MEETING OF HAEMOPHILIA CENTRE DIRECTORS OF THE UNITED KINGDOM

To be held on MONDAY, 24th OCTOBER, 1977

in the Conference Room of the Oxford Regional Health Authority, Old Road, Headington, Oxford, at 9.30am.

AGENDA

1.	Opening Address	Prof. E.K. Blackburn
2.	Apologies for Absence	
3.	Minutes of the Last Meeting	
4.	Matters arising from the Minutes:-	
	a) Report on setting-up of Working Parties (see enclosed Appendix A)	C.R. Rizza
	b) Report on Directors' Annual Statistics (see enclosed Appendix B)	C.R. Rizza & R.J.D. Spooner
	c) Hepatitis Study (see enclosed Appendix C and Item 8)	
	d) Treatment of patients who have anti-factor VIII antibodies (see Item 8)	
	e) Home Treatment (see also Item 8)	C.R. Rizza & G.I.C. Ingram
	f) Staffing of Haemophilia Centres	E.K. Blackburn
	g) Report on meeting regarding supplies of Factor VIII concentrate (see also Item 7)	G. McDonald
	h) Progress with Handbook on Haemophilia	P. Jones
	i) Transport for haemophiliacs	E.K. Blackburn
	j) Telephone repairs	E.K. Blackburn
5.	Report on Haemophilia Reference Centre Directors Meeting	C.R. Rizza
6.	Future arrangements for Haemophilia Centre Directors Meetings (see enclosed Appendix D)	G.I.C. Ingram
7.	Present position regarding supplies of Factor VIII and Factor IX concentrates and their distribution	W.d'A. Maycock & E. Bidwell
8.	Progress Reports from Working Party Chairman	
9.	Any Other Business	

Morning Coffee: 11.00 a.m.
Lunch: 1.00 p.m.
Afternoon Tea: 3.30 p.m.

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   b) Report on Directors' Annual Statistics (see enclosed Appendix B) — C.R. Rizza & R.J.D. Spoone
   c) Hepatitis Study (see enclosed Appendix C and Item 8)
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5. Report on Haemophilia Reference Centre Directors Meeting — C.R. Rizza
6. Future arrangements for Haemophilia Centre Directors Meetings (see enclosed Appendix D) — G.I.C. Ingram
7. Present position regarding supplies of Factor VIII and Factor IX concentrates and their distribution — W.d'A. Maycoc E. Bidwell
8. Progress Reports from Working Party Chairmen.
9. Any Other Business

Morning Coffee: 11.00 a.m.
Lunch: 1.00 p.m.
Afternoon Tea: 3.30 p.m.

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Haemophilia Centre Directors Sweden

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. W.S.A. Allan,
Wolverhampton.

Dr. A.M. Barlow,
Huddersfield.

Dr. D.L. Barnard,
Leeds.

Dr. O.H.A. Baugh,
Chelmsford.

Dr. Ethel Bidwell,
P.F.L., Oxford.

Dr. Rosemary Biggs,
Oxford.

Dr. G. Birchall,
Lancaster.

Prof. A.L. Bloom,
Cardiff.

Dr. F.E. Boulton,
Liverpool R.I.

Dr. Morag Chisholm,
Southampton.

Dr. V.M. Collins,
DHSS, London.

Dr. B. Colvin,
London Hospital.

Dr. S.H. Davies,
Edinburgh.

Sister G.S. Davis,
N.E. Thames Co-ordinator.

Dr. I.W. Delamore,
Manchester, R.I.

Dr. Helen Dodsworth,
St. Mary's Hosp., London.

Dr. J.A. Easton,
Wexham Park Hospital, Slough.

Dr. J.O.P. Edgcumbe,
Exeter.

Dr. D. Ellis,
B.P.L., Elstree.

Dr. D.I.K. Evans,
Manchester Children's Hospital.

Prof. P. Flute,
St. George's Hospital, London.

Dr. E.A. French,
Nottingham.

Dr. H. Greenburgh,
Plymouth.

Prof. R.M. Hardisty,
The Hospital for Sick Children,
Great Ormond Street, London.

Dr. N.E.M. Harker,
Middlesbrough.

