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Minutes of the 13th meeting of U.K. HAEMOPHILIA CENTRE DIRECTORS held at the University Hall of Residence, Owens Park, MANCHESTER on MONDAY 13th SEPTEMBER 1982 at 10.30 a.m.

Present:-

Professor A.L. Bloom (Chairman)

Dr. Saad Abdalla, St. Mary's Hospital, London.
Dr. M. Adelman, Lincoln County Hospital.
Dr. W.S.A. Allan, Royal Hospital, Wolverhampton.
Dr. S. Ardeman, Edgeware General Hospital.
Dr. A. Aronstam, Treloar Haemophilia Centre.
Dr. T.W. Barrowcliffe, NIBSC, London (afternoon only)
Dr. O.H.A. Baugh, Chelmsford and Essex Hospital.
Dr. A.J. Black, Norfolk and Norwich Hospital.
Dr. M.A. Boots, Essex County Hospital.
Dr. F.E. Boulton, Edinburgh B.T.S.
Dr. M. Chisholm, Southampton General Hospital.
Dr. M. Clarke (for Dr. Ransinghe) Charing Cross Hospital.
Dr. B.T. Colvin, London Hospital.
Dr. J. Craske, Public Health Laboratory, Withington Hospital.
Mr. A.D. Curtis, NIBSC, London.
Dr. H.M. Daly (for Dr. G. Scott) Bristol Royal Infirmary.
Dr. I.W. Delamore, Manchester Royal Infirmary.
Dr. J.A. Easton, Wexham Park Hospital, Slough.
Dr. J.O.P. Edgcumbe, Department of Pathology, Exeter.
Dr. D.I.K. Evans, R.M.C.H., Pendlebury.
Sister M. Fearns, Royal Victoria Infirmary, Newcastle.
Dr. C.D. Forbes, Glasgow Royal Infirmary.
Dr. B.E. Gilliver, County Laboratory, Dorchester.
Prof. R.M. Hardisty, Hospital for Sick Children, London.
Dr. N.E.M. Harker, Middlesbrough General Hospital.
Dr. J.P. Hayes, All Saints Hospital, Maidstone.
Dr. P.R. Hill, St. George's Hospital, Tooting.
Dr. R.L. Holman, Royal United Hospital, Bath.
Dr. R.M. Ibbotson, North Staffs Hospital.
Dr. P. Jones, Royal Victoria Infirmary, Newcastle.

Mr. G. Kemball Cook, NIBSC, London.
Dr. P.B.A. Kernoff, Royal Free Hospital, London.
Dr. R.S. Lane, Blood Products Laboratory, Elstree.
Dr. J.S. Lilleyman, Sheffield Children's Hospital.
Mrs. J. Lovie, Social Worker, Royal Victoria Infirmary.
Dr. C.A. Ludlam, Royal Infirmary, Edinburgh.
Dr. B.A. McVerry, Royal Liverpool Hospital.
Dr. S.J. Machin, The Middlesex Hospital.
Dr. E. Mayne, Royal Victoria Hospital, Belfast.
Dr. S. Mayne, Derby City Hospital.
Mr. K. Milne, Representative for Haemophilia Society.
Dr. D. Mitchell, Derbyshire Royal Infirmary.
Dr. V.E. Mitchell, Leicester Royal Infirmary.
Dr. D.A. Montgomery, Kingston General Hospital.
Dr. J.S. Oakey, Orsett Hospital, Essex.
Dr. D.G. Oscier, Royal Victoria Hospital, Bournemouth.
Dr. L. Parapia, Bradford Royal Infirmary.
Dr. I.R. Peake, University Hospital of Wales.
Mr. R.J. Perry (for Mr. Watt) S.N.B.T.S., Protein Fractionation Centre (afternoon only)
Dr. C.R.M. Prentice, Royal Infirmary, Glasgow.
Dr. C.R. Rizza, Oxford Haemophilia Centre.
Dr. B. Rotoli, Hammersmith Hospital, London.
Dr. G.F. Savidge, St. Thomas' Hospital, London.
Dr. M.J. Seghatchian, N.L.B.T.C., Edgware.
Dr. R.A. Sharp (for Dr. Tudhope) Ninewells Hospital, Dundee.
Dr. T.J. Snape, Blood Products Laboratory, Elstree.
Miss R.J.D. Spooner, Oxford Haemophilia Centre.
Dr. M.J. Strevens, Leamington.
Dr. L.M. Swinburne, St. James' Hospital, Leeds.
Dr. E. Thompson, Musgrove Park Hospital, Taunton.
Dr. E.G.D. Tuddenham, Royal Free Hospital, London.
Dr. P. Vosylius, Raigmore Hospital, Inverness.
Dr. R.T. Wensley, Manchester Royal Infirmary.
Dr. D.N. Whitmore, Lewisham Hospital, London.
Dr. M. Winter (for Dr. P. Barkhan) Guy's Hospital, London.

