MINUTES OF THE SECOND MEETING OF THE NBS vCJD STEERING GROUP HELD AT OAK HOUSE, WATFORD ON MONDAY 2ND APRIL 2001

PRESENT: Marcela Contreras
Roger Eglin
Peter Garwood
Martin Gorham (Chair)
John Kearney
Jim Moir (Communications)
Mike Murphy
Liz Reynolds
Lorna Williamson
Jane Minifie (Minutes)

1. Apologies had been received from Liz Caffrey, Pat Hewitt, Terry Male, Angela Robinson and Charles Lister. (JK, MM and LR left the meeting before the end).

2. **MINUTES OF THE LAST MEETING**

The minutes of the last meeting were agreed.

3. **MATTERS ARISING**

3.1 **Risk Assessments**

MG said he had written to the DoH and would be meeting the head of the EOR team on 30th April. He proposed contacting them in the meantime to ask them to proceed prior to confirming details at the meeting. **Action: MG**

3.2 **Actions to minimise the risk that vCJD could be transmitted by transfusion – SNBTS submission for MSBT on 22nd January**

MG had chased but the letter from MSBT had still not been received. Minutes of the meeting had not yet been circulated.

MG would raise the broad issue of the the NBS's interface with the DoH's arrangements for vCJD at the UK Co-ordinating Group on 6th April and then consider further discussions with the DoH. **Action: MG**

MG to check with EAER on points 4, 5, 6 and 9 which were to be considered by the Appropriate Use Sub Group. **Action: MG**

It was necessary to ensure the points under point 12 of submission to MSBT are picked up. **Action: MG EAER**

No members had made additional comments following a re-reading of the submission after the meeting.

3.3 **OTHER MEETINGS**

RE reported that no hard information on tests in preparation was forthcoming. However it was apparent that a range of different approaches were being undertaken and it was hoped that these would result in a range of assays being available in 18 months to 2 years time.

4. **PROJECT SUPPORT**

MG said he and PAG had discussed at length arrangements for support of the project. They had concluded that, apart from the Steering Group, there were three elements to the management of the project which would be handled best by three different individuals.

The first individual was the Project Manager. A group of new project managers was joining IT&F on 2nd April and one of these would be allocated to this project in the next two to three weeks.

The second individual would provide overall supervision of the project and be responsible to the Steering Group. This required someone with knowledge of the issues, the NBS and the various linkages. It was planned to fill that from our own existing resources and a senior member of staff had been approached; a response was expected within the next few days.

The third individual would review and challenge the project on behalf of the Board, with probably a quarterly review by the Board. This would be an NBA non-Executive or an external appointment.

The group were content with this approach and it was agreed that MG and PAG would work up a formal proposal for approval against PRINCE. **Action: MG PAG**

5. **RISK ASSESSMENTS**

At this point MG gave a summary of the recent judgement on the HCV litigation. He agreed to produce a written version for circulation as appropriate. It was suggested that this could be included in 'Blood Matters' although it was noted that the article may need to be approved by the DoH and NBA lawyers. **Action: MG**

The points which had come out during the litigation would affect some of the balances in risk assessment in the future. There was a discussion which included the following:

- decisions on testing would need to be taken against the background of scientific opinion; cost effectiveness; and public opinion;
- DoH committees' timescales;
- the need to assist the various committees to consider individual proposals within the context of an overall view.

LW had circulated a paper listing blood safety issues other than vCJD, with some details of incidence and possible actions together with her earlier paper which listed the

variables against which possible actions would need to be considered. It would be important for the prioritisation of vCJD actions to take place within the overall framework of all potential actions. There was a discussion and a number of comments on both papers were noted by LW. It was agreed that revised versions of the papers would be submitted to the Executive for consideration at its meeting on 19th April. Any additional information available to supplement the SHOT data in LW's list to be sent to her. **Action: LW All**

The discussion also covered the following points:

- It was necessary to check whether the possible interventions on bacterial contamination were being prioritised in his Donation Review. MG would do this before the next Executive meeting. **Action: MG**

- The new TM contracts include some capability for anti-HB core testing. PAG would follow up. **Action: PAG**

- Consideration of what action to take on TRALI would be affected by MSBT's decision on UK plasma. **Action: PAG**

- While the "wrong blood to patient" issue resided in hospitals it was important for the NBS to retain a focus on it with a view to influencing improvements.

