October 2003

First Annual Report 2002/3 Achievements

- Since the network started in April 2002, we have developed an Acute Care Network for management of sickle crisis including A & E.
- An information network is in progress with an initial fact-finding mission for meeting the social needs of patients..
- For the first time, we have an idea of the age distribution of patients in the four local hospitals that have joined the *haemoglobinopathy register* pilot. All these statistics are useful for service planning, and we wouldn't have them without the register.
- Hand-held records for patients and patient summary from the register, as means of easing access to individual patient records regardless of where patient is seen.
- Annual Stakeholders' Conference.
The second annual conference hosted by Brent PCT was held on 2nd July 2003, chaired by Professor Elizabeth Anionwu *CBE*.
- Initial meetings of the Steering Group.
The steering group is responsible for the strategic direction of the network and has held a series of meetings throughout the year.
- Two Local Haemoglobinopathy Sub-Groups collaborated with the steering group.
Local Group A: Hammersmith Hospital, West Middx University Hospital, Ealing Hospital, Queen Charlottes & Chelsea Hospital, Ealing PCT, Hounslow PCT, Hammersmith & Fulham PCT and Westminster PCT.
Local Group B: Central Middlesex Hospital, Northwick Park Hospital



Visit our new website on www.haemoglobinopathy.org

See overleaf for Plans for 2003/4

Plans for 2003-4

- Expansion of pilot research register to become sector-wide.
- Ensure equitable provision of specialist counsellors across all PCTs
- Equitable provision of social workers and psychologists throughout the network.

An audit conducted in May-June 2002 has identified gaps.

Recommendations to PCT Boards beyond noting the Annual Report

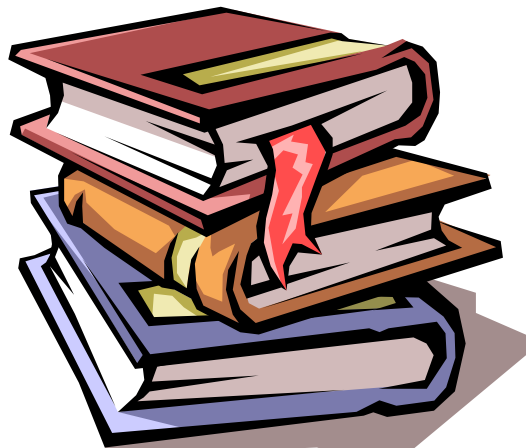
“That action plans for Sickle cell/Thalassaemia service provision are identified as an example of relevant services within the **Race Equality Scheme** of each Trust in respect to the Specific Duties that the Home Secretary has imposed on certain public authorities (such as NHS Trusts) that state what they must do in order to comply better with the general duty of the Race Relations (Amendment) Act 2000. One of them is “to monitor their policies to see how they affect race equality”. Professor Elizabeth Anionwu *CBE, Chair*



Congratulations

to Professor Inderjeet Dokal who recently became a Professor of Haematology at the Hammersmith Hospital.

Prof. Dokal's picture appears on the left.



FUTURE MEETINGS:

- 18th Nov:** NWL Specialist Commissioning Board
- 27th Nov:** Network Local Group B Brent
- 26th Jan:** Network Local Group A Ealing

Visit our new website on www.haemoglobinopathy.org

We have changed the format of this newsletter and would like your comments on it.
Contact Mabel Alli on 020 8795 6749 or Communications@brentpct.nhs.uk