Apologies received from:-

Dr. P. Barkhan (Rep. by Dr. M. Winter) Guy's Hospital, London.

Dr. D. Burman, Bristol Children's Hospital.

Dr. A.H. Goldstone, University College Hospital, London.

Dr. R.M. Hutchinson, Leicester Royal Infirmary.

Dr. J.R. Mann, Children's Hospital, Birmingham.

Dr. R. Mibashan, Kings College Hospital, London.

Dr. B. Murphy, Torbay Hospital, Torquay.

Dr. J.R.H. Pinkerton,General Infirmary, Salisbury.

Dr. E. Ranasinghe (Rep. by Dr. M. Clarke) Charing Cross Hospital, London.

Dr. J.D.M. Richards, University College Hospital, London.

Dr. D. Samson, Northwick Park Hospital, Middlesex.

Dr. G. Scott (Rep. by Dr. H. Daly) Bristol Royal Infirmary.

Dr. H. Sterndale, Isle of Thanet District Hospital, Margate.

Dr. D.S. Thompson, Luton and Dunstable Hospital.

Dr. G.R. Tudhope (Rep. by Dr. R.A. Sharp) Ninewells Hospital, Dundee.

Mr. J.G. Watt (Rep. by Mr. R.J. Perry) S.N.B.T.S., Edinburgh.

Mr. Watters (Rep. by Mr. K. Milne) Haemophilia Society.

Dr. J. Webster, Ashford Hospital, Middlesex.

Professor Bloom welcomed the Directors to the Meeting and thanked Dr. Delamore and Dr. Wensley for making all the arrangements so efficiently. The Directors stood for 1 minute to show their respect for Dr. Cook who had recently died. Professor Bloom welcomed to the meeting new Directors and other people attending the meeting for the first time. During the past year there had been several retirements and changes of Directorship at Haemophilia Centres. Dr. Hallam at Bedford had retired, his successor was Dr. D.T. Howes; Professor Turner at Bradford had retired, his successor was Dr. L.A. Parapia; Dr. MacKenzie at Sunderland had retired and the new Director was Dr. D.K. Goff; Dr. Greenburgh, Co-Director of the Plymouth Centre with Dr. Stafford had retired

in 1981 and Dr. A.G. Prentice had now joined Dr. Stafford as a new Co-Director of the Plymouth Centre; Dr. D.G. Oscier had taken over as Director of the Bournemouth Haemophilia Centre.

Professor Bloom welcomed to the meeting Mr. Kenneth Milne, who was representing the Haemophilia Society, Mrs. Jean Lovie, who was representing the British Association of Social Workers special interest group and Mrs. Maureen Fearns, who was representing the Haemophilia Nurses Association.

2. The Minutes of the Last Meeting

The Minutes were approved and signed.

3. Matters Arising from the Minutes

There were no matters arising from the Minutes for discussion under this section.

4. Report on Meetings of Haemophilia Reference Centre Directors

Professor Bloom said that the Reference Centre Directors had held two meetings in 1982 and reported on the business discussed at those two meetings.

Professor Bloom had raised with the Haemophilia Reference Centre Directors; The question of the Chairmanship of the Haemophilia Centre Directors Group was raised as his 3-year tenure of the Chairmanship had now expired. After discussion it had been unanimously agreed by the Haemophilia Reference Centre Directors that Professor Bloom should continue as Chairman for three more years providing this decision was approved at the AGM (See Item 8).

5. Haemophilia Centre Directors Annual Returns for 1981

Dr. Rizza presented the report on the 1981 Annual Returns which he and Miss Spooner had prepared. There were two main points arising from the analyses of the data received from the Haemophilia Centre Directors. One was the rise in the amount

of factor VIII used at Haemophilia Centres for the treatment of patients and the other was the encouraging rise in the amount of NHS factor VIII concentrate which had been used. There had been no change in the amount of commercial factor VIII concentrate compared with the amount used in 1980.

During the discussion of the report, Dr. Peter Kernoff said that he felt that some statistics which would be very useful were not available from the report as presented at present. For example, it would be useful if the amount of materials used for various categories of patients, such as the severely and moderately affected haemophilia A patients, could be analysed. It was pointed out that to provide the Directors with such information, the Haemophilia Centre Directors would have to send in additional data to Oxford. After discussion it was agreed that the collection of data should be left as at present.

