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(Revised February 1978)

Minutes of the 8th Meeting of the United Kingdom Haemophilia

Centre Directors. Held on 24th October 1977 in Oxford

Those present:- Prof. E.K. Blackburn (Chairman)

Dr. A. Aronstam, Alton.	Dr. J.O.P. Edgcumbe, Exeter.
Dr. W.S.A. Allan, Wolverhampton.	Dr. D. Ellis, B.P.L., Elstree.
Dr. A.M. Barlow, Huddersfield.	Dr. D.I.K. Evans, Manchester Children's Hospital.
Dr. D.L. Barnard, Leeds.	Prof. P. Flute, St. George's Hospital, London.
Dr. O.H.A. Baugh, Chelmsford.	Dr. E.A. French, Nottingham.
Dr. Ethel Bidwell, P.F.L., Oxford.	Dr. H. Greenburgh, Plymouth.
Dr. Rosemary Biggs, Oxford.	Prof. R.M. Hardisty, The Hospital for Sick Children, Great Ormond Street, London.
Dr. G. Birchall, Lancaster.	Dr. N.E.M. Harker, Middlesbrough.
Prof. A.L. Bloom, Cardiff.	Dr. J.P.L.A. Hayes, Chatham.
Dr. F.E. Boulton, Liverpool R.I.	Dr. F. Hill, Birmingham Children's Hospital.
Dr. Morag Chisholm, Southampton.	Dr. C.A. Holman, Lewisham.
Dr. V.M. Collins, DHSS, London.	Dr. J.F. Horley, Brighton.
Dr. B. Colvin, London Hospital.	Dr. Kay M. Hunt, Bradford.
Dr. S.H. Davies, Edinburgh.	
Sister G.S. Davis, N.E. Thames Co-ordinator.	Dr. R.M. Ibbotson, Stoke-on-Trent.
Dr. I.W. Delamore, Manchester, R.I.	Dr. A. Inglis, Carlisle.
Dr. Helen Dodsworth, St. Mary's Hosp., London.	Prof. G.I.C. Ingram, St. Thomas's, London.
Dr. J.A. Easton, Wexham Park Hospital, Slough.	

Dr. P. Jones, Newcastle.	Dr. C.R.M. Prentice, Glasgow.
Dr. P. Kirk, Bristol.	Dr. F.E. Preston, Sheffield.
Dr. T. Korn, Bangor.	Mr. J. Prothero, Haemophilia Society.
Dr. D. Lee, Lancaster.	Dr. S.G. Rainsford, Alton.
Dr. J. Leslie, Norwich.	Dr. J.D.M. Richards, U.C.H., London.
Dr. J.S. Lilleyman, Sheffield Children's Hospital.	Dr. C.R. Rizza, Oxford.
Dr. J.M. Matthews, Oxford.	Dr. Patricia Robb, Liverpool.
Dr. R.S. Mibashan, King's College Hospital.	Dr. Diana M. Samson, Harrow.
Dr. J. Murrell, Truro.	Dr. Shahriarhi, Westminster Hospital.
Dr. G.A. McDonald, Glasgow.	Dr. N.K. Shinton, Coventry.
Dr. N.M. Naik, Maidstone.	Prof. J.W. Stewart, Middlesex Hospital, London.
Prof. M.G. Nelson, Belfast.	Dr. J. Smith, P.F.L., Oxford.
Dr. D.A. Newsome, Blackburn.	Miss R.J.D. Spooner, Oxford.
Dr. E. Ntekim, Hillingdon.	Dr. J. Stuart, Birmingham.
Dr. J.S. Oakey, Grays, Essex.	Rev. A. Tanner, Haemophilia Society.
Dr. M.J. Painter, L.M.T. College, Alton.	Dr. C.G. Taylor, Pembury, Tunbridge Wells.
Miss Moira R. Patterson, P.F.C., Edinburgh.	Dr. D.S. Thompson, Luton.
Dr. M.J. Phillips, Taunton, Somerset.	Dr. J. Voke, Royal Free Hospital, London.
Dr. J.R.H. Pinkerton, Salisbury.	Dr. H.J. Voss, Kettering.
Mr. K.R. Polton, Haemophilia Society.	Dr. Sheila Waiter, DHSS, London.

