

**NOTE OF THE RECOMBINANT CLOTTING FACTORS WORKING
GROUP HELD AT 2PM ON THURSDAY 18 DECEMBER 2003, ROOM 117
EILEEN HOUSE, ELEPHANT AND CASTLE**

Present:

Richard Gutowski	Department of Health - Chairman
Julia Stallibrass	Department of Health
Karin Pappenheim	Haemophilia Society
Chris Hodgson	Haemophilia Society
Dr Charles Hay	UKHCDO
Professor Frank Hill	UKHCDO
Sybil Hirsch	UKHCDO
David Kemsley	London & SE Haemophilia Consortium
Dr Susan Schonfield	Croydon PCT
Diana Saunders	Haemophilia Commissioner – South West
Christine Harrington	RCN Haemophilia Nurses Association
Sunny Kathuria	Department of Health
Zubeda Seedat	Department of Health

WELCOME, INTRODUCTIONS AND APOLOGIES

1. Apologies were received from Carl Ashworth, **GRO-A** Andrew Whittome, Claire Bradford, Mike Maunder, and Mark Winter. The Chairman welcomed Sybil Hirsch who was appointed project manager at UKHCDO to assist with the roll-out.

MINUTES OF THE PREVIOUS MEETING

2. The note of the previous meeting was agreed subject to a correction at paragraph 9 which should read “5 September”.

COMMENCEMENT OF ROLL-OUT PROGRAMME

3. Frank Hill provided a summary of the work undertaken during the year to facilitate the roll-out of recombinant eg. the collection of data on patient usage, verification of data by PCT and commissioners, and modelling of data to help with negotiating the national contract.

4. Members were informed that the roll-out was expected to start early in the new year now that a decision had been made pending a judicial review. In summary, for year one and two all adult patients born between 2 April 1962-26 February 1982 can be changed to recombinant products. The roll-out will be extended to patients born before 2 April 1962 in the third year of the roll-out (2005-06). Inhibitor patients will also be addressed in 2005-06. It was proposed that an inhibitors working group would be set up to consider the issues.

5. Frank Hill explained that UKHCDO would circulate a detailed letter to Haemophilia Centre Directors prior to the roll-out, so that there was clarity about the amount of stock to be ordered and to explain the rationale behind the calculations.

6. DH tabled a draft letter to be circulated to Chief Executives about the allocation of money to PCTs. It was suggested that the letter should stress the need for PCTs to establish risk sharing through specialised commissioning groups to help them minimise their risks. DH confirmed that a cash limit adjustment/resource limit adjustment letter would be issued to PCT's to confirm their allocations.

7. Members of the group stressed the need to monitor the roll-out. Richard Gutowski confirmed that a monitoring group would be set up.

PROPOSALS FOR THE SUB-GROUPS

8. Richard Gutowski proposed that a new monitoring group and an inhibitors working group should be set up in the new year. He would write to members seeking nominations.

ANY OTHER BUSINESS

9. vCJD Statement - Richard Gutowski provided a report on the statement by the Secretary of State for Health on 17 December about the first possible case of vCJD transmission through blood transfusion. A copy of the statement had been sent to the Haemophilia Society and the UKHCDO.

DATE OF NEXT MEETING

10. To be arranged.