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Minutes of the 14th Meeting of UK Haemophilia Centre Directors held in the Conference Room of the Oxford Regional Health Authority on MONDAY 17th October, 1983.

Present:- Professor A.L. Bloom, Cardiff (Chairman)

Mr. H. Abrahams (Haemophilia Society representative)
Dr. K.A. Adamson, Inverness
Dr. W.S.A. Allan, Wolverhampton
Dr. A. Aronstam, Alton
Dr. B. Attock, Barnstaple
Dr. A.M. Barlow, Huddersfield
Dr. D.L. Barnard, Leeds
Dr. T. Barrowcliffe, NIBSC (Member of F.VIII Assay Working Party)
Dr. O.H.A. Baugh, Chelmsford
Dr. A. Bell, Bournemouth
Prof. A.J. Bellingham, Liverpool
Dr. M.A. Boots, Colchester
Dr. F.E. Boulton, SNBTC, Edinburgh
Dr. Eva Brookes, Dundee
Dr. D.G. Chalmers, Cambridge
Dr. M. Chisholm, Southampton
Dr. K.G.A. Clark, Guy's Hospital, London
Dr. B. Colvin, London Hospital
Dr. J. Craske, Manchester (Chairman, Hepatitis Working Party)
Dr. E.R. Craven, Kettering
Dr. P.E. Crome, Roehampton
Mr. A. Curtis, NIBSC (Member of F.VIII Assay Working Party)
Dr. J.F. Davidson, Glasgow
Dr. I.W. Delamore, Manchester R.I.
Dr. M. Desai, Charing Cross Hospital
Dr. Helen Dodsworth, St. Mary's Hospital, London
Dr. J.A. Easton, Slough
Dr. J.O.P. Edgcumbe, Exeter
Sister M. Fearns, Newcastle (Representing Haemophilia Nurses Association)
Mrs. M. Fletcher, Oxford (Member of Hepatitis Working Party)
Prof. P.T. Flute, St. George's Hospital, London
Dr. I.M. Franklin, Birmingham
Dr. P.L.F. Giangrande, Westminster Hospital, London
Dr. D.K. Goff, Sunderland
Sister Mary Greaney, Taunton
Dr. P.J. Green, Portsmouth
Dr. I.M. Hann, RHSC, Glasgow
Dr. P. Hamilton, Newcastle
Prof. R.M. Hardisty, Hospital for Sick Children, G.O.S., London
Dr. J.P.L.A. Hayes, Chatham
Dr. F. Hill, Birmingham
Dr. R.L. Holman, Bath
Dr. D.T. Howes, Bedford
Dr. R.M. Ibbotson, Stoke-on-Trent
Dr. P. Jones, Newcastle
Dr. R. Vaughan Jones, Chertsey

Dr. Judith Kemp, Lewisham
Dr. P.B.A. Kernoff, Royal Free Hospital, London
Dr. P. Kesteven, St. Thomas' Hospital, London
Dr. J. Leslie, Norwich
Dr. J.S. Lilleyman, Sheffield Children's Hospital
Dr. C. Ludlam, Edinburgh
Dr. S.J. Machin, Middlesex Hospital, London
Dr. J.M. Matthews, Oxford
Dr. Elizabeth Mayne, Belfast
Dr. S. Mayne, Derby
Dr. P.J.F. McHugh, Kingston-upon-Thames
Dr. B.A. McVerry, Liverpool
Dr. R.S. Mibashan, King's College Hospital, London
Dr. V.E. Mitchell, Leicester
Dr. D. Mitchell, Derby
Dr. L.A. Parapia, Bradford
Mrs. Kate Parkin, London Hospital (Representing Haemophilia Soc/BASW SIG)
Dr. I. Peake, Cardiff (Member Factor VIII Assay & von Willebrand's Working Party)
Dr. R.J. Perry, PFC, Edinburgh
Dr. M.J. Phillips, Taunton
Dr. J.R.H. Pinkerton, Salisbury
Dr. D.R. Prangnell, Lincoln
Dr. A.G. Prentice, Plymouth
Prof. C.R.M. Prentice, Leeds (Chairman, Working Party on the Treatment of Patients with Factor VIII Antibodies
Dr. F.E. Preston, Sheffield
Mr. J. Prothero (Haemophilia Society representative)
Dr. E.G. Rees, Shrewsbury
Dr. C.D.L. Reid, Harrow
Dr. C.R. Rizza, Oxford
Dr. G. Robbins, Hillingdon
Dr. A.W.W. Roques, Worthing
Dr. G.F. Savidge, St. Thomas' Hospital, London
Dr. M.J. Seghatchian, N.L.B.T.C., Edgeware (Member of Factor VIII Assay Working Party)
Dr. G.L. Scott, Bristol
Dr. N.K. Shinton, Coventry
Dr. Janet Shirley, Camberley
Dr. T.J. Snape, BPL, Elstree (Member of Factor VIII Assay and Factor VIII Antibodies Working Party
Miss R.J.D. Spooner, Oxford (Member of Hepatitis and von Willebrands Working Parties)
Dr. H. Sterndale, Margate
Dr. R.F. Stevens, Manchester
Dr. M.J. Strevens, Coventry
Dr. G.P. Summerfield, Middlesbrough
Dr. C.G. Taylor, Pembury
Prof. Ian Temperley, Dublin, Eire
Dr. D.S. Thompson, Luton
Dr. Elizabeth Thompson, Taunton
Dr. Joan Trowell, Oxford (Member of Hepatitis Working Party)
Dr. E.G.D. Tuddenham, Royal Free Hospital, London
Dr. J.R.B. Williams, Stevenage
Dr. J.K. Wood, Leicester.