Dr. R.T. Wensley,  
Manchester.

Dr. D.A. Winfield,  
Derby.

Dr. P.J. Whitehead,  
Whitehaven.

Dr. D.N. Whitmore,  
Lewisham.

Dr. J.R.B. Williams,  
Stevenage.

Dr. J.K. Wood,  
Leicester.

Prof. Blackburn welcomed the Directors especially the Directors of the newly designated Centres or Associate Centres who were attending the Directors' Meeting for the first time, also the representatives of the Plasma Fractionation Laboratories, Department of Health and Social Security and the Haemophilia Society.

Apologies for absence

Dr. S. Ardeman

Dr. P.A. Gover

Dr. P. Barkhan

Dr. R.C. Hallam

Prof. Bellingham (rep. by  
Dr. F.E. Boulton)

Dr. K.M. Harrison

Prof. Humble (rep. by Dr. Shahrairhi)

Dr. T.A. Blecher,

Dr. R.M. Hutchinson

Dr. R.P. Britt (rep. by  
Dr. E. Ntekim)

Dr. J. Kramer,

Dr. D.S. Carmichael

Dr. A. MacKenzie

Dr. D.G. Chalmers

Dr. J.R. Mann

Dr. I.A. Cook

Dr. J. Martin

Dr. K.P. Cotter

Dr. Maycock (rep. by Dr. Ellis)

Dr. J. Craske (Hepatitis W.P. report  
to be presented by Peter Kirk)

Dr. Mayne

Dr. T.R. Mitchell

Dr. A.A. Dawson

Prof. Mollison (rep. by Dr. H. Dodsworth)

Dr. K. Dormandy (rep. by  
Dr. J. Voke)

Dr. M.W. McEvoy

Dr. J.W. Nicholas

Dr. C.D. Forbes

Dr. J. O'Brien

Dr. B.E. Gilliver

Dr. M.J. O'Shea

Prof. R.H. Girdwood

Dr. R.W. Payne

Dr. E.G. Rees	Dr. R.D.H. Tierney
Dr. G.L. Scott (rep. by Dr. P. Kirk)	Dr. G. Tudhope
Dr. H. Sterndale	Prof. Turner (rep. by Dr. K.M. Hunt)
Dr. H.T. Swan (rep. by Prof. Blackburn & Dr. Lilleyman)	Mr. J.G. Watt (rep. by Miss Patterson)
Dr. L.M. Swinburne (rep. by Dr. D.L. Barnard)	Dr. M.L.N. Willoughby
	Dr. C.R.R. Wylie

Minutes of the last meeting were read and signed as a correct record of the last meeting.

Matters arising from the Minutes

(a) Report on setting up of Working Parties (Appendix A) outlining the background to the setting up of working parties had been circulated. The appendix also gave details of the 5 working parties which had been set up by the Reference Centre Directors. The meeting approved of the setting up of those working parties and approved their constitution.

(b) Report on Directors Annual Statistics

Appendix B giving details of the Annual Returns for 1976 had been previously circulated. The analysis of the figures was not complete owing to the fact that several Centres had not sent in their data. It was hoped that those Centres would send in their figures before the end of October so that the report on the Annual Returns for 1976 could be prepared before the end of the year for publication after approval by the Reference Centre Directors.

(c) Hepatitis Study

Dr. Peter Kirk presented the report (Appendix C) on behalf of Dr. Craske.

Discussion of the report was delayed until Item 8 on the Agenda.

(d) Treatment of patients with antibodies to factor VIII

Discussion of this was delayed until Item 8 on the Agenda.

