

Haemoglobinopathy News

Remodelling community services

PCT representatives to agree service model for a specialist nursing network across NW London

Rationale for Specialist Community Nursing

By

Ms Lola Oni

**Professional Services Director,
Brent Sickle Cell & Thalassaemia Centre
Tel: 020 8961 9005**



A **meeting** was held on June 28th 2006 at the Brent Teaching PCT in Wembley.

Picture shows Ms Jean Bradlow, chair of the network board and Director Public Health Harrow PCT leading the discussions. Also in the picture are: Ms Emma Sutcliffe, Community Nurse leader Hammersmith & Fulham PCT; Ms Norma Golding, Head of Nursing Kensington & Chelsea PCT; Ms Shirley Jenkins, Health Visitor Clinical Coordinator Harrow PCT; Dr Mabel Alli, network coordinator Brent Teaching PCT and Ms Jane Hibbert, Regional Antenatal Screening Coordinator East of England.

The sickle cell and thalassaemia clinical standards allude to the following rationale for use of specialist nurses in support and management of patients with haemoglobinopathies:

- Results should be given by 6 weeks of age and a referral to the paediatrician by 2 months of age
 - Children with sickle cell disease should commence prophylactic penicillin by 3 months of age
 - Parents should be given appropriate genetic and health counselling by a suitably qualified professional
 - Families require comprehensive education about the condition and how to manage and prevent complications, handicap, mortality and morbidity
 - All who failed to attend OPD should be followed up after 'one' missed appointment
- (Continued on page 2)**

Rationale for Specialist Community Nursing (continued from page 1)



- UKTS suggest that one 'Key Contact' health professional must be designated for each family / individual
- Health promotion resources must be produced and provided to support care
- Families need training in management of chelation therapy in the community
- Clarke (1991) commends the unique feature of Specialist Haemoglobinopathy Nursing, the author suggest that the combined genetic and clinical specialist role offers better support and care for families

Children and adults require long term management, education support and care. Community education is a crucial part of the client management. The role of the Specialist Haemoglobinopathy Nurse extends to the education of the family, outside carers (e.g. schools, colleges, and university), the public, health and allied professionals who come into contact with the clients.

Picture of PCT representatives discussing service remodelling for specialist nursing network during the 28th June 2006 meeting.

From left to right-
Ms Sharon Mensah, Ealing PCT; Ms Helen Hosking, Hillingdon Hospital; Dr Hilary Angwin, Welwyn Hatfield PCT; Ms Lola Oni, Brent Sickle Cell & Thalassaemia Centre; and Mr Andrew Benstead, North West London Hospital NHS Trust



SICKLE CELL DISEASE IN CHILDHOOD

Audit Standards

1. Penicillin Prophylaxis

90% of infants should have been offered and prescribed Penicillin V (or alternative) by 3 months.

2. Pneumococcal immunisation

95% of infants should have completed the primary Prevenar (conjugate pneumococcal vaccination) course by 15 months

3. Transcranial Doppler scanning (TCD)

90% of sickle cell centres should have the capability of offering annual TCDs to children with sickle cell disease from the age of 3 years by 2008

4. Failsafe arrangements

By 2008, 95% of sickle cell centres and local hospitals should have robust follow up arrangements to identify and follow up any child who does not attend their hospital appointments



Picture of Ms Lola Oni OBE, making a presentation to PCT representatives about the proposed specialist nursing network in North West London

Helping NW London to deliver standards for clinical care of Sickle Cell Disease and Thalassaemia

The Network Annual Study Day will be held on Wednesday July 5th to explore high impact, easy to do activities for meeting the standards. A network business plan will be prepared after the study day. For a copy of this business plan, please contact Rita, Tel: 020 87956780 Email: Rita.McCluskey@brentpct.nhs.uk

Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK

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

If you are a patient, you can print out your own copy by visiting UKTS website: www.ukts.org. Click on the section marked UKTS PDF Library.
Or Tel: 020 8882 0011
Email: office@ukts.org



Summary of Thalassaemia Standards

Section A: Organisation of thalassaemia services

- Thalassaemia as a long term condition
- A network for care

Section B: Core Management

- Initial management of the newly diagnosed infant.
- Decision to start regular transfusions
- Red cell transfusions
- Iron load, monitoring and treatment
- Psycho-social issues
- Acute clinical presentation in the treated patient.
- Referral for consideration of bone marrow transplant
- Surgery including splenectomy
- Transition from paediatric care and management of adults

Section C: Prevention and management of complications

- Cardiac complications
- Endocrine complications
- Liver complications
- Bone complications.
- Fertility, and management of pregnancy.

Section D: Specialist Review

- Annual review at Specialist Thalassaemia Centre.
- Review of patients previously treated outside the UK

Section E: Management of thalassaemia intermedia

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www.haemoglobinopathy.org

**NETWORK
BOARD
MEETINGS FOR
REST OF 2006**

5TH September and
5th December