Dr. J.P.L.A. Hayes,
Chatham.

Dr. F. Hill,
Birmingham Children's Hospital.

Dr. C.A. Holman,
Lewisham.

Dr. J.F. Horley,
Brighton.

Dr. Kay M. Hunt,
Bradford.

Dr. R.M. Ibbotson,
Stoke-on-Trent.

Dr. A. Inglis,
Carlisle.

Prof. G.I.C. Ingram,
St. Thomas's, London.

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Dr. P. Jones,
Newcastle.

Dr. P. Kirk,
Bristol.

Dr. T. Korn,
Bangor.

Dr. D. Lee,
Lancaster.

Dr. J. Leslie,
Norwich.

Dr. J.S. Lilleyman,
Sheffield Children's Hospital.

Dr. J.M. Matthews,
Oxford.

Dr. R.S. Mibashan,
King's College Hospital.

Dr. J. Murrell,
Truro.

Dr. G.A. McDonald,
Glasgow.

Dr. N.M. Naik,
Maidstone.

Prof. M.G. Nelson,
Belfast.

Dr. D.A. Newsome,
Blackburn.

Dr. E. Ntekim,
Hillingdon.

Dr. J.S. Oakey,
Grays, Essex.

Dr. M.J. Painter,
L.M.T. College, Alton.

Miss Moira R. Patterson,
P.F.C., Edinburgh.

Dr. M.J. Phillips,
Taunton, Somerset.

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

Mr. K.R. Polton,
Haemophilia Society.

Dr. C.R.M. Prentice,
Glasgow.

Dr. F.E. Preston,
Sheffield.

Mr. J. Prothero,
Haemophilia Society.

Dr. S.G. Rainsford,
Alton.

Dr. J.D.M. Richards,
U.C.H., London.

Dr. C.R. Rizza,
Oxford.

Dr. Patricia Robb,
Liverpool.

Dr. Diana M. Samson,
Harrow.

Dr. Shahriarhi,
Westminster Hospital.

Dr. N.K. Shinton,
Coventry.

Prof. J.W. Stewart,
Middlesex Hospital, London.

Dr. J. Smith,
P.F.L., Oxford.

Miss R.J.D. Spooner,
Oxford.

Dr. J. Stuart,
Birmingham.

Rev. A. Tanner,
Haemophilia Society.

Dr. C.G. Taylor,
Pembury, Tunbridge Wells.

Dr. D.S. Thompson,
Luton.

Dr. J. Voke,
Royal Free Hospital, London.

Dr. H.J. Voss,
Kettering.

Dr. Sheila Waiter,
DHSS, London.

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Dr. R.T. Wensley,
Manchester.

Dr. P.J. Whitehead,
Whitehaven.

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

Dr. D.A. Winfield,
Derby.

Dr. D.N. Whitmore,
Lewisham.

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 Director's 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. Barkhan

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

Dr. T.A. Blecher,

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

Dr. D.S. Carmichael

Dr. D.G. Chalmers

Dr. I.A. Cook

Dr. K.P. Cotter

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

Dr. A.A. Dawson

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

Dr. C.D. Forbes

Dr. B.E. Gilliver

Prof. R.H. Girdwood

Dr. P.A. Gover

Dr. R.C. Hallam

Dr. K.M. Harrison

Prof. Humble (rep. by Dr. Shahrairhi)

Dr. R.M. Hutchinson

Dr. J. Kramer,

Dr. A. MacKenzie

Dr. J.R. Mann

Dr. J. Martin

Dr. Maycock (rep. by Dr. Ellis)

Dr. Mayne

Dr. T.R. Mitchell

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

Dr. M.W. McEvoy

Dr. J.W. Nicholas

Dr. J. O'Brien

Dr. M.J. O'Shea

Dr. R.W. Payne

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

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(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 400 L of fresh frozen plasma per week and was producing approximately 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 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. Should it become possible to transfer plasma from Transfusion Centres in England for fractionation in Scotland the transfer would be probably centralized through the Blood Products Laboratory at Elstree. 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 Director's held in Oxford on the 23rd May, 1977.

