Minutes of the Nineteenth Meeting of Haemophilia Reference Centre Directors held at St. Thomas's Hospital on Monday 10th September 1984.

Present:	Professor A.L. Bloom (Chairman) Dr. J.F. Davidson Dr. C. Forbes Dr. P. Jones Dr. P. Kernoff Dr. C. Ludlam Dr. F.E. Preston Dr. G. Savidge Dr. E. Tuddenham Dr. J. Craske Dr. A. Aronstam Dr. Alison Smithies (DHSS by Invitation for Items 4-6) Miss R. Spooner

1. <u>Apologies for Absence</u> were received from:-

Dr. C.R. Rizza, Dr. J.M. Matthews, Prof. C. Prentice, Dr. G. McDonald (represented by Dr. J.F. Davidson), Dr. P. Hamilton, Dr. Elizabeth Mayne and Dr. I. Delamore.

Professor Bloom welcomed Dr. Alison Smithies of the DHSS to the meeting. Dr. Smithies was attending as she had a particular interest in items 4-6 of the Agenda.

Professor Bloom reported that Dr. Chalmers, Director of the Cambridge Haemophilia Centre, had died. The Reference Centre Directors paid their respects to Dr. Chalmers by observing a minutes silence.

2. <u>Minutes of the 18th meeting</u>

The following amendments were made to the Minutes:

<u>Page 5</u>: The sentence commencing on line 5 was amended to read "Dr. Craske asked that information should be sent to him by the Haemophilia Centre Directors on all significant" clinical

immunological disorders in haemophilic patients".

Page 8: The sentence commencing on line 9 should read "a) the possible opposition from Haematologists that a study of patients with inherited platelet disorders was outside the remit of the Haemophilia Centre Directors".

After these amendments had been made the Minutes were approved and signed by the Chairman.

3. Matters arising from the Minutes

Professor Bloom said that all matters arising from the Minutes would be dealt with under items on the Agenda, with the exception of item 13.1 on p;age 10 of the Minutes. Professor Bloom had received no comments from the Haemophilia Reference Centre Directors after the last meeting regarding the job description drawn up by the Haemophilia Nurses Association. Professor Bloom had therefore passed on to the HNA only those comments made by the Reference Centre Directors at their meeting.

4. Discussion document on the designation of Centres

Professor Bloom presented the new discussion document which he and Dr. Rizza had drawn up and also the document drawn up by the World Federation of Haemophilia. Professor Bloom outlined the background to the draft discussion document. With reference to the number of patients attending Haemophilia Centres set out in the World Federation of Haemophilia document, Dr. Peter Kernoff emphasised that the criteria regarding numbers of patients attending designated Haemophilia Centres had not been accepted at previous meeting of Haemophilia Centre Directors and that this had been one of the most controversial points raised in the earlier drafts.

Dr. Smithies was asked if the DHSS had any views on the designation of Haemophilia Centres. Dr. Smithies said that the booklet was out of date, and the DHSS now had staff available to deal with updating the booklet but they did not want to do this work until the views of Haemophilia Centre Directors and the definition of Centres was clear. There was also the question of Supraregional Fundings. A Supraregional Funding Committee was now sitting and the question of haemophilia being regarded as a Regional Speciality had been raised. Dr. Smithies was therefore at the meeting to find out the views of the Reference Centre Directors on:-

a) the recommendation to all the Haemophilia Centre Directors on the desirable criteria for the recognition of Haemophilia Centres and,

b) the Reference Centre Directors views on the case for haemophilia being regarded as a suitable case for Supraregional Funding.

Professor Bloom asked the Reference Centre Directors if they were all agreed that the concept of the designation of Haemophilia Centres as set out in the original document HC(76)4 was a good one. Dr. Savidge suggested that it would be better to define Reference Centres in detail before the definition of Centres was tackled but Dr. Ludlam said that he thought that it would be best to look at the designation of Associate Centres/Centres first before dealing with the Reference Centres and suggested that a document should urgently be prepared ready for discussion by the Haemophilia Centre Directors at the Cardiff meeting. Dr. Jones suggested that he should draw up a new document, combining his fourth draft with Professor Bloom's and Dr. Rizza's latest draft discussion document. Copies of the fourth draft prepared by Dr. Jones were handed around the table.

Professor Bloom raised the question of the establishment of a Review Body (page 8 of the draft discussion document prepared by Dr. Rizza and Professor Bloom). It had been suggested at the last meeting of the Haemophilia Reference Centre Directors that a Review Body should be set up and that the Review Body should recommend the status of each Haemophilia Centre as a Centre or an Associate Centre. Professor Bloom said that he would not like to see any hospital that treated haemophiliacs excluded from consideration by the Review Body.

Dr. Jones said that he had received a letter from the Haemophilia Society asking for an up-to-date list of hospitals, not necessarily Centres, where haemophilic patients could receive treatment. Professor Bloom suggested that Haemophilia Centres should be asked to draw up a list of the hospitals in their area whic provided treatment for Haemophilia A and Haemophilia B patients and sent the list to Oxford, so that Oxford could compile a list of all hospitals in the UK where haemophilic patients were treated. After lengthy discussion it was agreed:-

1. That the Reference Centre Directors and the Haemophilia Centre Directors would be asked to identify the hospitals within their geographical regions which treated Haemophilia A and Haemophilia B patients.

