Minutes of the 15th Meeting of UK Haemophilia Centre Directors, held in Cardiff on Thursday, 27th September 1984

Present

Prof. A. Bloom (Chairman)

Dr. W.S.A. Allan
Dr. V.E. Andrews
Dr. A. Aronstam
Dr. B. Attock
Dr P. Barkhan
Dr. D.L. Barnard
Dr. A.J. Black
Dr. P. Bolton-Maggs
Dr. M. Boots
Dr. B.T. Colvin
Dr. J.A. Coppleston
Dr. J. Craske
Dr. R. Craven
Dr. A.M. Cumming
Dr. B. Bennett
Dr. J.O.P. Edgcumbe
Dr. D.I.K. Evans
Dr. Jane Evans
Prof. P. Flute
Dr. C.D. Forbes
Dr. I.M. Franklin
Dr. E.A. French
Dr. P.L.F. Giangrande
Dr. A. Gracie
Dr. I. Grant
Dr. I.M. Hann
Dr. R.M. Hay
Dr. A. Heppleston
Dr. F.G.H. Hill
Dr. R.M. Ibbotson
Dr. P. Jones
Dr. P.B.A. Kernoff
Dr. J.S. Lilleyman
Dr. J.A. Liu Yin
Dr. C.A. Ludlam
Dr. S.J. Lewis
Dr. H. Magennis
Dr. V. Malkovska
Prof. P.M. Mannucci
Dr. J.H. Matthews
Dr. E. Mayne
Dr. P.J.F. McHugh
Dr. B.A. McVerry
Dr. R.S. Mibashan
Dr. E. Miller
Mr. K. Milne (Haem. Soc.)
Dr. D.C. Mitchell
Dr. V.E. Mitchell
Dr. L.A. Parapia
Dr. H.F. Parry
Dr. F. Pettigrew
Prof. C.R.M. Prentice
Dr. F.E. Preston
Mr. J.L. Prothero (Haem. Soc.)
Dr. C.R. Rizza
Dr. S. Robinson
Dr. D. Samson
Dr. G.F. Savidge
Dr. G.L. Scott
Dr. M.J. Seaman
Dr. M.H.M. Shulji
Miss R.J.D. Spooner
Dr. M.J. Strevens
Dr. L.M. Swinburne
Dr. C. Taylor
Dr. T.G. Taylor
Dr. I. Temperley
Dr. E.H. Thompson
Dr. N. Trayb
Dr. E.G.D. Tuddenham
Dr. E. Watts
Dr. R.T. Wensley
Dr. D.N. Whitmore
Dr. M. Winter
Mr. J. Wood

1. Apologies for absence had been received from the following people:-

Dr. S. Ardeman, Edgware, Middlesex.
Dr. A.M. Barlow, Huddersfield.

Prof. A.J. Bellingham, Liverpool.
Dr. D. Burman, Bristol.
Dr. J.D. Cash, NIBSC, Scotland.
(Rep. by Dr. Boulton)
Dr. I.W. Delamore, Manchester.
Dr. S.I. Dempsey, Belfast.
Dr. J.A. Easton, Slough.
Dr. P. Hamilton, Newcastle.
Prof. R.M. Hardisty, Hosp. for Sick Children
Great Ormond Street, London.
Dr. J.P.L.A. Hayes, Chatham, Kent.
Dr. Judith Kemp, Lewisham.
Dr. M.W. Kenny, Brighton.
Dr. T. Korn, Bangor.
Dr. J. Leslie, Norfolk.
Dr. J.M. Matthews, Oxford.
Dr. B. Murphy, Torquay.
Dr. E.G. Rees, Shrewsbury.
Dr. C.D.L. Reid, Harrow, Middlesex. (Rep. by
Dr. V. Malkovska),
Dr. J.D.M. Richards, University College Hospital,
London.
Dr. Alison Smithies, DHSS, London.
Dr. T. Snape, Elstree.
Dr. G.P. Summerfield, Middlesbrough.
Dr. D.S. Thompson, Luton.
Dr. G.R. Tudhope, Dundee.
Dr. R.T. Wensley, Manchester.

Professor Bloom welcomed to the meeting the Directors or their nominated representatives and the people who had received special invitations to attend, i.e. Professor Ian Temperley from Dublin, Mr. Milne and Mr. Prothero who were representing the Haemophilia Society, Dr. Boulton from the Scottish NBTS and Professor P. Mannucci from Italy. He apologised that the date of the meeting had clashed with other medical and scientific meetings. Professor Bloom reported the death of Dr. D.G. Chalmers and the Directors observed one minute's silence in respect for Dr. Chalmers.