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

Dr. S. Ardeman, Edgware
Dr. P. Barkhan, Guy's Hospital, London (rep. by Dr. K.G.A. Clark)
Dr. A.J. Barrett, Westminster Hospital (rep. by Dr. P.L. Giangrande)
Dr. C.J.T. Bateman, Chichester
Dr. B. Bennett, Aberdeen
Dr. A.J. Black, Norwich (rep. by Dr. J. Leslie)
Dr. T.E. Blecher, Nottingham
Dr. R.P. Britt, Hillingdon (rep. by Dr. G. Robbins)
Dr. D. Burman, Bristol Children's Hospital
Dr. J. Cash, SNBTS (rep. by Dr. F.E. Boulton)
Dr. A.A. Dawson, Aberdeen
Dr. D.I.K. Evans, Manchester Children's Hospital (rep. by Dr. R.F. Stevens)
Dr. C.D. Forbes, Glasgow
Dr. E.C. French, Nottingham
Dr. H.H. Gunson, DHSS
Dr. C. Haworth, Charing Cross Hospital (rep. by Dr. M. Desai)
Dr. A.M. Hurdle, Epsom
Dr. R.M. Hutchinson, Leicester (rep. by Dr. V.E. Mitchell)
Dr. M. Khurshid, Swansea
Dr. R.S. Lane, BPL, Elstree (rep. by Dr. T. Snape)
Dr. S.M. Lewis, Hammersmith Hospital
Dr. J. Martin, Alder Hey Children's Hospital, Liverpool
Dr. G.A. McDonald, Glasgow R.I. (rep. by Dr. J.F. Davidson)
Dr. M. McEvoy, Harrogate
Dr. M. Mills, Westcliffe-on-Sea
Dr. B. Murphy, Torquay
Dr. J.S. Oakey, Orsett Hospital
Dr. R.A.M. Oliver, Thornton Heath
Dr. R.W. Payne, Worcester
Mr. I. Rhymes, Oxford (Member Factor VIII Assay Working Party)
Dr. J.D. Richards, University College Hospital
Dr. C.L. Rist, Worthing (rep. by Dr. A.W.W. Roques)
Prof. J.M. Stewart, Middlesex Hospital, London (rep. by Dr. S.J. Machin)
Dr. L. Swinburne, Leeds (rep. by Dr. D.L. Barnard)
Dr. G.R. Tudhope, Dundee (rep. by Dr. Eva Brookes)
Dr. Diana Walford, DNSS
Mr. J. Watt, PFC, Edinburgh (rep. by Dr. R.J. Perry)
Dr. J.M. Webster, Ashford, Middlesex
Dr. D.N. Whitmore, Lewisham (rep. by Dr. Judith Kemp)
Dr. H.J.H. Williams, Maidstone
Dr. D.A. Winfield, Sheffield

Professor Bloom welcomed the Directors to the Meeting and also welcomed the people who had received special invitations to

attend, i.e. Professor Ian Temperley from Dublin, Mr. Abrahams and Mr. Prothero who were representing the Haemophilia Society, Dr. Snape, who was representing Dr. Lane of the Blood Products Laboratory, Dr. Boulton from the Scottish NBTS and Dr. Barrowcliffe from NIBSC.

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 13th meeting would be dealt with under the items on the Agenda for the 14th meeting.

