[redacted] Minutes of the Twelfth Meeting of Haemophilia Reference Centre Directors held at the Royal Free Hospital on Monday, 23rd February, 1981.

Present:-

Prof. A. Bloom (Chairman)
Dr. C.R. Rizza
Dr. I. Delamore
Dr. C. Forbes
Dr. P. Hamilton
Dr. P. Jones
Dr. P. Kernoff
Dr. C. Ludlam
Dr. J. Matthews
Dr. F.E. Preston
Dr. G. Savidge
Dr. E. Tuddenham
Miss R.J.D. Spooner

1. Apologies for Absence were received from Dr. Elizabeth Mayne, Professor E.K. Blackburn, Dr. John Craske, Dr. G. McDonald, Dr. H.T. Swan and Dr. R.T. Wensley.

2. The Minutes of the last meeting of the Reference Centre Directors were approved.

3. Matters arising from the Minutes

(a) Northern Ireland and Scotland

Northern Ireland. Professor Bloom said that Professor McTaggart at the Northern Ireland office had not replied to his letter asking that Belfast should be recognised as a Haemophilia Reference Centre.

Scotland. Dr. Forbes said that there had been a meeting of the Scottish Haemophilia Centre Directors. There was apparently some reluctance at the moment about officially designating the Centres in Glasgow and Edinburgh as Reference Centres but

he thought that the recommendation would probably go through without too much difficulty.

(b) Dr. Poller's Factor VIII Quality Control Study

A letter dated 28th January which Dr. Rizza had received from Dr. Poller was circulated and discussed. Dr. Poller had written following a comment by Dr. Barrowcliffe of NIBSC that the samples which had been distributed by Dr. Poller for quality control of factor VIII:C assay were not appropriate. Dr. Poller was therefore asking the Haemophilia Reference Centre Directors for their help in supplying him with the necessary deficient plasma. Dr. Delamore said that the Manchester Haemophilia Centre had always supplied Dr. Poller with haemophilic plasma but that he had not had a request from Dr. Poller recently. Dr. Prentice wondered which official body was supporting Dr. Poller's studies; this was not clear from the correspondence received. Professor Bloom thought that the studies served a useful purpose not undertaken by anyone else and they showed the distribution of assay results throughout the U.K. Dr. Hamilton thought that the results were very unclear and that the work in its present form should not be encouraged. Professor Bloom said that he thought the results were of interest and reminded Dr. Hamilton that only the first stage of the study had been completed so far. Dr. Rizza said that Dr. Poller had said that he would be prepared to collaborate with the Haemophilia Centre Directors Factor VIII Assay Working Party. It was agreed in principle that the Reference Centre Directors should help Dr. Poller with his studies and Dr. Rizza said that he would write to Dr. Poller suggesting that he should get in touch with Dr. Delamore to obtain plasma deficient in

the appropriate factors. It was agreed also that Professor Bloom should write to Dr. Poller asking him to explain the nature, function and composition of the steering committee of the U.K. External Quality Control assessment scheme for blood coagulation. Dr. Rizza said that he would also make some informal enquiries through Dr. Barrowcliffe. Professor Bloom referred to the Minutes of the Glasgow Meeting of all Haemophilia Centre Directors and asked whether the Reference Centre Directors were in agreement with the suggestion that Dr. Poller should be invited to attend the next annual meeting of Directors. It was agreed that Dr. Poller should be invited to give a report to the Haemophilia Centre Directors at their 1981 meeting.

(c) Report from Mr. Rosenblatt

A letter dated 20th October from Mr. Rosenblatt to Miss Spooner enclosing his report was given to the Reference Centre Directors. Discussion was deferred until the next meeting of the Reference Centre Directors.

(d) Home Therapy Working Party

Dr. Jones referred to the problem of the disposal of equipment used for home therapy. He said that this topic was covered by the Home Therapy Working Party's handbook (page 14) which covered all problems concerning the disposal of home therapy materials. Dr. Rizza said that in Oxford it had been found necessary to make special arrangements for some of the patients who lived a long way from the Centre so that they could dispose of their home therapy equipment via a local hospital and Dr. Kernoff said that after the subject had been raised at the previous Reference Centre Directors meeting he had looked at the Royal Free patients and found that some of

their patients were not disposing of used equipment in the way recommended. He thought that perhaps patients who had been on home therapy for a long time needed to be reminded about the correct procedures. Dr. Savidge then raised the question of management of patients who do not co-operate with their Haemophilia Centres. He had a patient who refused to come for home therapy follow-up appointments and he was particularly concerned about this as liver function tests etc. could not be checked. Dr. Jones suggested that home therapy could be withdrawn from patients who did not co-operate with their Centres and who refused to attend for follow-up appointments.