With reference to the use of commercial factor IX concentrates, Dr. Snape of the Plasma Fractionation Laboratory pointed out that the P.F.L. was able to meet all demands made to them for supplies of factor IX concentrate. No request for factor IX had been turned down, therefore the use of commercial factor IX did not mean that the NHS was unable to meet its demands for NHS factor IX concentrate.

Regarding the treatment of von Willebrand's disease patients with commercial factor VIII, Professor Bloom pointed out that much of the commercial factor VIII which had been used in the treatment of this category of patients, had been used in Cardiff for the treatment of a patient with von Willebrand's disease who also had factor VIII inhibitors. He felt therefore that the figures for the von Willebrand's disease patients were heavily biased by the Cardiff patient who required very high

level treatment.

Dr. Preston said that he thought the information on deaths was not very meaningful or helpful. He stressed the importance of autopsies being carried out on all haemophilic patients who died, and he felt that much useful information was being lost because this information was not being collected and collated. Dr. Preston said that he had been asked by the Haemophilia Reference Centre Directors to draw up a simple form for the Reference Centre Directors' approval and subsequent distribution to all Haemophilia Centre Directors so that information regarding autopsies could be collected and returned for central analysis.

Dr. Kernoff said that many interesting points had been raised in the report and by the discussion from the floor of the meeting. He suggested that it would be helpful to the Haemophilia Centre Directors if Dr. Rizza could in future years write a memorandum which could be attached to the tables highlighting the points which he felt should be emphasised. This was agreed.

Following the statistical report, Dr. Lane gave a brief account of progress of the building programme at Elstree and of the increased factor VIII production from the Blood Products Laboratory. There was some discussion concerning future packaging of NHS factor VIII and IX, the need for larger proportions of plasma collected being fractionated, and the place of plasmapheresis in the fractionation programme. It was also pointed out that the DHSS was encouraging stricter auditing and accountability in the use of factor VIII and IX.

6. Criteria for the Designation of Haemophilia Centres/ Associate Centres

Introducing this item on the agenda, Professor Bloom said that there had been a trend towards the designation of more and more Haemophilia Centres over the last few years. Some of the Haemophilia Centres only treated one or two patients per year; no one would wish to stop these hospitals from treating patients on a day-to-day basis, but it could be questioned whether it was appropriate for those centres to be acknowledged as centres in view of their limited experience. The question had been discussed by the Haemophilia Reference Centre Directors at recent meetings and the Reference Centre Directors had asked Dr. Jones to draw up a discussion document based on the 1976 Health Circular (HC(76)4) for presentation to the Haemophilia Centre Directors.

Dr. Jones outlined the points made in the document, drawing attention to suggested changes. The discussion which followed showed that there was some strong feeling against the suggested changes and most of the comments from the floor were critical of the document, in particular concerning the proposed role of Reference Centres.

After further discussion it was agreed that the Haemophilia Centre Directors should send their comments on the draft document to Professor Bloom and that the matter would be discussed again by the Haemophilia Reference Centre Directors at their next meeting.

7. Provisional date and place for the next meeting of all the Haemophilia Centre Directors

It was agreed that the next meeting of the Haemophilia Centre Directors would be held in Oxford on 17th October 1983.

8. Any Other Business

a) Chairmanship of the Haemophilia Centre Directors

There being no other nominations, it was agreed that Professor Bloom should be asked to continue as Chairman for a further three years. Professor Bloom agreed to this.

9. Report on behalf of the Haemophilia Nurses Association

Sister Maureen Fearns presented a report on behalf of the Haemophilia Nurses Association. A Symposium was to be held in Newcastle the following weekend at which it was expected that 42 nurses would attend. There were three main topics at present under consideration by the Association. 1. To draw up a document defining the role of nurses at Haemophilia Centres. 2. To publish a newsletter. 3. To review the literature and other items relevant to haemophilia care put out by the Drug Companies.

Professor Bloom thought that it would be very useful if the Haemophilia nurses could draw up a job description for the nurses at the Haemophilia Centre and asked Sister Fearns if she could let him have a copy of such a document for assessment by the Haemophilia Reference Centre Directors and ultimately sent to all Directors. Sister Fearns agreed to do this.

10. Report on behalf of the Haemophilia Society/BASW Special Interest Group

Mrs. Jean Lovie presented a report on behalf of the Special Interest Group. The Group had been formed in 1979 under the auspices of the Haemophilia Society and the British Association of Social Workers. The Group is concerned to see the development of a social work service in all the major

Treatment Centres at least. Aware of the fight for resources the Group would like Directors to know that the Group will be pleased to add support in any negotiations that a Director may have in hand with his local Director of Social Services. The Group held two conferences a year, published a newsletter and other papers. They had had a meeting in May and a further meeting was to be held in November, on the problems of Unemployment and Disability.