4. Report on meetings of Haemophilia Reference Centre Directors

Professor Bloom said that the Reference Centre Directors had held three meetings during 1983. Most of the matters which had been discussed by the Reference Centre Directors at these meetings were included in the Agenda for the present meeting.

A special meeting was held in May to discuss the AIDS problem; Dr. Craske would be reporting on AIDS during the afternoon session.

Three items which had been discussed by the Reference Centre Directors were:

a) A proposal that the Haemophilia Centre Directors should collect details of post-mortems carried out on haemophiliacs: Dr. Preston had drafted a form for the collection of this information and it had been discussed by the Haemophilia Reference Centre Directors; Dr. Preston had also discussed the matter with Professor Woolf. It seemed that if data were to be collected by the Haemophilia Centre Directors a very

detailed protocol would need to be drawn up. Dr. Preston would welcome comments from Haemophilia Centre Directors.

b) The possibility of Haemophilia Centre Directors setting up a register of patients with platelet disorders: Dr. Preston was drawing up a protocol and would welcome comments from the Haemophilia Centre Directors.

c) Expansion of the Haemophilia Centre Directors' National Register to include patients with other coagulation deficiencies had been considered by the Haemophilia Reference Centre Directors. Miss Spooner was looking into the proposals and the Directors were invited to send her their comments and suggestions. It was suggested that only patients with congenital defects should be included in the Register and that information about patients with acquired coagulation defects should continue to be collected in an informal manner as at present.

The next meeting of the Haemophilia Reference Centre Directors would be held in February 1984.

5. Haemophilia Centre Directors' Annual Returns for 1982

Dr. Rizza presented the report on the 1982 annual returns which he and Miss Spooner had prepared. Dr. Rizza urged the Haemophilia Centre Directors to send in details of the dates of birth and the coagulation defects of the patients, both in their annual returns and on the registration documents. There were 172 haemophilia A patients and 34 haemophilia B patients in the register for whom neither their date of birth or coagulation factor level was known. Dr. Rizza said that the apparent increase in the reporting of factor VIII inhibitors

in haemophilia A patients was interesting to note. It would be seen in future years whether this was an unusual phenomenon or a real increase in the incidence of inhibitors in haemophilia A patients.

Following Dr. Rizza's presentation of the report, several questions were raised by the Directors and discussed. It was agreed that it would be useful to know how well the figures obtained from the Haemophilia Centre Directors annual returns correlated with the figures for the manufacture of both the NHS and Commercial materials. It was pointed out that there was no restriction at the present on the sale of factor VIII to hospitals which were not official Haemophilia Centres. It was agreed that Dr. Rizza and Miss Spooner would look into the possibilities of comparing the figures obtained from the Annual Returns with those from the Commercial companies and the Blood Products Laboratories.

The use of factor IX concentrate for the treatment of haemophilia A patients who had factor VIII inhibitors was discussed. Several Directors had used factor IX concentrate to treat patients with factor VIII inhibitors and were impressed with the benefit obtained. Dr. Snape said there was no problem at present in meeting the demands for factor IX concentrate but this might change if there was a considerable increase in the use of Factor IX for haemophilic patients with antibodies.

The materials used for the treatment of von Willebrand's disease patients was discussed and it was suggested that it would be useful for information on the use of DDAVP in von Willebrand's disease patients to be included in the next report. There was clear bias towards the use of cryoprecipitate for the

treatment of von Willebrand's disease patients. The majority of Directors limited the use of concentrate in von Willebrand's disease patients to reduce the risk of hepatitis.

Dr. Rizza was asked if any figures were available from the annual returns regarding the number of new cases of haemophilia which were included in the register each year and if there had been a reduction in the number of new haemophiliacs since the pre-natal diagnosis of haemophilia had been introduced. The question of the collection of information regarding the family history of all new patients entered into the register was also raised, but no decision was taken regarding this point. It was agreed that Dr. Rizza and Miss Spooner would give the Directors information regarding the number of new cases entered into the register at their next meeting.

It was suggested that when the 1983 annual returns were collected the Directors should mark on the computer print-out which of their patients were receiving more than 50,000 units of factor VIII or IX concentrate per year. This would then give an indication of the number of patients who were receiving large amounts of material annually and it was not thought that this would give rise to a considerable amount of additional work. There was no discussion on this point and no decision was taken.

The question of the production of an artificial source of factor VIII in the near future (that is within the next two to three years) was raised and discussed. Professor Bloom said that he thought that there was still a lot of work to be done on this type of product before any material would be available for use in patients and it was not likely to be available in the near future. The question of oral preparations

of factor VIII concentrate was also raised.