- It would be necessary to propose implementation plans for the actions within the next few weeks, in order to introduce them to the NCG at an early stage. **Action: LR/All**

- It was agreed that EAER and MG would arrange to meet with Pat Troop. **Action: EAER**

- In the light of this list, it would be necessary to check that the existing sub-groups were still correct. **Action: MG**

6. UPDATES ON SUB-GROUPS

6.1 TISSUES, INCLUDING CORD AND STEM CELLS

JK presented the minutes of the meeting on 21st March and the Executive Summary of the Tissue Services Bone Risk Assessment Report, both of which had been circulated. The full Bone Risk Assessment Report would be sent to the DoH EOR group through the Steering Group. **Action: MG**

6.2 DONORS

The minutes of the meeting held on 5th February and 23rd March had been circulated together with some scenario flow charts and a media impact assessment for scenario planning. Scenario 6 was 'availability of a test' and it was agreed that RE would comment on this scenario prior to a review to establish next steps. **Action: RE**

The Donor sub group would work up scenario 5 (at least in part) and some of the other scenarios which were expected to become reality in the near future. **Action: LR**

6.3 TESTING

PAG presented the minutes of the inaugural meeting of the Testing sub group. There was a discussion which included the following points:

- The significant implications, including cost, other resources, and ethics, of developing an archive were brought to the attention of the group. It was agreed that MG would notify the DoH of these implications. It might be appropriate for the UK blood services to create a UK archive. MG would discuss this possibility with Ian Franklin. **Action: MG**

- The NBA would need ethical permission to carry out anonymous testing if this was considered appropriate. It was anticipated that the Board would require independent legal advice on this issue. It would be important that 'anonymous' was clearly defined. MC was in discussion with Terry Stacey (National Lead R & D Director for Ethical Committees) and she would report back to the Steering Group. **Action: MC**

- An initial assessment of costs was required at an early date in order to commence discussions with the DoH. **Action: PAG MC**

6.4 PROCESSING

The first formal meeting of the group would take place at the end of April but work on the SPIC project was ongoing. A paper would be going to the MSBT meeting on 19th April and this would be circulated. PAG highlighted some of the key points contained in the paper. In particular the increase in resources that might be required would not be easy to achieve and this issue would require attention.

6.5 APPROPRIATE USE

This group would meet for the first time on 3rd April and MM ran through the agenda. The steering group asked the sub group to cover the following points:

- the need for liaison between the autologous sub group and the UK autologous group;
- informed consent;
- alternatives to blood;
- possibility of including certain requirements in SLAs;
- the possibility of the NBS doing certain things for hospitals;
- medium/long term training issues;
- to consider whether NBS Consultants are carrying out duties that could be performed by others.

6.6 **R & D**

MC circulated the minutes of the group's meeting on 5th March. The steering group agreed to the proposed expansion of membership of this sub group. It was agreed that Jim Moir would be briefed after each meeting. **Action: MC**

7. **EXTERNAL GROUPS**

Most information had now been received. MG would provide a collated report for the next meeting. **Action: MG**

8. **PRIORITISATION OF OUTSTANDING AGREED ACTIVITIES**

The following additional actions were agreed:

8.1 MG would check with EAER regarding the current position on the issue of new advice for Consultants as to whether to notify patients of possible exposure to vCJD, the draft of which had been rejected by the chairman of the Clinical Incidents Panel. **Action: MG**

8.2 MG would arrange to meet with Nigel Crisp. **Action: MG**

9. **NEXT MEETING**

The next meeting will take place at Oak House on Friday 25th May at 10.30am.