(e) Home Treatment

An interim report was given on the progress of the collaborative study on Home Treatment being carried out at St. Thomas' Hospital and Oxford. The study had been completed and was being prepared for publication.

The question of hepatitis in the households of haemophiliacs having home treatment was raised. In answer Prof. Ingram said that he had looked into the incidence of cross infection with hepatitis in haemophilic households (Transfusion (1976) 16, 237-241) but not specifically in homes in which home treatment was taking place. It was felt that the Hepatitis Working Party might look at this problem.

(f) Staffing of Haemophilia Centres

Prof. Blackburn reported that he had over the years had much correspondence with the Directors regarding their staffing problems. Shortage of secretarial, nursing and junior medical staff seemed to be the main problem. As in the past it was felt that each Centre's problem should in the meantime be solved locally. Several speakers felt that the Survey carried out by Dr. Biggs some years ago into the staffing and workload at Reference Centres might provide useful guidelines for staffing at other Centres. The general feeling of the Meeting was that the publication of any information on staffing of Haemophilia Centre's would be of value.

Decision. The matter would be discussed further at the next Reference Centre Directors' Meeting possibly with a view to publishing the data collected by Dr. Biggs.

(g) Setting up of Meeting to discuss supply of factor VIII concentrates

Dr. McDonald reported that at the last meeting of Reference Centre Directors held in Oxford in May 1977, he had been invited to organize a meeting of representatives of those closely involved in the problem of factor VIII supplies namely DHSS, Scottish Home and Health

Department, Fractionation Laboratories, Blood Transfusion Centres and Haemophilia Centres. Preliminary enquiries showed that in some quarters there was little enthusiasm for such a meeting and so the meeting was not arranged.

There then followed a general discussion of the supply of factor VIII in the United Kingdom. Dr. Ellis said that the Laboratory at Elstree had a capacity to produce approximately 14 million units of factor VIII. Miss Patterson representing Protein Fractionation Centre, (PFC), Edinburgh said that PFC was at present processing up to 400 l of frozen plasma per week and Scotland was approaching the target of 1 million units of factor VIII per million of population per annum which was sufficient to meet the Scottish needs. No factor VIII was being sent to England. Dr. Prentice replied that in his opinion there was still a shortage of factor VIII in Scotland and that he had to buy commercial factor VIII to treat his patients.

In view of the large fractionation capacity at PFC some Directors wondered if it would not be possible to send plasma from England to Scotland for fractionation. Dr. Waiter said that approaches had been made to PFC on this point and that there were several major problems which stood in the way of such a step. Any increase in the amount of plasma fractionated at PFC would require the running of 2 or eventually 3 shifts per day. This along with other factors e.g. pay structure etc. required to be discussed with the unions and the Whitley Council before any progress could be made. It could become possible to transfer plasma from Transfusion Centres in England for fractionation in Scotland but further discussion between the Departments (DHSS and SHHD) will take place before final arrangements are made. The point was made again that there is a need for 50 million units of factor VIII/annum for the United Kingdom and that this should be in the form of freeze-dried concentrates.

(h) Handbook on Haemophilia

Dr. Jones reported that a draft of the handbook had been prepared and copies were available at the Meeting for Directors to take away and comment on. He wished to have all comments by the end of November, 1977.

(i) Transport

Mr. Polton (Haemophilia Society) said that the Society was extremely unhappy with the £7 per week mobility allowance and drew attention to the fact that it was not only a very small sum of money but was also taxable. He also drew attention to the great variation from Region to Region in how the assessment for mobility allowance was made. The Haemophilia Society is at present preparing a document on the present situation concerning mobility allowance and cars, and will send it to all Haemophilia Centres for comments. The meeting felt that this document would be of value and agreed to support the Haemophilia Society in its efforts.

