

**NOTE OF RECOMBINANT CLOTTING FACTORS WORKING GROUP
HELD AT 10AM ON THURSDAY 10 APRIL 2003, ROOM 117 EILEEN
HOUSE**

Present:

Charles Lister	Department of Health – Chair
Karin Pappenheim	Haemophilia Society
Dr Frank Hill	UKHCDO
Dr Charles Hay	UKHCDO
Christine Harrington	RCN Haemophilia Nurses Association
David Kemsley	London & SE Haemophilia Consortium
Dr Susan Schonfield	Croydon PCT
Mick O'Donnell	Haemophilia Commissioner – West Midlands
Mike Maunder	Haemophilia Commissioner – North Tyneside
Steve Davies	NHS Purchasing & Supply Agency
Dr Mark Winter	Haemophilia Alliance
Dr Claire Bradford	Newcastle PCT
Carl Ashworth	Haemophilia Commissioner - Manchester
Andrew Whittome	Guy's & St Thomas'
Zubeda Seedat	Department of Health

WELCOME, INTRODUCTIONS AND APOLOGIES

1. Charles Lister welcomed members to the second meeting of the working group and Andrew Whittome to his first meeting.
2. Apologies were received from GRO-A, Chris Hodgson, Sophie Heiser, and Trudi Mann.

MINUTES OF THE LAST MEETING

3. The note of the previous meeting was agreed. Charles Lister proposed that the membership and remit of the group, the minutes of meetings and other relevant documents (eg the agreed statement on patient priority order) should be posted on the DH website. This would enhance the openness of the decision-making process and enable PCTs, clinicians and patients to stay in touch with developments. This suggestion was supported by the group.

Action: Secretariat to set up a link on the DH website.

REVISED REMIT & MEMBERSHIP

4. The remit and the membership of the group had been revised to reflect comments made at the last meeting. Mick O'Donnell suggested that the words "...on a ad hoc basis..." should be amended to "...on a continuing basis...". This was agreed.

Action: Secretariat to revise the draft remit.

PATIENT PRIORITY ORDER

5. Charles Lister invited comments on the draft statement explaining the rationale for the group's decision on patient priority order. The statement was primarily targeted at haemophilia patients. In discussion the following suggestions were made:

- there should be clarity on why recombinant products were being provided to adults over the age of 22;
- the statement should set out the composition of the group;
- there should be reference to the proposed link on the DH website;
- the last sentence was considered to be too optimistic, the group should avoid raising false expectations;
- the statement should stress that giving first priority to those infected with HIV would involve associating treatment for haemophilia patients with the confidential nature of their condition;
- the statement should refer to co-morbidity, instead of a specific condition such as HIV;
- the statement should stress the ethical issues involved if priority were given to patients with HIV and emphasise that phasing by age group was the most equitable way forward.

6. Charles Lister asked the group to suggest wording on the messages the group should convey to patients on the transition period. Members of the group were invited to provide any additional suggestions to the secretariat. A revised draft statement would be circulated to members of the group for further comment.

Action: Members to suggest any additional comments by e-mail.

Action: Secretariat to redraft the statement for consideration in advance of the next meeting.

NATIONAL CONTRACT/TENDERING SUB GROUP

7. At the last meeting it was agreed that there should be a national contract with all the manufacturers for recombinant factor VII & IX to be purchased with the new money. It was agreed that a small sub-group would be set up to support PASA in the management of the tendering process. The following members agreed to support Steve Davies of PASA: Charles Hay, Karin Pappenheim and Carl Ashworth. It was suggested that the sub-group should include representation from a Trust. Charles Hay suggested Linda Roberts, contract manager at Central Manchester, Manchester Children's Trust. Members of the tendering sub-group would meet to discuss the timetable for the tender and to have a preliminary discussion on the specification for tender. They agreed to provide a report at the next meeting.

8. The group had previously agreed to use the accelerated tendering procedures. Steve Davies suggested that Charles Lister should write to PASA requesting the use of accelerated tendering. This would require the approval of PASA's Chief Executive.

9. Charles Lister said that he would be attending the next joint DH/Collaborative Commissioning Groups (CCGs) meeting on 25 April to seek their views on the proposal. Charles Hay had sought, on an informal basis, the views of UKHCDO members.

Action: Secretariat to write to PASA requesting the use of the accelerated tendering procedure.

Action: Steve Davies to invite Linda Roberts to join the tendering sub-group.

Action: Tendering sub-group to report on progress at the next meeting.

ALLOCATION OF FUNDS TO PCTS

10. The group considered the paper on options for the allocation of resources to PCTs. Charles Lister explained that these were off the cuff ideas intended to stimulate discussion rather than firm proposals. The Department's central finance unit which deals with allocation of resources to PCTs would assist the secretariat in working up proposals once the group had formed a view of how they would like to see the money allocated.

11. Members expressed a strong preference for targeting money to PCTs in line with patient population, using lead commissioning arrangements to provide greater flexibility in the management of resources. It was agreed that further discussion should wait until data had been collected on patients by PCT.

12. The phasing in strategy would require close monitoring at PCT level on an on-going basis over the three-year period. It was suggested that a framework for monitoring should be discussed at the next meeting.

DATA COLLECTION

13. Dr Hay presented a revised proposal. This showed that under the age based strategy all haemophilia A and B patients up to the age of 33 could be on recombinant in the first year. The proposal for the first year was costed at £12.8m. The group agreed that it would be equitable to begin the roll out by including patients with haemophilia A and B.

14. Given that there were still gaps in the data which prevented the group from validating the proposals, it was agreed that the UKHCDO would ask Centres to provide the following information for all haemophilia patients over 22:

Date of Birth;
The PCT post code;

The GP practice code;
Usage in the last financial year;
Who the existing supplier is if plasma derived products are used.

Frank Hill agreed to write in the next week, requesting information by early May and to present an analysis for the next meeting of the working group.

Action: UKHCDO to ask centres for data to help with the allocation of funds.

DH GUIDANCE

15. Once the phasing strategy had been firmed up, the Department planned to issue guidance to PCTs explaining the purpose of the funding, how it was being allocated and the requirements for the first year of the phasing process. The group were made aware that in some centres, some patients under 22 had not been placed on recombinant. It was agreed that this issue would also be picked up in the guidance. Charles Hay suggested that guidance should also be issued to haemophilia centres, to make them aware of the requirement to operate within a national framework.

DATE OF NEXT MEETING

16. The next meeting would be at 12:30pm on Tuesday 13 May 2003 in room 117 Eileen House.