(e) Publishing of Data Collected by Haemophilia Centre Directors

Dr. Jones said that he thought that this item had arisen as a result of his request to the Chairman for permission to publish a graph summarizing the 1978 data collected by the U.K. Directors. The graph was to be published in a paper which would appear in "Plasma Quarterly". He said that it would be a mistake for the Reference Centre Directors to insist that prior permission had to be requested and obtained before any of the data could be presented. The paper which he was publishing had arisen as a reply to statements made at a meeting he attended in the United States. He had felt obliged to make some statements and to show a slide setting out the U.K. data to rectify misleading statements made by other persons. Professor Bloom said that he did not think that there could be any objections to a Reference Centre Director showing at a meeting a slide outlining the results of the Directors' survey but if data were published in the medical press by an individual Director prior to publication

of the full report by the Committee and the results were different from those finally presented for publication, there might be considerable confusion. Dr. Preston reminded the Directors that since published work became the copyright of the publishersit might be difficult to republish the same data later without obtaining permission from the original publishers. Dr. Rizza said that he had been concerned for some time about the delay in publishing the results of the Haemophilia Centre Directors Surveys. Journals were not happy about taking annual updates, so he wondered if perhaps it might be sensible to look into the possibility of publishing the data privately and then circulating it to interested persons and bodies. There followed some discussion about suitable methods of achieving publication of the National Data. It was suggested that "Clinical and Laboratory Haematology" or the DHSS's "Health Trends" might be suitable journals. It was agreed that Dr. Rizza would look into various possibilities and would approach the DHSS to ask if they would consider publishing the Annual Reports in their Journal.

4. Annual Returns for 1979 from Haemophilia Centre Directors

A report which had been prepared by Dr. Rizza and Miss Spooner was circulated and discussed. Dr. Jones requested that an official committee should be set up by the Haemophilia Reference Centre Directors to look into mortality in Haemophilia on the same lines as that set up to look into maternal mortality. It was suggested that the Royal College of Physicians should be contacted and asked if they would be willing to collaborate with the Haemophilia Reference Centre Directors. Dr. Forbes said that he had studied haemophilic deaths which had taken

place in the last twenty-five years and he wondered whether a new study would help in any way with haemophilia care. Dr. Jones said that he was very worried about the report of deaths which he would regard as avoidable deaths, and of patients who were being treated and dying at hospitals which were not recognised Haemophilia Centres. Professor Bloom suggested that a further investigation into deaths would be best carried out on a supraregional basis by the individual Reference Centre Directors. There was some discussion regarding the study which Dr. Forbes was undertaking and it was agreed that Dr. Forbes should write to the Reference Centre Directors whenever necessary for more details of causes of death. Dr. Prentice suggested that the names of all patients in the Haemophilia Centre Directors register should be put into the Registrar General's computer with a request for a copy of the death certificate to be sent to the appropriate Director as soon as any of those patients died. He said that this system was used by other bodies, for example the Civil Service, so that deaths were automatically reported to the person interested. He thought that there was a small charge for this service, approximately £1 per name. The Directors were reminded that there were now approximately 7,000 names in the Haemophilia Centre Directors register, and that if all these names were put into the computer a large sum of money would be required. It was also felt that the permission of all Haemophilia Centre Directors would be needed before setting up such a scheme. It was agreed that Dr. Prentice would find out more about the system and report back to the Reference Centre Directors at their next meeting.

Arising from discussion of the current usage of factor VIII in the U.K., Dr. Prentice referred to a meeting in Scotland of Haemophilia Centre Directors and Blood Transfusion Centre Directors at which Dr. John Cash had suggested that a figure of approximately 150 million units of Factor VIII would be required by the Haemophilia Centre Directors for the treatment of Haemophilia A patients in five years' time. Dr. Cash felt that the Haemophilia Centre Directors present estimates were too low. Professor Bloom said that he and Dr. Rizza had written a letter to the Secretary of State for Social Services with the revised estimate of 85 million units which had been agreed at the Glasgow meeting. The letter had been passed on to the DHSS and Sir George Young had replied. Dr. Kernoff said that Dr. Lane of B.P.L. was concerned about the estimates and the expansion which would be required. He suggested that 100 million units would be a more realistic estimate for five years ahead. It was agreed that 100 million units would be a reasonable new target.