2. The identified "treaters" were to be asked to list the

facilities and the number of patients treated by them.

3. The criteria for the designation of Haemophilia Centres should be drawn up by the Reference Centre Directoors.

4. A Review Body should be set up and the Review Body should decide which of the hospitals identified as treating patients should be classified as Haemophilia Centres.

5. Other hospitals, i.e. those not classified as Centres, would not be in the DHSS booklet but would be encouraged to liaise with the Haemophilia Reference Centre Directors regarding the treatment of patients.

6. The concept of a review system should be raised with all the Haemophilia Centre Directors at the Cardiff meeting.

7. If the Haemophilia Centre Directors agree to the setting up of a Review Body the present designation of individual Haemophilia Centres could be changed by the Review Body.

Professor Bloom pointed out that if it was agreed that a Review Body should be set up it would be done entirely within the Haemophilia Centre Directors remit and the review body would not refer to other bodies such as the British Society of Haematology. It was also agreed that a new document should be drawn up by Dr. Peter Jones, based on his earlier 4th Draft, for circulation to all the Haemophilia Centre Directors before the Cardiff meeting, but that the discussion at the Cardiff meeting should only deal with Reference Centres. It was agreed that the term Associate Centre should be dropped. There would therefore only be two types of Centres in the U.K., i.e. Reference Centres and Haemophilia Centres.

5. Supraregional funding for Haemophilia Reference Centres

Professor Bloom asked Dr. Smithies if the Reference Centre Directors could make general recommendations regarding supraregional fundings for haemophilia care or whether applications had to come from the individual Reference Centres. At present the Districts were responsible for funding the work of the Reference Centres. After discussion, Professor Bloom suggested that the case for supraregional funding should be drawn up by each Reference Centre Director and should be put together for discussion at an *ad hoc* meeting of the Reference Centre Directors. It was agreed that the Reference Centre Directors should write to Professor Bloom before the February meeting of Reference Centre Directors giving general points which they would wish to raise with the DHSS and copies of their applications for supraregional funding. The matter would be discussed again at the February meeting of Haemophilia Reference Centre Directors.

6. Staffing of Haemophilia Centres

Professor Bloom felt that there were problems regarding recommendations for the staffing and funding of Haemophilia Reference Centres as the Reference Centres had widely different numbers of patients to deal with, different responsibilites and different facilities available to them. Professor Bloom thought that it would be a useful exercise for the Reference Centre Directors to:-

1. Draw up a statement of the optimal staffing levels (types of staff and their functions) of Reference Centres.
2. To draw up a table showing the existing staff of the Reference Centres.

3. To compare the two sets of data.

Dr. Savidge said it was important that the term "Reference Centre Director" should be defined and the work of the Reference Centres should be clarified. If the DHSS expected the work to be done by the Reference Centres then staff must be made available to the Centres to enable them to do this. He also thought that it was important that any statement of optimal staff should include facilities such as the space requirements and Professor Bloom suggested that it would be useful for the Reference Centre Directors to include a note of the laboratory facilities, out-patient and in-patient facilities, numbers of beds available to the Haemophilia Centre etc.

After discussion, the item was deferred for further consideration at a later date.

7. <u>Haemophilia Centre Directors' Annual Returns</u>

Miss Spooner presented the written report which she and Dr. Rizza had drawn up on the Annual Returns for 1983 which had been received from Centres. It was emphasised that this report was a provisional report only as the Returns from some Centres were still incomplete. There was a brief discussion regarding the report. <u>It was agreed</u> that the information on von Willebrand's disease patients (table 4) was useful and should be collected and presented annually. The information on the miscellaneous products used to treat patients (table 12) was also thought to be useful and <u>it was agreed</u> that the Haemophilia Centre Directors should be reminded at the Cardiff meeting that they should include such materials in their Annual Returns to Oxford.

8. Current situation regarding AIDS

Dr. Craske presented some graphs which he had drawn up outlining the current situation regarding the analysis of the data he had received from Haemophilia Centres on patients who had been treated "suspected" batches of concentrate. Also Dr. Craske referred the Reference Centre Directors to a paper which had been published in the Lancet of 1st September on HTLV 3. He said that he and his colleagues were very guarded about the significance of the positive antibody results they had found but they proposed to continue this study. A further twenty patients with AIDS-related symptoms had been notified to him. There seemed to be a problem over centres reporting to Dr. Craske identified patients who had AIDS-related symptoms. He suggested that the reports should give only the Haemophilia Centre Directors National Register numbers rather than the names of the patients. He felt that extensive testing of patients "at risk" was now required. Follow-ups at six monthly intervals, terminating five years after the receipt of the "suspect" batch should be undertaken by the Haemophilia Centres concerned. Data from CDC indicated that the first AIDS case was in January 1982, two years after the material had been received by the patient. No two AIDS cases in the USA had received the same batch of Factor VIII concentrate. There were now 41 cases of AIDS in the USA in haemophiliacs. Dr. Craske offered to arrange for HTLV-3 testing on samples from Haemophilia Centres if the Haemophilia Centre Directors would like him to organise this for them.

