

Mann Pat (RQ3) BCH

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Subject: Recombinant Clotting Factors Working Group



RWG Agenda 18 Dec.doc



RWG - Minutes 9 Sept.doc

I attach the agenda for the meeting on Thursday 18 December and the note of the last meeting. We will table a copy of the letter about the roll-out to Chief Executives of PCTs, Hospital Trusts, Strategic Health Authorities, Local Specialised Commissioning Groups and Specialised Commissioning Groups at the meeting.

Can you please note that lunch will be available from 1pm.

Thanks
 Zubeda

(See attached file: RWG Agenda 18 Dec.doc) (See attached file: RWG - Minutes 9 Sept.doc)

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RECOMBINANT CLOTTING FACTORS WORKING GROUP

**MEETING: 2PM, THURSDAY 18 DECEMBER ROOM 117 EILEEN HOUSE,
ELEPHANT & CASTLE, LONDON, SE1**

AGENDA

1. Minutes of the 9 September meeting - attached
2. Commencement of roll-out programme
3. Proposals for the sub-groups
4. Any Other Business
5. Date of the next meeting

**NOTE OF THE RECOMBINANT CLOTTING FACTORS WORKING
GROUP HELD AT 11:00AM ON TUESDAY 9 SEPTEMBER, ROOM 136B
SKIPTON HOUSE**

Present:

Richard Gutowski	Department of Health - Chairman
Karin Pappenheim	Haemophilia Society
Chris Hodgson	Haemophilia Society
Dr Charles Hay	UKHCDO
Professor Frank Hill	UKHCDO
David Kemsley	London & SE Haemophilia Consortium
Dr Susan Schonfield	Croydon PCT
Mick O'Donnell	Haemophilia Commissioner – West Midlands
Natalie Howell	NHS Purchasing & Supply Agency
Emily Costello	NHS Purchasing & Supply Agency
Dr Claire Bradford	Newcastle PCT
Dr Mark Winter	Haemophilia Alliance
Mike Maunder	Haemophilia Commissioner – North Tyneside
Andrew Whittome	Guy's & St Thomas'
Sophie Heiser	Haemophilia Commissioner - Croydon
Diana Saunders	Haemophilia Commissioner – South West
Zubeda Seedat	Department of Health

WELCOME, INTRODUCTIONS AND APOLOGIES

1. Apologies were received from Carl Ashworth, ~~Paul Bauman~~, Christine Harrington and Trudi Mann,

MINUTES OF THE PREVIOUS MEETING

2. The note of the previous meeting was agreed.

MATTERS ARISING

3. (Para: 4) Charles Hay had contacted the Macfarlane Trust to reconcile the accuracy of the data. A comparison of the Macfarlane Trust database and the UKHCDO database indicated that the Macfarlane Trust had only 16 deaths which the UKHCDO were unaware of, whereas the Macfarlane trust were unaware of 70 deaths known to the UKDCHO. There were also a couple of minor discrepancies which had been resolved. However, it was clear that the UKHCDO data was fairly complete.
4. (Para 13) Richard Gutowski confirmed that he had consulted with lawyers about the decision to roll-out recombinant products by age group, and subsequent comments that the decision was discriminatory. The advice received was that the roll-out was not in breach of Article 14 of the European Convention on Human Rights.

PROGRESS REPORT ON THE NATIONAL TENDER

5. Emily Costello reported that PASA had produced a briefing note on their website about the contract following queries from customers and suppliers. The weblink was available at www.pasa.nhs.uk.

6. Members of the UKHCDO Advisory Committee would be asked to agree the draft contract at a meeting on 15 September; the purpose of this was to ensure that the contract was supported from a clinical perspective. The aim was to place the contract by 1 October.

7. The contract would be placed with the four main suppliers: Aventis, Baxter, Bayer and Wyeth to ensure security of supplies. The group noted comments about the volatility of the international markets. Susan Schonfield said that the group would need to carefully monitor the impact at PCT level and for the group to identify on-going risks during the roll-out period. In discussion, some members of the group talked about 'risk shared arrangements' between PCTs to help minimise financial risks.

8. Richard Gutowski confirmed that a sub-group would be set up to monitor the roll-out. A sub-group will also be set up to address the treatment of inhibitor patients.

UKHCDO DATA COLLECTION AND ANALYSIS

9. The data collection exercise by UKHCDO was almost complete. The data was sent to Haemophilia Commissioners for verification on 5 ~~December~~ ^{September}. UKHCDO confirmed that those patients between 35-40 were expected to be treated in the first year of the roll-out.

ANY OTHER BUSINESS

FUTURE OF THE WORKING GROUP

10. Richard Gutowski proposed that he would set up a number of small sub-groups to address monitoring the roll-out, guidance to Centre Directors & Chief Executives and on the treatment for inhibitor patients. He suggested that the working group should meet again in December.

HEPATITIS C PAYMENT SCHEME

11. Richard Gutowski informed the group that he would take forward arrangements to establish a payment scheme following the decision by the Secretary of State on 29 August to establish a financial assistance scheme for people infected with Hepatitis C as a result of being given blood products by the NHS. Richard Gutowski confirmed that discussions would take place with the Haemophilia Society and the Macfarlane Trust.

DATE OF THE NEXT MEETING

12. The next meeting has been arranged for 18 December 2003.