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6. Future Arrangements for Haemophilia Centre Director's 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 meetingsshould 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 Transfusion Centres with factor VIII 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 questionaire 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

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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_sAg 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 was 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.

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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 was now available for use in 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 Director 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.

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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. W.S.A. Allan,
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Dr. D.L. Barnard,
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Dr. O.H.A. Baugh,
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Dr. Ethel Bidwell,
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Dr. Rosemary Biggs,
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Dr. G. Birchall,
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Prof. A.L. Bloom,
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Dr. A. Inglis,
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Prof. G.I.C. Ingram,
St. Thomas's, London.

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Dr. P. Jones,
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Dr. P. Kirk,
Bristol.

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Bangor.

Dr. D. Lee,
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Dr. J. Leslie,
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U.C.H., London.

Dr. C.R. Rizza,
Oxford.

Dr. Patricia Robb,
Liverpool.

Dr. Diana M. Samson,
Harrow.

Dr. Shahriarhi,
Westminster Hospital.

Dr. N.K. Shinton,
Coventry.

Prof. J.W. Stewart,
Middlesex Hospital, London.

Dr. J. Smith,
P.F.L., Oxford.

Miss R.J.D. Spooner,
Oxford.

Dr. J. Stuart,
Birmingham.

Rev. A. Tanner,
Haemophilia Society.

Dr. C.G. Taylor,
Pembury, Tunbridge Wells.

Dr. D.S. Thompson,
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Dr. J. Voke,
Royal Free Hospital, London.

Dr. H.J. Voss,
Kettering.

Dr. Sheila Waiter,
DHSS, London.

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Dr. R.T. Wensley,
Manchester.

Dr. P.J. Whitehead,
Whitehaven.

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

Dr. D.A. Winfield,
Derby.

Dr. D.N. Whitmore,
Lewisham.

Dr. J.K. Wood,
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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.

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Dr. M.J. O'Shea

Dr. R.W. Payne

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Dr. E.G. Rees

Dr. G.L. Scott (rep. by Dr. P. Kirk)

Dr. H. Sterndale

Dr. H.T. Swan (rep. by Prof. Blackburn & Dr. Lilleyman)

Dr. L.M. Swinburne (rep. by Dr. D.L. Barnard)

Dr. R.D.H. Tierney

Dr. G. Tudhope

Prof. Turner (rep. by Dr. K.M. Hunt)

Mr. J.G. Watt (rep. by Miss Patterson)

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.

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(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.

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(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.

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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 questionaire 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_sAg 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 liklihood a reflection of the improvement in haemophilia treatment throughtout 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.

Appendix A

Report on Setting-up of Working Parties

At the last meeting of the Haemophilia Centre Directors held on 13.1.77 at the Middlesex Hospital, London, it was agreed that working parties should be set up "to study problems of interest to Haemophilia Centre Directors and patients". A questionnaire has been sent round asking Haemophilia Centre Directors and others interested in the problems of haemophilia for their views about possible subjects for study by working parties. The answers obtained showed that there was interest in the setting-up of working parties on a number of topics. Those topics were discussed at the meeting of Reference Centre Directors held in Oxford in May, 1977, and it was agreed that working parties should be set-up as shown below:-

1. Home therapy and prophylaxis of haemophilia and Christmas disease:

   Chairman - Dr. P. Jones (Newcastle)

   Members - Sister M. Fearns (Newcastle)
   Dr. C.D. Forbes (Glasgow)
   Dr. J. Stuart (Birmingham)

2. Treatment of patients having factor VIII antibodies

   Chairman - Dr. C.R.M. Prentice (Glasgow)

   Members - Dr. F.E. Preston (Sheffield)
   Dr. I.W. Delamore (Manchester)
   Mr. T. Snape (Oxford)
   Prof. A.L. Bloom (Cardiff)
   Prof. G.I.C. Ingram (London)

3. Detection of Carriers of haemophilia

   Chairman - Prof. A.L. Bloom (Cardiff)

   Members - Dr. C.R.M. Prentice (Glasgow)
   Dr. C.D. Forbes (Glasgow)
   Dr. C.R. Rizza (Oxford)

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4. Hepatitis in haemophilia and Christmas disease

Chairman - Dr. J. Craske (Manchester)