2. Minutes of the last meeting

The Minutes were approved and signed.

3. Matters arising from the Minutes

All matters arising from the Minutes of the 14th meeting would be dealt with under the items on the Agenda for the 15th meeting.

4. Report on meetings of Haemophilia Reference Centre Directors

Professor Bloom said that the Reference Centre Directors had held two meetings during 1984. All of the matters which had been discussed by the Reference Centre Directors at these meetings were included in the Agenda for the present meeting. The question regarding the designation of Haemophilia Centres (which had been discussed at previous meetings of all Directors) had been raised again by the DHSS as a matter of some urgency. The Department had informed the Reference Centre Directors that they considered that their circular HC(76)4 and booklet "List of Haemophilia Centres in the United Kingdom" were out of date and the Department wished to up-date them. The Department requested the Reference Centre Directors' advice on the up-dating. After discussion, a revised Discussion Document had been drawn up by the Reference Centre Directors and circulated to all Directors for discussion at the present meeting (Item 7).

5. Report on the 1983 Annual Returns from Haemophilia Centres

Dr. Rizza presented the report which he and Miss Spooner had prepared and pre-circulated to the Directors. Dr. Rizza drew attention to the incomplete data presented in Table 12 and asked Directors to ensure that information on "other products" was included on the Annual Returns print-out in the column provided. He also emphasised that it was important to have as much

information as was possible regarding the cause of deaths (Table 13) and suggested that copies of autopsy reports should be sent to Oxford whenever they were available. Dr. Rizza asked if the Directors were satisfied with the way the data on the Annual Returns was presented to them, in particular if they would like to have the information on the von Willebrands Disease patients (Table 4) up-dated annually. It was agreed that all the information presented in the report was useful to the Directors and should continue to be collected. During discussion, several points were raised including the usefulness or otherwise of "average" amounts of materials used to treat patients, the number of patients known to have inhibitors who were not receiving treatment and the mortality rates for haemophiliacs. Professor Bloom thanked Dr. Rizza for presenting the Report and asked Directors to let Dr. Rizza and Miss Spooner have their comments in writing as soon as possible so they could be considered before the next annual report was prepared.

6. Proposal for the expansion of the Haemophilia Centre Directors National Register

Professor Bloom referred Directors to the document Miss Spooner had prepared and pre-circulated. The objectives for extending the register were:-

a) to determine the incidence of the rarer coagulation defects;

b) to determine the number of patients with the rarer coagulation defects who were treated each year and the

treatment they received.

During discussion, some concern was expressed regarding the "registration" of mildly affected patients. It was agreed that these patients should be issued with Special Medical (green) Cards and be included in the National Register. It was agreed that symptomless heterozygotes should not be included. In reply to a query, Miss Spooner emphasised the policy of strict confidentiality which had always been followed in Oxford regarding all information received from Haemophilia Centres for inclusion in the Directors' National Register and statistical reports. Professor Bloom suggested that if any Director felt that the present policy on confidentiality should be changed he should put in writing a formal request for the matter to be discussed. Following the discussion, it was agreed that the National Register should be extended.

7. Discussion document on the designation of Haemophilia Centres

Professor Bloom summarised the events which had followed the presentation of the first draft document to all Directors at their 1982 meeting and suggested that the view of Directors might have changed in view of the AIDS problem and the acknowledged need for good treatment records to be maintained etc. The Reference Centre Directors had held several meetings specifically to discuss the criteria for the designation of Centres and several points had been agreed.

a) The UK was recognised throughout the World as having the best organisation for the treatment of haemophilic patients. The UK system had been used as a model for setting up of treatment

centres throughout the World.

b) The WFH's recommendations for the designation of Haemophilia Treatment Centres were more stringent than the present UK criteria. The WFH suggested 3 categories of Centres, related to the number of patients treated - >100, 50-100, 10-49. The Reference Centre Directors would not suggest that the UK adopt this formula of relating designated status to patient numbers. The Reference Centre Directors would prefer to include all hospitals treating haemophilic patients in the organisation, thus enabling the hospitals with small numbers of patients to benefit from receiving information on advances in treatment. The data from these hospitals would be available for inclusion in the Directors Statistics.

