

24

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Minutes of the SEVENTEENTH MEETING OF HAEMOPHILIA REFERENCE
CENTRE DIRECTORS held at St. THOMAS'S HOSPITAL on MONDAY
19th SEPTEMBER 1983 at 10.30 a.m.

Present:-

Professor A. Bloom (Chairman)
Dr. C.R. Rizza
Dr. I. Delamore
Dr. P. Jones
Dr. P. Kernoff
Dr. C. Ludlam
Dr. J. Matthews
Dr. F.E. Preston
Dr. G. Savidge
Dr. E. Tuddenham
Dr. R. Wensley
Dr. Diana Walford (DHSS)
Dr. J. Craske
Dr. A. Aronstam
Miss R. Spooner

Professor Bloom welcomed Dr. Walford, who had been invited to attend the meeting in view of the Department's interest in AIDS.

1. Apologies for Absence were received from Professor C. Prentice, Dr. E. Mayne, Dr. G. MacDonald and Dr. D. Winfield.

2. Minutes of the Sixteenth Meeting

Dr. Delamore requested that his name be added to the list of those present at the Sixteenth meeting. After this amendment had been made, the Minutes were approved and signed.

Professor Bloom read the Minutes of the Special Meeting regarding AIDS which had been held at St. Thomas's Hospital in May 1983. The Minutes were approved, and signed.

3. Matters arising from the Minutes

All matters arising would be dealt with as items on the Agenda.

4. Discussion document on the designation of Centres

Professor Bloom said that a start had been made in drafting a new document but was not yet finalised. He understood that the Haemophilia Society had now modified their views on decentralization of haemophilia treatment; the Society realised the distinct advantages of centralised treatment, especially when problems like AIDS arose. Professor Bloom suggested that the new draft document should be sent to the Reference Centre Directors for their comments before the February meeting and should be discussed in detail at that meeting. This was agreed. It was also agreed that the new discussion document should be mentioned at the October meeting of all Haemophilia Centre Directors.

5. Annual Returns for 1982

Dr. Rizza presented the documents which he and Miss Spooner had drawn up giving the provisional statistics available from the 1982 Annual Returns. There was some discussion regarding details in the report. It was requested that some more detailed analyses should be made regarding the materials used to treat the von Willebrand's disease patients and it was agreed that Miss Spooner would give these details to the Reference Centre Directors at the February meeting. Reference Centre Directors agreed that the preliminary report on the 1982 statistics should be presented to the Haemophilia Centre Directors at their meeting on 17th October.

6. Current situation regarding AIDS

Dr. Craske presented a paper he had written up-dating the situation regarding AIDS in the United Kingdom. The document was discussed at length and several points were raised. It was agreed that the patients who had received the same batches of NHS or commercial factor VIII as the patient who had died in Bristol, should be followed up. Dr. Craske said that the donors of the cryoprecipitate received by the Bristol patients were being traced. He would inform the Centre Directors of the batch numbers of commercial and NHS factor VIII received by the Bristol patient. Concern was expressed at the use of commercial concentrates at hospitals which were not Haemophilia Centres. It was agreed that although the Reference Centre Directors realised that there was nothing to prohibit the sale of the concentrates to any hospital, the manufacturers should be discouraged from selling material to hospitals that were not recognised as Haemophilia Centres.

Dr. Walford said that it was possible that some centralisation and control of supplies of commercial factor VIII concentrates would be introduced by the Department of Health and Social Security. The Supply Council had been asked to look into the problem and it was felt that there was a strong case for all orders of factor VIII, both NHS and commercial, to be made via the Blood Transfusion Service mechanism. Many of the Reference Centre Directors had grave misgivings about this scheme but since the DHSS recommendation had not yet been circulated, discussion of the subject was limited. Dr. Walford assured the Reference Centre Directors that they would be

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involved in any discussions regarding a new arrangement for the purchase and distribution of factor VIII. Professor Bloom suggested that an ad hoc meeting of Reference Centre Directors should be convened when the Department of Health's proposals were known. Also that the Reference Centre Directors should write to him with their views on the matter. This was agreed.

The position regarding the collaboration of the Haemophilia Centre Directors, Dr. Craske and the Communicable Disease Surveillance Centre (CDSC) was raised. Professor Bloom said that Dr. Galbraith, Director of CDSC, was somewhat concerned that he had not heard about the Bristol case until after the patient's death. Professor Bloom felt that it was the responsibility of the Haemophilia Centre Directors themselves to report directly to CDSC as well as to Dr. Craske regarding suspected AIDS patients. Differing views were expressed by the Directors. Some felt that the official body (CDSC) should be informed directly whereas others were concerned that the notification of suspected cases might result in unnecessary publicity and possibly even identification of patients by the press. Dr. Walford said that the Department of Health relied on the CDSC for confirmation of cases. After discussion it was agreed by a majority that reporting to CDSC should be through Dr. Craske, after discussion with the Director involved in the patient's management.