Members - Miss R.J.D. Spooner (Oxford)

Dr. P. Kirk (Bristol)

Dr. S.H. Davies (Edinburgh)

5. Standardization of reagents and assay methods for factor VIII

Chairman - Dr. C.R. Rizza (Oxford)

Members - Prof. G.I.C. Ingram (London)

Dr. T. Barrowcliffe (NIBSC)

Dr. T.B.L. Kirkwood (NIBSC)

Mr. I.L. Rhymes (Oxford)

It is envisaged that additional member(s) will be co-opted to the Working Parties from time-to-time to provide the Working Parties with Specialist advice and/or Services.

C.R. Rizza
Oxford Haemophilia Centr

15.9.77

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Appendix B

Annual Returns from Haemophilia Centres

Annual Statistics for 1975:

The Annual Statistics for 1975 has been published in the British Journal of Haematology on behalf of the Haemophilia Centre Directors (Brit. J. Haemat. 36, 447 (1977). Reprints of the published report have been ordered and a copy will be sent to all Haemophilia Centre Directors as soon as possible.

Annual Statistics for 1976:

To date (14.9.77) Annual Returns for 1977 have been received from 51 of the 75 Haemophilia Centres established by December 1976 (Ref. HM 8974 Dd 565831 5M 12/76 McC3309). During 1977 several additional Centres have been designated and to date 9 of these new Centres have been able to supply information relating to patients treated during 1976. This information is included in the following report.

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Haemophilia A

Number of patients treated: 1434*

Materials received by these patients:

	F.VIII units	% of all human blood products
Plasma	15,480	0.06
Cryo	12,235,630	46.13
NHS Concs.	6,196,641	23.36
Commercial Concs.(Human)	8,074,187	30.44
Other Human Concs.	3,807	0.01
Total human blood products	26,525,745	100.00
Animal F.VIII Concs.	92,240	
Total all materials	26,617,985	

Average per patient of human blood products = 18,498 units F.VIII

* adjusted for duplicates on the basis of the percentage duplication (13%) of patients in the 1975 Annual Returns. This figure will be corrected when the analysishas been completed.

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Haemophilia B (Christmas Disease)

Number of patients treated: 258*

Materials received by these patients:-

	F. IX Units	% of all Materials
Plasma	16,480	0.36
NHS Concs.	4,509,762	99.37
Commercial Concs.	12,400	0.27
Total	4,538,642	100

Average per patient = 17,592 units F.IX.

* Adjusted for duplicates on the basis of the percentage duplication (10%) of patients in the 1975 Annual Returns. This figure will be corrected when the analysis has been completed.

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Carriers of Haemophilia A

Total number of patients treated: 15

Materials received by these patients:-

	F.VIII Units	% Total all Materials
Cryo	15,045	31.23
NHS Concs.	28,330	58.81
Commercial Concs.	4,800	9.96
Total	48,175	100.00

Average per patient = 3,212 units of F.VIII

Carriers of Haemophilia B (Christmas disease)

Total number of patients treated: 5

Materials used to treat these patients:-

	F.IX Units	% Total all Materials
Plasma	1,600	25.40
NHS Concs.	4,700	74.60
Total	6,300	100.00

Average per patient = 1,260 units F.IX

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von Willebrand's disease

Total number of patients treated: 152

Materials used to treat these patients:-

	F.VIII Units	% Total all Materials
Plasma	7,600	1.09
Cryo	613,085	88.51
NHS Concs.	37,650	5.44
Commercial Concs.	34,337	4.96
Total	692,672	100.00

Average per patient = 4,557 units F.VIII

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Cases of Jaundice (Hepatitis) reported since preparation of 1975 Statistics:-

Haemophilia A

Treatment Year	No Haemophiliacs treated	Incidence of Jaundice	% patients who developed Jaundice
1976	1434	49 (55)	3.42 (3.84)
1977	?	3	

( ) the number in brackets indicates the total including patients who were asymptomatic.

Carriers of Haemophilia A:

1 Patient treated during 1976 (6.6%) was reported to have developed hepatitis.

Haemophilia B (Christmas disease):

7 Patients treated during 1976 (2.71%) were reported as having developed hepatitis.

Carriers of Haemophilia B:

None of the patients treated during 1976 were reported as having developed hepatitis.