c) The Reference Centre Directors suggested that they should proceed as follows:-

i) Establish a small Working Party made up of representaives from Reference Centres, Haemophilia Centres and Associate Centres, and possibly with representatives from the Haemophilia Society, to act as a Peer Review Body.

ii) Identify by postal survey all hospitals where Haemophilia A and Haemophilia B patients were treated.

iii) Work with existing Directors and Oxford to find out what facilities existed at these hospitals.

iv) Analyse the results of the survey and decide which hospitals should be designated as "Centres". Other hospitals would be called something else, e.g. "Treatment

Hospitals", but would be brought into the system.

v) Compile an up-to-date list of places and facilities for the treatment of Haemophilia A and Haemophilia B patients.

Professor Bloom invited comments and suggestions from the Directors, resulting in a lengthy discussion during which the following points were raised:-

1. Reference Centres: It was suggested that Reference Centres should be included for Peer Review. Concern was expressed at the "hierarchical system", which no other speciality had. One suggestion was that in the future haemophilia care should be organised on a Regional, rather than Supraregional basis. Although some Reference Centres see patients on a Regional basis several are already functioning at a supraregional level. It was pointed out that the Directors of Reference Centres spent up to 90% of their time dealing with haemophiliacs, and had considerable expertise, both clinically and in the laboratory, which had been built up over many years. To abolish Reference Centres would be to dilute this expertise and would not be in the patients best interest.

2. Associate Centres: Professor Bloom assured the Directors that the present Associate Centres would be represented on the Peer Review Body and included in the system, but proposed that the words "Associate Centre" be replaced with some other term to designate hospitals treating very few patients and with limited facilities.

3. Staffing and Facilities: Worries were expressed about the possibility that rigid criteria might be laid down which could not be met outside the Reference Centres. It was pointed out that the facilities and staffing varied widely even between the Reference Centres. The Haemophilia Society's representatives thought it was important for the facilities available at each Centre to be known to the patients, thus avoiding disappointments etc. It was suggested that a Review Body should look at laboratory facilities and type of tests carried out by Centres as well as considering the treatment facilities. It was agreed that 24-hour clinical cover was the key to good haemophilia care and there were difficulties at many Centres in organising this.

4. Meetings: It was suggested that local meetings should be organised by individual Reference Centre Directors 2-3 times a year, with an AGM for all Directors as at present.

5. Patients: A proposal was made that the treatment and laboratory facilities for all haemorrhagic disorders should be taken into account by the Review Body, instead of limiting the survey to cover only Haemophilia A and Haemophilia B patients. However, it was confirmed that the remit of Haemophilia Centres was only for the hereditary haemostatic defects and for recording patients with acquired defects requiring treatment with blood products.

6. Education: Concern was expressed regarding the problems over training junior medical staff in good haemophilia care at hospitals which are not Haemophilia Centres. It was suggested

that the Review Body should give some thought to this matter, although this is a question for the JCMMT.

7. "What is a Haemophilia Centre": Professor Bloom said this was the main question to be answered by the proposed Review Body. Also, how not to "lose" from the Haemophilia Centre Directors' Organisation non-designated hospitals that treated patients.

8. Home Treatment: Concern was expressed by the Haemophilia Society over patients on home treatment who did not get follow-up appointments for 3 years or more, either from their local Centre or from a Reference Centre.

9. Record Keeping: Professor Bloom emphasised the need for good, accurate records to be kept by Centres.

10. Location of Centres: It was emphasised that the location of Centres should be identified quite specifically with direct access for patients to the Centre and that patients should not be treated via Casualty Departments.

11. Function of Centres: Reference Centres were not expected to supervise the work of the Haemophilia Centres but a close collaboration between Reference Centres, Centres and other hospitals treating haemophilic patients was envisaged. Anxiety was expressed about the possibility of every District General Hospital becoming a "treatment hospital" and attempting ambitious procedures they were not able to cope with. It was suggested that Factor VIII supplies should be controlled by the Reference Centres; at present any hospital could obtain supplies of Factor VIII concentrates.