Regarding the production of NHS factor VIII concentrate, Professor Bloom said that the development at the Blood Products Laboratory at Elstree was moving fast and it seemed likely that the new building would be open in 1985-86. Dr. Snape said that the factor VIII concentrates were distributed to the Transfusion Centres strictly on a pro rata basis depending on the amount of plasma which these Centres had sent in for fractionation, so if the Haemophilia Centre Directors required additional factor VIII concentrates they would need to persuade their Transfusion Centres to increase the supply of plasma to the BPL. It was pointed out that some Regions needed to supply large amounts of platelet concentrate therefore could not send so much plasma for fractionation at BPL. It was suggested that one way of making more plasma available for fractionation would be by means of plasmapheresis of donors. There were however problems in the Regions with regard to the funding of plasmapheresis programmes. It was suggested that methods for increasing the yield from the plasma sent to the BPL should be investigated further.

6. Criteria for the designation of Haemophilia Centres

Referring to the 1982 meeting of Haemophilia Centre Directors, Professor Bloom said that he and Dr. Rizza had agreed to write a new document for discussion by the Haemophilia Centre Directors at their 1983 meeting but had been unable to produce a finalised document in time for the meeting. He and Dr. Rizza would make efforts to prepare a paper for circulation well in advance of next year's meeting so that the matter could be discussed further then. Professor Bloom thanked the Haemophilia Centre Directors who had sent in comments to

them regarding the preparation of the document.

7. Dr. Snape, talking on behalf of Dr. Lane, presented two points of information to the Directors.

a) Antithrombin III concentrate had been available for over a year now. The original product had also contained factor XI but a new pasteurised antithrombin III concentrate was now available; this also contained factor XI. The material had been used successfully in two patients without side effects. Dr. Snape asked the Haemophilia Centre Directors to let him know their requirements and what possible uses for the material the Directors envisaged.

b) "Virus-safe" Products: The Blood Products Laboratory was looking at methods for making the factor VIII and factor IX products safer with regard to transmission of hepatitis. BPL would let the Directors know when any material was available for clinical use.

In reply to a query Dr. Snape said that BPL hoped that not more than 10-15% of the factor VIII yield would be lost in the making of the virus free products. It was agreed that the BPL should go ahead on a limited basis with a new product for clinical trial. This trial would be on a named patient basis.

Dr. Craske reported on the use of the commercial "virus-free" products. He said that the first reports that he had received on the use of this material made it clear that the problem was far from solved and he urged that proper follow-up of patients who received these materials should be made and also that details of the patients past therapeutic history should be noted. It was hoped that limited supplies of the

NHS materials would be made available for clinical trial as soon as possible.

8. Date and place for the next meeting of all Haemophilia Centre Directors

The next meeting of all Haemophilia Centre Directors would be held in Cardiff on Thursday and Friday, 27-28th September 1984. The first day would be a Business meeting for the Haemophilia Centre Directors only and the second day would be a General Scientific meeting. Each Haemophilia Centre would be invited to send their Director and one other representative to the general Scientific meeting. Further details would be distributed as soon as they were available.

9. Any Other Business

Dr. Chisholm raised the problem of patients refusing to take up commercial factor VIII concentrate because of the AIDS scare. She wondered in view of the worry of the patients whether the Directors could revert to using cryoprecipitate for home therapy. Professor Bloom replied that he felt that there was no need for patients to stop using the commercial concentrates because at present there was no proof that the commercial concentrates were the cause of AIDS. Dr. Chisholm pointed out that there was a further problem in her region because of problems in getting large amounts of commercial concentrates whereas she could get unlimited supplies of cryoprecipitate. Other Directors reported that they had the same problems. After discussion it was agreed that patients should not be encouraged to go over to cryoprecipitate for home therapy but should continue to receive the NHS or commercial concentrates in their usual way.

When the meeting reconvened after lunch, Professor Bloom welcomed Working Party members who had joined the Directors for the Afternoon Session.

10. Current situation regarding AIDS

Dr. Craske presented the paper which had been pre-circulated to Directors. He also outlined his proposals for investigating the UK cases of AIDS in haemophiliacs and proposed follow-up for three years of patients who had received "suspect batches of concentrate". He said that he was proposing to look at a control group of haemophiliacs and spouses of haemophilia A patients who had received concentrates. There was some discussion regarding the two cases of AIDS in haemophiliacs in the United Kingdom and Dr. Scott gave details about his case. Dr. Craske urged Haemophilia Centre Directors not to put the word AIDS on pathology request forms. He said that he could supply Directors with a copy of the United States recommendations regarding the handling of samples if they would like him to do this. It was agreed that Dr. Craske would send out details regarding his proposals to the Haemophilia Centre Directors as soon as possible.