Von Willebrand's disease:

5 Patients treated during 1976 (3.29%) were reported as having developed hepatitis.

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Cases of Jaundice (Hepatitis) - 1976 Treatment Year

Material(s) received during the 6 months prior to developing hepatitis	Number of Cases Reported
Haemophilia A Patients	
NHS Concs. only	2
Cryo. only	5
Hemofil only	1
Cryo. + NHS Concs.	2
Cryo. + NHS Concs. + Commercial concs.	7
Cryo. + Commercial concs.	11
NHS + Commercial concs.	6
Commercial concs. only (more than 1 type)	2
Details incomplete	18
Jaundice unlikely to be due to blood products	1
TOTAL	55
Carriers of Haemophilia A	
Details incomplete	1
Haemophilia B (Christmas Disease)	
NHS F.IX Conc. only	2
NHS F.IX Conc. + Plasma	1
Jaundice unlikely to be due to blood products	1
Details incomplete	3
TOTAL	7
von Willebrand's disease	
NHS F.VIII Concs. only	1
Kryobulin only	1
Cryo. + Kryobulin	2
Cryo. + Pkt. cells	1
TOTAL	5

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Home Treatment

The returns so far received indicate that approximately 24% of the haemophilia A patients and 19% of the haemophilia B (Christmas disease) patients treated during 1976 were receiving regular home therapy.

Haemophiliacs with Anti-Factor VIII antibodies (Inhibitors)

14 new cases were detected during 1976 and 1 patient with a long-standing inhibitor was included in Annual Returns for the first time in 1976.

4 new cases have so far been detected and reported for 1977.

Christmas disease patients with Anti-Factor IX Antibodies

No new cases have been reported.

Total Number of Patients in the National Register

Patients reported on Form B1 during 1976 and those traced through the Reference Centre Directors Survey of patients treated at other hospitals in the United Kingdom in 1975 or known at Centres but not treated in 1969-1975 have now been included in the Register. New patients treated for the first time in 1976 for whom no form B1 was received are not yet fully included. The number of patients at present included in the register is as follows:-

	Total known
Haemophilia A	3,176
Haemophilia B	528
von Willebrand's disease	152
Carriers of Haemophilia A	15
Carriers of Haemophilia B	5

We hope it will be possible for the Annual Statistics for 1976 to be completed in the near future so that a report can be prepared for publication on behalf of all Haemophilia

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Centre Directors.

Annual Statistics for 1977

Forms will be circulated early in 1978 for Directors to complete and return to Oxford for analysis. These forms will be very similar to those used for the 1976 Annual Returns but will be slightly amended to assist with the analysis of data required by the Hepatitis Working Party.

C.R. Rizza
R.J.D. Spooner
Oxford Haemophilia Centre

15.9.1977.

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British Journal of Haematology, 1977, 36, 447.

Correspondence

HAEMOPHILIA CENTRE DIRECTORS' ANNUAL STATISTICS FOR 1975

Since 1969 the Directors of Haemophilia Centres in the United Kingdom have collected information about the numbers of patients having haemophilia A and B, about the treatment received by these patients and about the complications of treatment. A report on the statistics for the 6 years 1969–74 has appeared in *British Journal of Haematology* (Biggs & Spooner, 1977). The purpose of the present letter is to bring the statistics up to date by adding the main figures for 1975. It is intended to carry out this updating process annually until the accumulation of data warrants a more complete report. The data now presented will enable those who wish to do so to fill in one further year's figures for Tables III, VI, IX, X, XI, and XIV of the prior publication (Biggs & Spooner, 1977).

TABLE III. Deaths during 1975

Haemophilia A	6 deaths (1 cancer, 1 cerebral haemorrhage, 1 cardiovascular disease, 1 no information, 1 hepatitis B, 1 post-operative bronchopneumonia)
Haemophilia B	2 deaths (both come under the heading of 'Other types of bleeding')

TABLE VI. Factor VIII preparations used during 1975 to treat haemophilia A

Type of material	*Factor VIII (units)*	*% total*
Plasma	355400	1.43
Cryoprecipitate	16286998	65.45
NHS VIII concentrate	3085465	12.40
Commercial VIII concentrate	5151935	20.70
Other	6420	0.02
Total	24886218	100.00

Number of Haemophilia Centres	53
Number of patients treated*	1670
Average amount of factor VIII units used per patient	14902

* Excluding those not transfused and adjusted for duplicates.