11. Factor VIII Quality Control Study

Dr. Savidge said that Dr. Poller's group had met in May 1982 and he had been invited to attend as a representative of the Haemophilia Centre Directors. Four matters had been discussed at the meeting. (1) The Prothrombin Ratio: more than 600 laboratories had been involved in the study and only seven laboratories gave poor performances. (2) The Partial Thromboplastin time. (3) Factor $VIII_C$: The assay results on the normal plasma varied greatly from less than 10% to more than 100%. The best results had been obtained from the sample which contained 25% of factor $VIII_C$. (4) Factor $VIII_{Rag}$: There have been a considerable scatter of results for this assay. Dr. Savidge thought that the results were interesting but that further studies should be undertaken. Professor Bloom pointed out that Dr. Poller's factor VIII assay scheme covered not only Haemophilia Centres but included other hospitals who might not have wide experience of the assay.

12. Reports from Working Party Chairmen:-

a) Hepatitis

Dr. Craske said there had been no meetings of the Working Party for six months but a meeting was to be held at the end

of the Haemophilia Centre Directors' Meeting. A preliminary study in Oxford of hepatitis in mildly-affected or seldom-treated haemophilic patients had provided interesting data and the results of this study were currently being prepared for publication. He suggested that the advantage of the hepatitis-reduced risk materials which might soon be available should be evaluated along similar lines to the study which had been conducted in Oxford on the seldom-treated patients. The protocol which had been used for the Oxford study was available and he would be willing to provide the protocol to any Haemophilia Centre Director who would like to follow a similar study.

Hepatitis-B Vaccine. The vaccine had been licensed in the United Kingdom in May 1982. The DHSS had decided not to purchase centrally any vaccine owing to the high cost and each Region had to find the funds from existing budgets to purchase supplies. The vaccine would be available at the end of September and the DHSS had drawn up a list of priority patients who should be offered the vaccine. A trial was to be conducted in Oxford, giving the vaccine subcutaneously to Haemophilia A patients.

The acquired immune deficiency syndrome. The Reference Centre Directors had asked Dr. Craske to look into the report from the United States of this syndrome mainly in homosexuals but including three haemophiliacs. It appeared that there was a remote possibility that commercial blood products had been involved. Dr. Craske asked the Directors to let him know if they had any cases of the syndrome. The Working Party was considering the implications of the reports from the U.S.A.

b) Home Therapy

Dr. Jones said that the Home Therapy Working Party had finished its work and could be wound up. 84% of the predicted number of people for home therapy were now receiving home therapy, and he felt that the Working Party could now be disbanded subject to the agreement of the Haemophilia Centre Directors. This was unanimously agreed and Professor Bloom thanked Dr. Jones for the work he had done on behalf of the Directors during his time as Chairman of the Home Therapy Working Party.

c) Treatment of Patients who have Factor VIII Antibodies

Dr. Prentice said that a trial of Autoplex versus factor VIII concentrate was now under way. He outlined the protocol to be used for the trial and said that he hoped that approximately 30 patients with a total of 150 bleeding episodes would be included.

Dr. Peake then presented the results of a collaborative study he had carried out regarding the use of an inhibitor standard in an attempt to improve agreement in assay of factor VIII antibody between laboratories. Dr. Peake's studies showed that the introduction of a standard made results more variable. He thought this was due to compounding of errors in an assay which has a large variance.

d) Factor VIII Assay

Dr. Rizza reported that there had been several topics considered by the Working Party during the past year, including 1) a continuing study of barium citrate and aluminium hydroxide as absorbing agent in the 2-stage assay of factor VIII. 2) A collaborative study of commercial factor VIII concentrate comparing labelled potency with potency found by the user.

3) Involvement in calibration of 1st International Plasma Reference Material for factor VIII. Dr. Barrowcliffe presented an account of the 1st International Plasma Reference Material and said that the standard had been accepted by the World Health Organization.

e) Von Willebrand's disease

Dr. Tuddenham presented the report of the Working Party on von Willebrand's disease. A survey of the condition in the U.K. was being carried out in collaboration with Miss Spooner. So far clinical and laboratory information had been received concerning 557 patients with von Willebrand's disease. The survey was by no means complete as many Centres had not sent in any information and some Centres had only sent in information on a few of the patients whom they had registered with them. It was hoped that more information would come in in the near future and he drew the Directors attention to the documents which had been distributed to them with the 1981 Annual Returns forms circulated by Miss Spooner.

Any Other Business

There being no other business Professor Bloom thanked Dr. Wensley and Dr. Delamore and their staff for the hospitality they had shown to the Directors and the meeting closed at 5.00 p.m.