(j) Telephone repairs

Prof. Blackburn said he had had much correspondence on this subject with officials at various levels in the P.O. Telephone Service. In summary it seems that it is extremely difficult to put haemophiliacs on the emergency repair list as a special category since there are others with illnesses which could be regarded as equally requiring this service. If large numbers of people were put on the emergency list the load of work would be too heavy and would cause a breakdown in the service. The general feeling was that each case should be dealt with at a local level and on an individual basis.

5. Report on Haemophilia Reference Centre Directors' Meeting

Dr. Rizza reported on the 4th meeting of Reference Centre Directors held in Oxford on the 23rd May, 1977.

6. Future Arrangements for Haemophilia Centre Directors' meeting

Prof. Ingram referred to his document (Appendix D) which had been previously circulated. He suggested that the Annual Meeting should in future be held in two parts, the business session taking place in the morning and a scientific session being held in the afternoon. He suggested also that any topics raised at the various Supra-regional meetings should be dealt with at the main Annual Meeting especially if they were of major interest and required national support. There was some discussion as to whether or not the meetings should be open to all personnel of the Centres. The general feeling was that the large numbers might give rise to problems. It was agreed that the next Haemophilia Centre Directors' Meeting should be organized along the lines set out in Prof. Ingram's Memorandum.

7. Supplies of factor VIII and factor IX concentrate

Dr. Ellis informed the meeting that Elstree was now supplying Regional Transfusion Centres with factor VIII concentrate for issue to Haemophilia Centres, the supply being based on information received from Centres concerning numbers of patients treated annually. Dr. Ellis also said that they were aiming at producing standard bottles containing 250 i.u. of factor VIII. Dr. Jones congratulated Elstree on the quality of factor VIII being produced.

With regard to factor IX supplies Dr. Bidwell commented that the amount being issued from the Plasma Fractionation Laboratory at Oxford was still rising but was showing signs of levelling off. Dr. Bidwell reminded Directors that the product was licensed for use only in patients with congenital deficiencies of factor II, IX and X. Its use in other deficiency states requires a prescription for a named patient, and also a detailed report of the circumstances in which it was used, and its effect.

8. Progress Report from Working Party Chairmen

(a) Home Treatment

Dr. Jones said that the Home Treatment Working Party planned to meet twice each year. They had already held one meeting and planned to undertake 4 projects:-

1. Study of minimum dose required for control of haemorrhage
2. Study of prophylaxis
3. Study of employment of haemophiliacs
4. Study of long term side effects of replacement therapy. It was agreed that all publications resulting from the above projects would be published on behalf of all the Haemophilia Centre Directors.

The Working Party felt that some funds might be required to cover the costs of some projects and suggested that the Haemophilia Society should be asked for money. It was agreed that the Haemophilia Society should be approached in a more formal fashion and be allowed to consider the proposals. In the meantime the Working Party Chairmen and the Reference Centre Directors should come to some agreement about the various projects and their priorities for funding. There were other sources of research funds in the Regions and from the Department of Health and Social Security. Any proposals put forward would presumably have to compete with the many other research projects submitted.

Dr. Jones gave the results obtained from a questionnaire on home treatment sent to Haemophilia Centres in the United Kingdom during 1976. The replies showed that there were 729 patients on home treatment and that they used on average 19,920 units of factor VIII per patient per year.

(b) The Working Party on the treatment of patients with factor VIII antibodies. Dr. Prentice reported on work so far carried out by their Working Party. At present he was collecting information from the various Centres on the numbers of patients with antibodies being treated and on

the type and amount of materials being used. It was stressed that information should be gathered also about patients who had received no replacement therapy or who had received local treatment. There is considerable variation in the methods used for detecting and assessing antibodies and it was felt that some attempt should be made to standardize methods in the United Kingdom.