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TABLE IX. Material used to treat haemophilia B (Christmas disease) patients during 1975

Type of material	*Factor IX(units)*	*% Total*
Plasma	23450	0.48
NHS factor IX concentrate	4832393	98.33
Commercial factor IX concentrate	58800	1.19
Total	4914643	100.00
Number of Centres with Christmas disease patients		43
Number of patients treated*		275
Average amount of factor IX units used per patient		17871

* Excluding those not transfused and adjusted for duplicates.

TABLE X. The incidence of jaundice in haemophilia A patients during 1975

Patient-treatment-years	*No. of incidents of jaundice*		*%*
1670	45*	(56)	2.69

* One patient had two attacks of jaundice. The figure in parentheses includes patients who had raised LFTs but were not ill.

TABLE XI. The incidence of jaundice in Christmas disease patients during 1975

No. of patient-treatment-years	*No. of incidents of jaundice*	*%*
275	2	0.73

TABLE XIV. Incidence of factor VIII or factor IX antibodies in patients having haemophilia A or B

Haemophilia A				*Haemophilia B*			
Cumulative total number of patients in survey	*Cumulative number with factor VIII antibody*	*%*	*New cases detected in 1975*	*Cumulative total number of patients in survey*	*Cumulative number with factor IX antibody*	*%*	*New cases detected in 1975*
2854	184	6.45	13	446	5	1.12	0

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Points which may be emphasized in the figures for 1975 are:

(1) The total number of haemophilia A patients who have been treated at the Centres is now nearly 3000, which was the number originally estimated to be the total for the United Kingdom.

(2) The amount of commercial factor VIII used has increased from 13% in 1974 to 20% in 1975.

(3) The incidence of jaundice in 1975 was substantially less than that in 1974.

Oxford Haemophilia Centre, Churchill Hospital, Headington, Oxford OX3 7LJ

ROSEMARY BIGGS
ROSEMARY J. D. SPOONER
(on behalf of the Haemophilia Centre Directors of the United Kingdom)

REFERENCE

BIGGS, R. & SPOONER, R. (1977) Haemophilia treatment in the United Kingdom from 1969 to 1974. *British Journal of Haematology*, **35**, 487.

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HAEMOPHILIA DIRECTORS HEPATITIS WORKING PARTY

HEPATITIS ASSOCIATED COMMERCIAL FACTOR VIII 1976

As a continuation of the study of Hemofil begun in 1974, it was decided to study the incidence of hepatitis after transfusions of Kryobulin in 1976 and to compare this with that due to Hemofil.

The methods used were the same as in the first Hemofil survey. Six batches of Hemofil were studied and transfusion records were available on 16 batches of Kryobulin. One out of 16 batches of Kryobulin and one of six batches of Hemofil were positive for HB_sAg when tested by Radioimmunoassay (RIA) by Dr. Dane at the Virus Laboratory, Middlesex Hospital. It is probable that this is a reflection of the introduction of the screening of donors by RIA by all commercial firms in 1975.

RESULTS

Returns were received from 24 Haemophilia Centres. There was epidemiological evidence that 2/6 batches of Hemofil and 2/16 batches of Kryobulin contained hepatitis B virus. Similarly, 4/6 batches of Hemofil and 3/17 batches of Kryobulin were associated with cases of Non-B hepatitis. Of 371 patients transfused with Hemofil in 1974-5, 111 received further transfusions in 1976. In addition 77 patients received Hemofil for the first time. A total of 101 patients were transfused with Kryobulin of whom 31 had previously received Hemofil in 1974-5.