After the discussion it was agreed:-

a) That the concept of Reference Centres should continue.

b) That a Review Body should be set up.

c) That the Review Body would be made up of 2 Reference Centre Directors, 2 Centre Directors, 2 Associate Centre Directors and 2 Haemophilia Society representatives.

d) That the Review Body should arrange for a questionnaire to be sent to Centres as soon as possible regarding the identification of hospitals treating Haemophilia A and Haemophilia B patients. Treated patients were defined as patients who received blood products.

e) The following people were provisionally nominated as Members of the Review Body:-

Chairman:	Prof. A. Bloom
Reference Centre Directors:	Dr. P. Jones, Newcastle
	Dr. C. Ludlam, Edinburgh
Centre Directors:	Dr. F. Hill, Birmingham
	Dr. B. Colvin, London Hosp.
	Dr. D.L. Barnard, Leeds
Associate Centre Directors:	Dr. P. McHugh, Kingston-on-Thames
	Dr. S. Ardeman*, Edgeware
Haemophilia Society:	To appoint own representatives (2)

f) Professor Bloom (through Dr. Peter Jones) should take the following action:-

*withdrew name from list Feb. 1985

(i) Write to all Directors requesting nominations in writing of Directors as Members of the Review Body.

(ii) Draw up Terms of Reference for the Review Body.

(iii) Organise the setting up of the Review Body.

g) The Review Body would report back to the Directors at their 1985 AGM on the results of the Survey of hospitals treating Haemophilia A and Haemophilia B patients.

8. Factor VIII Quality Control Study

Dr. Preston reported the results of Dr. Poller's latest study on Factor VIIIc Assays, which were a big improvement on the previous year's results. He stressed that this was important work which the Haemophilia Centre Directors should support. Any queries or criticisms of Dr. Poller's work should be referred to Dr. Preston, who would take the matter up with Dr. Poller on the Director's behalf.

9. Provisional Date and Place for Next Meeting of All Haemophilia Centre Directors

It was agreed that the 1985 meeting of all Haemophilia Centre Directors would be held in Oxford in October 1985.

10. A.O.B.

a) Haemophilia Society

Mr. Milne thanked the Haemophilia Centre Directors for inviting the Society to send 2 observers to the Meeting and conveyed the apologies of the Society's Chairman (Mr. Tanner) for not being able to attend personally.

The Society were pleased to report that they now had an

organisation in India (Haemophilia Federation of India), based on the New Delhi Haemophilia Centre. The New Delhi Centre needed equipment of all sorts and would welcome offers from UK Centres; a refridgerated centrifuge for the preparation of cryoprecipitate was particularly urgently required.

b) Pre-Natal Diagnosis of Haemophilia

Dr. Mibashan gave an update on the pre-natal diagnosis of haemophilia and related disorders at Kings College Hospital. Haemophilia was the second most common indication for fetal blood sampling. Since Mr. Rodeck started this work in 1979, 183 Haemophilia A Carriers and 24 Haemophilia B Carriers had been tested at Kings. A total of 392 patients had been referred for pre-natal diagnosis (202 from the UK) and 216 fetal bloods had been sampled. There was 2.5% fetal loss of pregnancies intended to continue.

11. AIDS

Dr. Craske referred Directors to his report on the current situation regarding AIDS (Appendix E), outlined progress to date with the UK Haemophilia Centre Directors Study and reviewed the literature. Directors were asked to give special attention to the work on HTLV3. Regarding the AIDS Survey Returns from the UK Haemophilia Centres, Dr. Craske stressed the importance of accurate assessment of the incidence in the UK and the need for better reporting. So far no patients who have only received NHS concentrates had shown HTLV3+ results; HTLV3 testing had only been available since August 1984 and he would only give Directors

reports on the results when he was sure of the information. A research grant had been obtained from the Medical Research Council, who had given the project top priority for funding. Dr. Craske would send Directors progress reports 2-3 times a year on the AIDS Project and the situation generally. The disease in the USA and the UK was following the same trends in the homosexual population.

12. Reports from Working Party Chairmen

a) Hepatitis:

Dr. Craske referred to the report which had been circulated (Appendix D). The main projects with which the Working Party had been involved during the year were -

i) Heat-treated Factor VIII: Studies were underway as planned. Dr. Craske would welcome reports from Directors if hepatitis occurred in patients who had received treatment with these products.

ii) Vaccine Trial (Appendix D(ii)): The number of patients in the Oxford study were small and the results should be interpreted bearing that in mind. Dr. Craske would like information from other Centres to see if the Oxford results were confirmed. Dr. Craske recommended vaccination of haemophiliacs. People over 40 years old may not respond to the vaccine.

iii) Chronic Hepatitis: The reports of cases of chronic hepatitis received from Centres had been reviewed (Appendix D(i), Table 4) and the Working Party had decided to drop this Survey for the time being as there were many difficulties with the Survey in its present form. The Working