5. Hepatitis Working Party

As Dr. John Craske was not able to be present at the meeting, there was no report from the Working Party.

(b) Home Therapy Working Party

Dr. Jones presented a written report from the Working Party and the results of the competition for prizes awarded by Miss Catherine Cookson and Mr. Brendan Foster for achievement in education and sport. He also presented the Directors with a copy of The Manpower Services Commission booklet which had recently been published and was now available to all Haemophilia Centres and Employment Offices. Dr. Jones went on to say that

the Centres at Alton and Newcastle were investigating the recent claims that high purity factor VIII concentrate had a longer in vivo half-life than other forms of factor VIII. Finally Dr. Jones said that there was still a significant amount of cryoprecipitate being used for home therapy and the Working Party was looking into the reasons for this. Dr. Prentice asked about lyophilised cryoprecipitate and its suitability for use in home therapy. Dr. Jones said that he thought it took a long time to dissolve, therefore it was not practicable for home therapy. Dr. Kernoff said that he had some reservations about the prizes which were being awarded. He thought that there was a danger that patients might think that they could have a dose of factor VIII be "normalized" and then try to achieve very high standards in some sport. One of his patients was a keen badminton player who appeared to be aiming for the British or even the World Championships! Dr. Kernoff did not think that it was a good idea to encourage haemophilic patients to take these risks with sport. The possible advantages and disadvantages of the scheme were discussed in detail and it was agreed that as the prizes had been donated the Reference Centre Directors should collaborate and should write reports on their patients and achievements when asked.

(c) Working Party on the Treatment of Patients with Factor VIII Antibodies

Dr. Prentice circulated a report on the meeting of the Working Party which was held in December 1980 at which a controlled trial of FEIBA and other materials was discussed. He asked the Reference Centre Directors for their comments and

approval of the plans. He suggested that any patients with more than 5 units of inhibitor should be included in the trial. Dr. Kernoff gave an outline of the Royal Free Hospital's experience with the use of the Porcine Factor VIII in the treatment of patients with factor VIII antibodies over the last nine months. On the basis of this Dr. Kernoff said that he would prefer the trial to be of Human Factor VIII concentrates versus Porcine Factor VIII concentrates rather than of FEIBA versus Human Factor VIII concentrates. The Royal Free used FEIBA only for patients with very high levels of antibodies. Dr. Preston agreed with Dr. Kernoff and also thought that Porcine Factor VIII would be a better choice of material. Dr. Delamore said that he thought that the price of the Porcine Factor VIII would be an advantage as it was considerably cheaper than FEIBA. Professor Bloom wondered whether there was sufficient Porcine Factor VIII available for a trial to be undertaken using this material. Dr. Matthews reported on the 25 Oxford patients with factor VIII inhibitors who have been treated with the Human Factor VIII concentrates with good results. There had been an initial rise in the inhibitor titre but later there was a drop in the inhibitor titre and eight of the patients had lost their antibodies. Dr. Jones supported the suggestion that factor VIII concentrates should be used but also said that he had two patients who had responded very well to the Oxford factor IX concentrate. He would find it very difficult to join in a trial using FEIBA, but he would be interested in the proposed trial using Porcine Factor VIII. Following a lengthy discussion the Reference Centre Directors were each in turn asked for their opinion and the decision

was that no protocol for any trial could be agreed at the present time as there was insufficient support for a trial using FEIBA and it was too early for a formal trial of porcine factor VIII to be undertaken. Dr. Prentice agreed to organise a meeting of the Factor VIII Antibodies Working Party in the near future and to look into the availability of the Porcine factor VIII concentrates.

6. Hepatitis-free Concentrate

Dr. Kernoff said that he had been asked by Travenol to indicate which category of patients would be treated with a hepatitis-free concentrate should it become available in the U.K. A hepatitis-free Factor IX concentrate was now available in Germany and it was hoped that a hepatitis-free Factor VIII concentrate would become available in the U.K. He felt that if hepatitis-free concentrates were marketed in the U.K. clinicians would find themselves in the difficult position of having to decide whether or not to give this material to all patients or to restrict its use to certain categories of patients. Dr. Rizza said that the U.K. fractionators were aware of this work and of its implications with regard to use of NHS factor VIII. Dr. Kernoff thought that if hepatitis-free concentrates were available in the U.K. they should be used and that the Department of Health should be aware that the Commercial firms were planning to market the material soon. It was agreed that the matter should be referred to the Hepatitis Working Party for consideration and recommendation.