9. Reports from Working Party Chairmen

a) Hepatitis Working Party Report

The report which had been prepared by Dr. Craske and Miss Spooner was presented and discussed. Dr. Craske said that it had been agreed at the Hepatitis Working Party meeting held in Oxford the previous week that the Chronic Hepatitis Survey should be discontinued in its present form. He thought that it would be more profitable for the Haemophilia Centre Directors to look at HBsAg carriers and he would put a proposal up to the Directors at the Cardiff Meeting. He referred to Colindale's inaccurate reporting of the numbers of carriers and felt that there was need to define what was meant by the term "Carrier". Dr. Craske also reported briefly on the Oxford trial of Hepatitis B Vaccine and said that he would give a more detailed report at the Cardiff meeting.

b) Factor VIII Antibodies Working Party

Professor Prentice had written to say that he was preparing a report on the Factor VIII Inhibitor Working Party study which he would present at the Cardiff meeting. In brief there was no significant difference between the Factor VIII and Autoplex treatment in that both seem to work equally well (or badly). Professor Bloom raised the question of a successor to Professor Prentice as Working Party Chairman. He said that Dr. Savidge had proposed that Peter Kernoff should take over as Chairman of the Working Party. This proposal was seconded by Dr. Tuddenham and <u>it was agreed</u> by the Reference Centre Directors that a proposal should be put to the Cardiff meeting that Dr. Kernoff should take over as Chairman of the Working Party on the Treatment of

Patients with Factor VIII Antibodies.

c) <u>Factor VIII Assay Working Party</u>

Dr. Rizza had presented the final report of the Working Party at the previous meeting of the Reference Centre Directors and would circulate this to all the Haemophilia Centre Directors prior to the Cardiff meeting, together with the results of a further study which had been undertaken in collaboration with NIBSC.

d) <u>von Willebrand's Disease Working Party</u>

Dr. Tuddenham said that by 27th July 1984 1,210 patients had been included in the von Willebrand's Disease Working Party survey. The forms were still coming in steadily from Haemophilia Centres and he did not propose to give a detailed report at present as he felt that it would be better to defer a detailed report for about one year, when he hoped that the survey would be nearer completion.

10. <u>Proposals for a Working Party on patients with Inherited Platelet Disorders</u>

Dr. Preston presented a revised registration form which he had drawn up. There was some discussion regarding Dr. Preston's proposal and it was queried as to what would be done with the data once it had been obtained from Haemophilia Centres. Dr. Preston said that he felt that Haemophilia Centres had responsibility to this group of patients, he felt that at the present time they were a neglected group of patients and it was important that information on them should be obtained. <u>It was agreed</u> that Dr. Preston should raise the matter with all the

Haemophilia Centre Directors at the Cardiff meeting.

11. <u>Expansion of the Directors' National Register</u>

Miss Spooner presented the document she had prepared regarding the proposed expansion of the register, and said that if this was approved by the Haemophilia Reference Centre Directors it would be pre-circulated to all the Haemophilia Centres Directors for discussion at the Cardiff meeting. <u>This was agreed</u>.

12. <u>Dr. Poller's Quality Control Systems</u>

a) Dr. Preston said that he had been unable to attend the last meeting of Dr. Poller's committee and he was waiting for the documents to arrive from Dr. Poller. He hoped that these would be available shortly and he would give a report to the Cardiff meeting regarding Dr. Poller's systems.

b) Dr. Savidge said that he had encountered considerable problems with Dr. Poller and his Control Systems. The results came in late and were very confusing. There was insufficient plasma in the samples received for testing and he felt that things could be greatly improved. Dr. Davidson said that the DHSS had agreed that if any criticisms were made of Dr. Poller's handling of the systems they should be put in writing to the National Haematology Panel which met regularly (Dr. Davidson was a member of this panel). Professor Bloom emphasised that the Haemophilia Centre Directors were only concerned with the tests which affected the diagnosis of haemophilia patients; they were not interested in the anticoagulant control systems, etc.. and Dr. Preston asked Dr. Savidge to put the queries and problems he had in writing to him, he would then take them up with Dr. Poller. Dr. Savidge said that the basic reagents in the system, had been changed without prior consultation although it was agreed that this should not happen. After further discussion it was agreed that Dr. Preston would raise the matter with Dr. Poller.

13. Arrangements for the 1984 meeting of all Haemophilia Centre Directors

Professor Bloom said that all the arrangements had been made for the meeting.

14. Arrangements for the 1985 meeting of all Haemophilia Centre Directors

It was agreed that this would take place in Oxford in October 1985.

15. Date and place of next meeting of Reference Centre Directors

It was agreed that the next meeting of the Haemophilia Reference Centre Directors should be held at the Royal Free Hospital on Monday 18th February, 1985.

16. Any Other Business

No additional matters were raised and the meeting closed at 4.20 p.m.

GRO-C: Bloom 18/2/85