Party would reconsider the matter at a later date if non-invasive tests for Chronic Hepatitis became available. It was agreed that Directors would no longer report on Hepatitis Survey Forms H1 and H2 cases of Chronic Hepatitis.

iv) Acute Hepatitis: Appendix D(i) gave provisional results of the survey of acute hepatitis for 1980-83. It was agreed that Directors should continue to use Forms C1 and C2 to report cases of Acute Hepatitis.

b) Treatment of Patients who have Factor VIII Antibodies

Professor Prentice reported on the controlled trial of Factor VIII v. Autoplex which the Working Party had organised. The design of the trial was outlined. Only 2 Centres (Manchester and Belfast) had put patients into the trial; 18 haemorrhagic episodes were included. The number of patients and episodes involved were too small for any conclusions to be reached regarding the comparative effectiveness of the two types of materials and the results were not statistically significant.

Professor Bloom thanked Professor Prentice for his report and the work he had done on behalf of the Directors during his time as Chairman of the Working Party. Professor Prentice was retiring as Chairman and the Reference Centre Directors recommended that Dr. Peter Kernoff be invited to take over as Chairman of the Working Party; this was agreed.

c) Factor VIII Assay:

Dr. Rizza said that the Final Report from the Working Party

had been pre-circulated to the Directors. He thanked the Directors and Dr. Trevor Barrowcliffe for their help with the studies. It was hoped that a report would be published in the Medical Press soon. Any queries should be sent to Dr. Rizza or Mr. Curtis. Professor Bloom thanked Dr. Rizza and the Working Party Members for the work they had done on behalf of the Directors.

d) von Willebrands Disease:

Professor Bloom conveyed to the meeting Dr. Tuddenham's apologies for his absence due to unavoidable circumstances. Dr. Tuddenham's report had been pre-circulated (Appendix G) and Professor Bloom asked if the Directors wished to discuss any points. In reply to a query, Dr. Hill said he was willing to do multimer analysis for other Centres and Professor Bloom encouraged Directors to let Dr. Hill have samples for testing.

13. Inherited Platelet Disorders

Dr. Preston referred Directors to his proposals for the setting up of a Working Party on Patients with Inherited Platelet Disorders (Appendix H) and asked how Directors viewed their responsibilities to this group of patients. Dr. Preston felt that there were good reasons for setting up a Working Party. After discussion, it was agreed that a Working Party on Patients with Inherited Platelet Disorders should be set up under the Chairmanship of Dr. F.E. Preston.

14. Haemophilia Nurses Association

Sister Jenny Jones (Cardiff) presented a report on behalf of the Association. A new Committee had been appointed in 1984;

Sister Fearns (Newcastle) remained Chairman of the Association. The Survey on reactions to blood products was underway. So far only 4 Centres had reported reactions, which were related to NHS Concentrate (3 batches), Koate and Factorate. It was expected that the Survey would continue for 1-2 years. The HNA would like the opinion of the Haemophilia Centre Directors on:-

(i) The value of survey by the HNA

(ii) What the Directors would like the HNA to do

(iii) Was Hepatitis B vaccination recommended for Haemophilia Nurses? Also, in what circumstances should nurses be given gamma globulin?

The HNA's AGM had been attended by 52 delegates; a report would be distributed to Haemophilia Centre Directors in the New Year.

In reply to (iii), Dr. Craske said that Hepatitis B vaccine was available to Centres via their local DHA; there were no central funds available to cover the cost. According to CPHL Colindale, risk from accidental needle injuries was very, very small.

15. Haemophilia Society/BASW Special Interest Group

Mrs. Helen Bates (Cardiff) presented a report on behalf of the SIG, outlining the activities of the past year and future plans. An International Social Work Group had been set up under the Chairmanship of Elizabeth Wincott; Mrs. Reva Miller was the UK representative on the Group. The 1983 meeting organised by the SIG had been held at St. Thomas's Hospital and was well

supported. Copies of the papers presented at the meeting were available. The 1984 meeting would be held at St. Thomas's Hospital in November; it would run as a Study Day and funds were available from SIG to assist with delegates travelling expenses. The SIG planned to send a questionnaire to all Directors later in the year regarding social work at Centres.

Professor Bloom thanked Dr. J. Giddings for his work organising the International Scientific Meeting which was to take place the following day.

The meeting closed at 5.10 p.m.