11. Reports from Working Party Chairmen:-

a) Hepatitis

Dr. Craske presented the written report which he had prepared. The question of vaccination of Haemophilia Centre staff was raised. Professor Bloom said that no one on the staff of his Haemophilia Centre was obliged to have vaccination nor would they be penalised if after refusing to have the vaccination they contracted hepatitis. Dr. Craske reported briefly on the use of experimental NHS "hepatitis reduced" material which was being used in Oxford. This material was

not yet available for general use.

b) Treatment of patients who have Factor VIII Antibodies

Professor Prentice presented the written report which he had prepared on the progress with the control trial of factor VIII versus Autoplex in Haemophilia A patients who had factor VIII antibodies.

c) Factor VIII Assay

Dr. Rizza said that he felt that the Working Party could probably be wound up now but there would be one more meeting of the Working Party members before this decision was taken. He porposed to ask Dr. Barrowcliffe to report to the present meeting on the work on factor VIII standardisation and he hoped that even if the Working Party was disbanded Dr. Barrowcliffe would be able to continue to report to the meetings of Haemophilia Centre Directors. Dr. Barrowcliffe and Mr. Curtis presented information on the work on the standardisation reference materials which had been done at NIBSC and there was some discussion of this work. It was agreed that Dr. Barrowcliffe would be invited to attend future meetings of the Haemophilia Centre Directors when there was something of interest to report to them.

d) von Willebrand's disease

Dr. Tuddenham presented the written report which he had prepared. He said that the analysis was proving most interesting and he hoped that a paper would be prepared in the not too distant future for publication.

12. Factor VIII Quality Control Study

Dr. Preston reported on the meetings which he had had with Dr. Poller and his colleagues. He gave information briefly regarding trials which Dr. Poller had carried out involving

325 laboratories throughout the United Kingdom. These laboratories included some of the Haemophilia Centres and the results had identified laboratories which were giving poor performances on assay. Results on the whole were quite good but 5.6% of the laboratories classified normals as abnormals and four laboratories persistently gave poor performances. Dr. Poller required donations of mild or moderate factor VIII deficient plasma samples and he would be pleased if the Haemophilia Centre Directors could help him with this.

13. Report on behalf of the Haemophilia Nurses Association (HNA)

Sister Maureen Fearns said that the Association now had 70 members but not all the members were qualified nurses. At the last meeting of Haemophilia Centre Directors she had been asked to prepare a job description for haemophilia nurses. This had now been done and she gave a copy of the job description to Professor Bloom for his comments. It was agreed after discussion that the job description which the HNA had drawn up should be circulated to all Haemophilia Centre Directors when it had been approved by the Reference Centre Directors. The Association was compiling a bibliography of publications relevant to nurses and any one who would like a copy should write to Sister Jane Fountain at St. Thomas' Hospital. There were 74 delegates at the 1982 Symposium organised by the HNA which had been a very successful meeting. The first newsletter of the HNA would be published at the end of October. The HNA was now funding new nurses to enable them to visit other haemophilia centres to see how comprehensive care of haemophilic patients was carried out. Sister Fearns showed the Haemophilia Centre Directors an illustrated haemophilia guide which had been prepared for the World Federation of Haemophilia meeting

at Stockholm. The nurses thought that this was a most useful document and should be made available at all Haemophilia Centres. There was also a poster of inheritance of haemophilia which was available free from Sister Fearns. The A.G.M. of the HNA would be held in November at St. Thomas' Hospital.

14. Report on behalf of the Haemophilia Society/BASW Special Interest Group (SIG)

Mrs. Kate Parkin presented a report on behalf of the S.I.G. The S.I.G. had held two meetings since the 1982 meeting of Haemophilia Centre Directors. In November 1982 a conference had been held on employment problems and in June 1983 the A.G.M. of the group was held. On the 25th November at St. Thomas' Hospital the SIG, in association with the Haemophilia Nurses Association, would hold a conference on the side-effects of treatment on patients and their families; Professor Bloom was to be the guest speaker at the meeting. The S.I.G. had presented a poster at the Stockholm meeting of the W.F.H. The S.I.G. was the only group of its kind in the World and much interest had been shown in it by delegates at the meeting. The S.I.G. had been asked to help with the setting up of a Social Work Sub-group of the World Federation of Haemophilia.

Professor Bloom thanked Dr. Rizza and all the Staff in Oxford for their hospitality and the meeting finished at 5.00 p.m.