

Haemoglobinopathy News



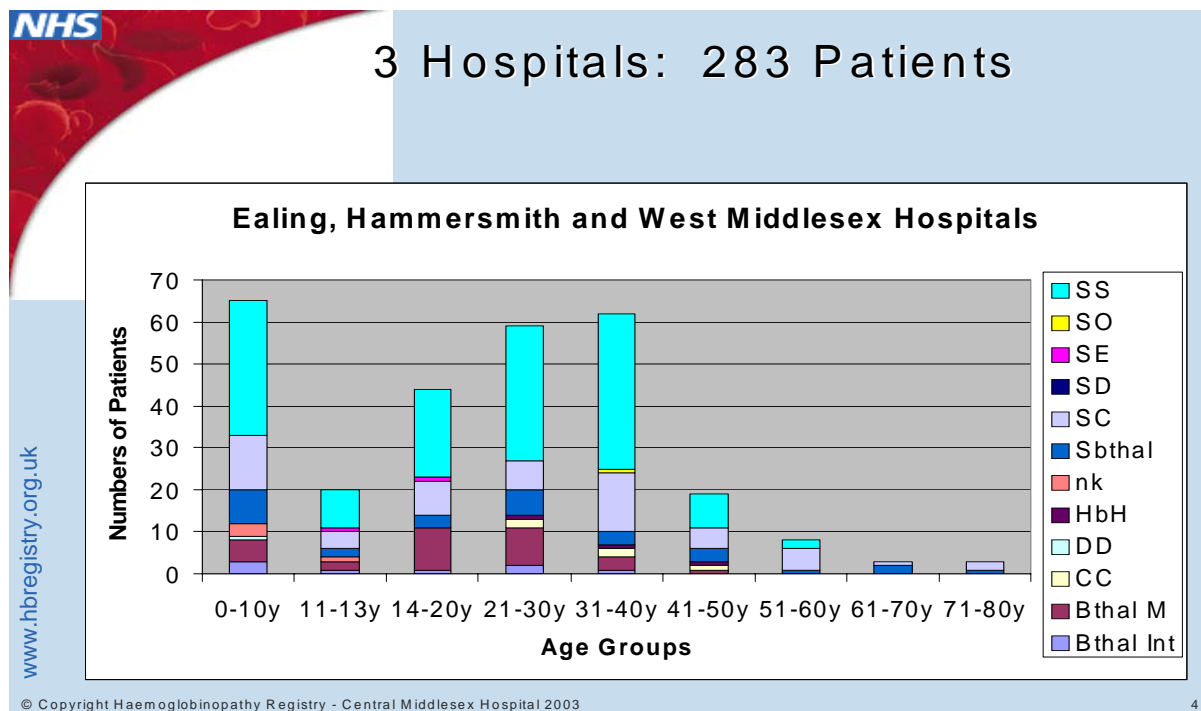
Issue 5 July 2003

Improving Standards

Progress in 2002

Dr Mark Layton, Consultant Haematologist in charge of the Hammersmith Hospital – based pilot of the register has had recent cause to celebrate. For the first time we have an idea of the age distribution of Sickle Cell and Thalassaemia patients in the three hospitals that have joined the register. This means we can plan better plan for the large group of young adults going to be at risk for chronic conditions and needing appropriate services. See Graph below. We urge the other hospitals in the sector to join the register as we endeavour to expand this project further which will help us develop a more comprehensive service.

Graph of Demographic Information for Monitoring & Service Provision:
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Visit our new website on www.haemoglobinopathy.org

WANT TO JOIN THE REGISTER? Visit website at www.hbregistry.org.uk

Agreed Outcomes of the Annual Conference

56 people attended the recently concluded annual conference on July 3rd

It was agreed that:

- Psycho-social needs of patients are huge. In the past efforts have been thin, isolated and scattered. Future aim is to promote access to welfare benefits like financial help, Blue badge etc for patients in need. A Project Group should look at where benefits are at the moment and advise.

- More should be done to explore the impact of Sickle cell & Thalassaemia on families with child sufferers.

- The most important role of the network in the next three years is to improve delivery of agreed standards of service in all hospitals and PCTs in the sector.

- Wider groups are to come on board to share current and new developments

- Every sector should network with each other for pan-London benefit.

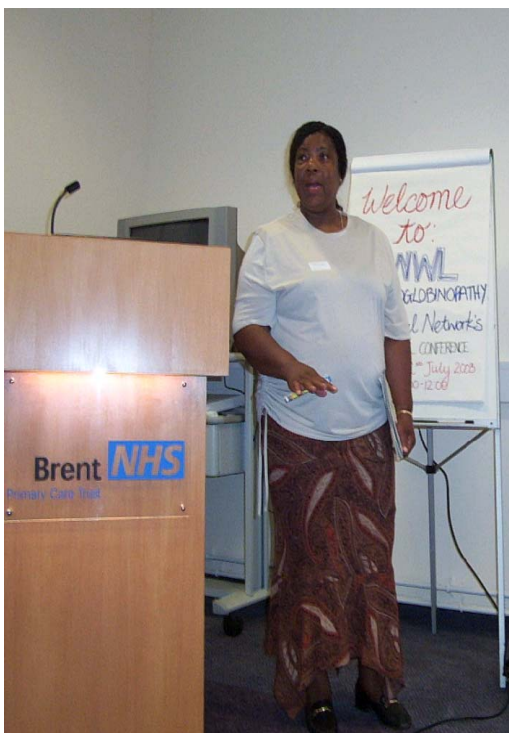


L/R Annette Gilmore and Priscilla Plocki who run the Register pictured above



The Audience during the Conference
- thanks to all who attended. -Ed

Better Life for child sufferers of sickle cell & Thalassaemia.



Picture on the left shows Ms Emma Quarshie, Specialist Nurse for Hounslow, during a local workshop she organised for child sufferers and their siblings. The workshop was about coping with sickle cell in the family .

FUTURE MEETINGS

4TH Sept: Network Local Group B, Brent

29th Sept: Network steering Group

6th Oct: Network Local Gr A, Ealing

9th Oct: Protocol Group

16th Oct: Registry Board



FOR COMMENTS on the newsletter ,
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