(c) Working Party on Detection of Carriers of Haemophilia

Prof. Bloom reported that this Working Party had not yet had any formal meetings but aspects which could be studied included: the implications of the introduction of standards for factor VIII coagulant activity and factor VIII-related antigen on carrier detection; detailed follow-up of women examined for carrier status. The preparation of a broadsheet on carrier detection would also be considered.

Hepatitis Working Party

Dr. Kirk presented the report on behalf of Dr. Craske. He mentioned that Dr. Craske has suggested that information should be collected regarding patients who were HB<sub>s</sub>Ag Carriers. Some Directors expressed concern about this data being included in the National Register as they were worried that the information might become available to unauthorised persons and be used in a manner detrimental to the interests of the patients. It was pointed out that all data provided by the Haemophilia Centre Directors were regarded as confidential.

There then followed a discussion of the advisability of liver biopsy in haemophiliacs. The consensus was that each case must be considered individually and in particular that the Hepatitis Working Party should be informed of any such patients.

Working Party on factor VIII assay

Dr. Rizza reported that the Working Party had not yet held a formal meeting. The first project of the Working Party was to follow up the findings of the Workshop held in Oxford - November 1976.

Any Other Business

(a) Macfarlane Award

The Reverend Tanner of the Haemophilia Society said that the Society wished to pay tribute to the work of Professor Macfarlane by making an award, the "Macfarlane Award" to a doctor, scientist or other person who makes a contribution to the cause of haemophilia. The Award would take the form of a gold medal and citation and would be awarded annually or less frequently. The Council of the Haemophilia Society had decided that the first award should be made to Dr. Katharine Dormandy and expressed their pleasure at making the announcement at the Directors' Meeting. The meeting showed its appreciation of the award and asked the Chairman to write to Dr. Dormandy conveying to her their congratulations.

(b) Analgesics in haemophilia

The problem of excessive use of analgesics and of possible drug addiction in haemophiliacs was discussed at some length. Pain of chronic arthropathy is one of the greatest problems facing the haemophiliac today. Hopefully this would be a diminishing problem with the young haemophiliac on home therapy. In the meantime great care should be exercised when prescribing addictive drugs. It was generally felt that this topic should be referred to the Haemophilia Reference Centre Directors for discussion.

(c) Home treatment packs

Dr. J. Stuart (Birmingham) raised the question of home treatment packs and asked how valuable such packs were. Several commercial companies provided home treatment packs and he wondered if the NHS would produce similar packs if they were thought suitable. It was suggested that this matter should be dealt with by the Working Party on Home Treatment.

(d) Supplies of factor VII

Dr. Bidwell drew attention to the fact that a concentrate of factor VII had been prepared at the Plasma Fractionation Laboratory at

Oxford and could be supplied on prescription for treatment of named patients suffering from congenital factor VII deficiency. If any Centres required this material they were advised to get in touch with Dr. Bidwell.

(e) Anti-A and Anti-B Agglutinins in factor VIII concentrate

Dr. Rizza referred to a letter from Dr. Lane (Director-Designate, Lister Institute, B.P.L.) raising the question of anti-A and anti-B agglutinins in factor VIII concentrate. Dr. Lane wished to know to what extent clinicians are concerned about the presence of anti-A and anti-B in concentrates and would like if possible to have some feed-back of clinical information on this matter. It was decided in the first instance to try to ascertain the size of the problem and to ask the Directors to write to Dr. Rizza giving details of any patients who had suffered haemolysis following the administration of factor VIII concentrate.

(f) Lord Mayor Treloar College

Dr. Rainsford drew attention to the fact that the number of haemophilic boys applying for admission to the College had decreased and that there were only 4 applications this year compared with 7 last year. He wished to know if Haemophilia Centre Directors were changing their policy with regard to sending boys to the College. The comment was made that the decrease in haemophiliacs applying for admission was in all likelihood a reflection of the improvement in haemophilia treatment throughout the United Kingdom both at Centres and by home therapy.

As no other matters were raised, the Chairman closed the meeting at 4.00 p.m.