Dr. Craske outlined the proposals he had set out in his document AIDS/7 regarding an investigation of the epidemiology of the Acquired Immune Deficiency Syndrome in patients with bleeding disorders. The importance of collecting complete

9 p

data was stressed as was the need for a properly conducted epidemiological study of the haemophilic population. Attention was drawn to an International study which would shortly be underway; Dr. Jones and Dr. Forbes were both taking part in this study.

Mr. Watters of the Haemophilia Society had asked Professor Bloom for an up-date of the AIDS circular which was sent out in May for distribution to all the Society's members. Professor Bloom read through the document he had prepared for the Society and this was approved by the Reference Centre Directors.

7. Proposals for a form for reporting Post-Mortem details

Dr. Preston had discussed the matter with several colleagues including Dr. Charles Forbes, and Professor Wolfe. From these discussions it became clear that a long and detailed protocol would be required to collect the information being sought. Dr. Preston said that he still thought that it was important for the information to be collected from Haemophilia Centres but that it was not appropriate for this to be done at present. It was agreed that the matter should be left for the time being.

8. Reports from Working Party Chairmen:-

(a) Hepatitis

Dr. Craske reported that the Working Party had undertaken four main projects during the year.

i) The prospective study on the use of factor VIII concentrates in patients infrequently transfused or receiving concentrate for the first time. A paper had been accepted for publication in the BMJ reporting on this study in Oxford.

ii) The 1974 Hemofil study was being reviewed and it

- 6 -

99

was hoped to have a report early next year on the findings of this work.

iii) Hepatitis-reduced commercial factor VIII concentrates.

Dr. Craske had received unofficial reports regarding patients who had been treated with these products and it appeared that several patients had developed hepatitis. In view of the concern about AIDS it was felt that the ^{slow} commercial products ^(where possible) non-heat-treated or heat-treated should not be given to previously untransfused patients.

iv) Testing of hepatitis B vaccine. A study was underway in Oxford using this vaccine and Dr. Craske would be carrying out the serological tests over the next few weeks.

b) Factor VIII Antibodies Working Party

Professor Prentice was not present to give his report but had raised by letter two matters for discussion at the meeting.

i) In view of the slow entry rate into the UK Directors' trial of Autoplex versus Factor VIII in the management of patients with factor VIII antibodies Professor Prentice suggested that French Haemophilia Centres should be asked to collaborate with the UK Centres in the trial. This was discussed and agreed.

ii) In view of his new appointment Professor Prentice wished to resign as Chairman of the Working Party but said that he would like to see the present study completed before his resignation took effect. Professor Bloom asked that the Reference Centre Directors should send him, in writing, their suggestions regarding the future Chairmanship of the Working Party. The matter would be discussed further at the next meeting of the Reference Centre Directors.

c) Factor VIII Assay Working Party

Dr. Rizza said that the Working Party had held no meetings or conducted any projects during the last few months and he planned to review the situation regarding the Working Party in the near future.

d) von Willebrand's Disease Working Party

Dr. Tuddenham said that the Working Party had had a meeting in July to consider the analysis of the Working Party's data. Another meeting was planned to draw up a report for presentation at the October meeting giving details of the findings to date. The aim of the Working Party was to try to improve the diagnosis of this very difficult group of patients.

9. Proposals for a register of patients with Inherited Platelet Disorders

Dr. Preston presented a draft form aimed at collecting basic information on inherited platelet defects. It was agreed that the Reference Centre Directors should send their comments on the draft form, in writing, to Dr. Preston before the February meeting of Reference Centre Directors and that Dr. Preston should prepare a new document outlining his proposals in more detail, for discussion at the February meeting. The possibility of setting up a Working Party to deal with the subject was discussed but no decision was taken.

10. Proposals for including in the Directors' National Register patients with miscellaneous coagulation defects

The paper and forms drawn up by Miss Spooner were briefly discussed. It was agreed that the Reference Centre Directors should write to Miss Spooner with their comments and suggestions regarding the possible expansion of the Register and that the

matter would be discussed further at the February meeting of the Reference Centre Directors.

11. Request from Professor Ian Temperley

Professor Bloom said that he had received from Professor Temperley a request that he be allowed to attend the Haemophilia Centre Directors' meetings. After discussion it was agreed that Professor Temperley should be invited to attend the annual meetings of the Haemophilia Centre Directors but not the meetings of the Reference Centre Directors.

12. Arrangements for the 1983 meeting of all Haemophilia Centre Directors

Dr. Rizza and Miss Spooner reported that the arrangements were in hand for the October meeting, which was to be held in Oxford. The draft agenda was discussed and approved.

13. Date and place of the next meeting of Reference Centre Directors

It was agreed that the next meeting would be held on Monday 13th February at the Royal Free Hospital at 10.30 a.m.

14. Any Other Business

No other matters were raised and the meeting closed at 4.30 p.m.