7. Criteria for the Designation of Haemophilia Centres and Associate Centres

Dr. Kernoff said that there was a problem with the proliferation of Associate Haemophilia Centres. He felt that no firm decision had been reached at the last meeting regarding the criteria for the establishment of an Associate Centre. He thought clear guidelines should be drawn up. Dr. Jones said that he was particularly concerned about the problems that he had noticed when patients from some Associate Centres were visiting the Newcastle Centre. In some instances there appeared to be very little counselling of patients especially children. Dr. Jones wondered if there was a need for formal inspections of Associate Centres by a team approved by the Reference Centre Directors and possibly including a representative of the Haemophilia Society. The inspection team would be made up of people coming from outside the Supraregion concerned. Dr. Forbes said that he thought it would be very costly to run such a scheme. Also he was not in favour of a representative of the Haemophilia Society being involved in such inspection. Dr. Hamilton pointed out that it was very difficult for doctors to tell doctors what to do. He suggested that a better scheme would be for the patients attending Associate Centres to be seen by the appropriate Reference Centre at least once a year. It was agreed that this was a good idea but in some of the larger Supraregions it would be very difficult for every individual patient to be seen at the Reference Centre once a year. Dr. Delamore said that he agreed with Dr. Forbes about the costs involved. He suggested that a form should be drawn up which the aspiring Associate Haemophilia Centres

would fill in and submit to the Reference Centre Directors via their Supraregional Centre for consideration. It was agreed that Dr. Peter Jones and Dr. Peter Kernoff should draw up such a form for discussion by the Haemophilia Reference Centre Directors at their next meeting.

8. Haemophilia Nurses Association

Dr. Jones asked the Haemophilia Reference Centre Directors to approve the formation of the Association and suggested that a representative of the Association should be invited to the Annual Meetings of Haemophilia Centre Directors to report on the activities of the Association during the preceeding year. This was agreed.

9. Summer Camp for Haemophiliacs

Dr. Tuddenham said that five haemophilic boys had attended the Camp which was held in Felixstowe last summer. This year a camp would be held in Chepstowe and could again take five boys. The dates were 13th-22nd August and there would be about 100 children in all at the camp. Dr. Savidge asked if the Lord Mayor Treloar College had ever been used during the summer vacations for a summer camp. He thought it would be an ideal place for such a camp.

10. Any Other Business

a) Dr. Jones said that Dr. Collins of the Blood Transfusion Service had pointed out that on the Agenda for the next meeting of the Central Co-ordinating Committee of the Regional Blood Transfusion Centres, there was an item recommending that all factor VIII, including Commercial factor VIII, should be held and distributed by the Regional Blood Transfusion

Centres. Dr. Jones said that he had undertaken to draw the Reference Centre Director's attention to this item on the Agenda. Dr. Kernoff said that he thought that this would be a backward step. At one time the Royal Free Hospital's material had been supplied via the Blood Transfusion Service and this had resulted in many difficulties. Professor Bloom agreed. After discussion it was agreed that it was much better for the Haemophilia Reference Centres to be in control of the Factor VIII stocks rather than the Regional Blood Transfusion Service.

b) Dr. Savidge said that he had been visited by someone who was planning to set up a company to market factor VIII in the U.K. and who would be selling Travenol and Cutter material at a reduced proce (7p per unit). He was concerned about this and felt that he should draw the Reference Centre Directors attention to the matter.

11. The 1981 Meeting of Haemophilia Centre Directors

Dr. Tuddenham offered the facilities at the Royal Free Hospital for the Meeting and it was agreed that the Meeting would be held on Friday 9th October 1981 at the Royal Free Hospital.

12. Next Meeting of Haemophilia Reference Centre Directors

It was agreed that the next meeting of the Reference Centre Directors would be held at St. Thomas' Hospital on 14th September at 10.30 a.m.

Professor Bloom thanked Dr. Tuddenham and Dr. Kernoff for making the arrangements for the meeting, which closed at 3.30 p.m.

GRO-C: Bloom