HEPATITIS B

Table 1 summarises the cases of hepatitis detected so far. Two cases of hepatitis B occurred in patients previously known to have had transfusions of Hemofil in 1974. There were two asymptomatic cases not included in Table 1 which were detected by chance when they were found to have become HB_sAg positive. These patients received one and two bottles respectively of one batch of Hemofil in 1974, so they were probably not infected with Hepatitis B when transfused

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with Hemofil. Studies at Alton show that of 14 patients susceptible before transfusion with Hemofil, 13 had hepatitis or seroconverted to Anti-HB_s positive, giving an attack rate of 92.8%. It is not possible to measure the effect of donor screening on the incidence of hepatitis B yet as more cases are needed to produce a significant result.

NON-B HEPATITIS

Cases of Hemofil associated Non-B hepatitis have continued to occur, all in patients receiving Hemofil for the first time. Evidence of specific protection conferred by a previous batch of Hemofil against contracting Non-B hepatitis is given in Table 2. With the exception of batch X, all 47 cases of hepatitis after transfusion of batches Q - W are in patients receiving Hemofil for the first time. The evidence relating to Hemofil associated Non-B hepatitis is the best we have so far that this is an infective agent which confers specific protection against re-exposure from further batches infected with the same agent, as is shown in Table 2. One case associated with batch X occurred in a patient who received 201 bottles from 7 batches, 6 of which were known to produce Non-B hepatitis in other patients. There was no other known source for his hepatitis, so that one explanation may be that a second agent is involved in transfusion associated Non-B hepatitis.

MULTIPLE ATTACKS OF HEPATITIS

Further evidence in favour of a second type of Non-B hepatitis is given in Table 3. Fourteen out of 512 patients in this survey have had multiple attacks of hepatitis; 11 had Hemofil associated Non-B + Hepatitis B; one had Lister associated Non-B hepatitis in 1973 at Alton followed by Hemofil associated Non-B in 1974. Two patients, one of whom also had Hemofil associated hepatitis B, had Hemofil associated Non-B hepatitis in 1974 followed by Kryobulin associated hepatitis in 1976, i.e. one patient had 3 attacks. This suggests that an attack of Hemofil associated Non-B hepatitis fails to protect against Kryobulin Non-B hepatitis, i.e. a second type of Non-B hepatitis is probably associated with Kryobulin transfusions, and possibly batch X of Hemofil (Table 2). Further

analysis of these data should be available shortly.

The incubation period of Kryobulin associated Non-B hepatitis has a range of 7-91 days whereas that for Hemofil is 8-60 (figure 1). Further information may be obtained during the next year when it is proposed to compare Hemofil and Kryobulin in the same way.

CONCLUSIONS

These results indicate that it is essential to continue these studies with the object of answering the following questions.

1) The effect of the RIA screening for HB_sAg of the plasma donations used to prepare plasma pools on the incidence of commercial Factor VIII hepatitis B

2) The number of types and incidence of Non-B hepatitis.

3) The incidence of sequelae after acute hepatitis. One of the first schemes to be put forward by the Hepatitis Working Party will be a project to follow up every case of hepatitis associated with commerci l Factor VIII which has been included in this survey. This will be put forward at the meeting of the Supra Regional Directors in the New Year.

Further projects proposed are as follows:

1) A study of hepatitis after NHS concentrate. Some Centres have already agreed to take part but anyone who is interested should contact me at the Public Health Laboratory, Withington Hospital, Manchester M20 8LR (Tel: 061-445-2416). It is hoped to start this project sometime in November or December, 1977.

2) A retrospective survey of the records of past years at Oxford to study the incidence of multiple attacks of hepatitis.

3) The compilation of a register of carriers of HB_sAg to be kept with the other patient data at Oxford so that this information is readily available. This might include a patient's E antigen status. Carriers who are E antigen posit are known to be far more effective transmitters of hepatitis B to contacts than E antibody positive carriers.

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4) I also suggest that a collection of sera which are discarded after laboratory use be made, so that retrospective studies can be undertaken should tests for Non-B hepatitis become available. Storage facilities can be made available at the Public Health Laboratory, Manchester. This will not preclude any other interested persons making their own collections.

We are also interested in receiving faeces and urine from cases of Non-B hepatitis, if possible taken within one week of the onset of illness, to attempt isolation of possible infective agents. Specimen containers and packaging can be obtained if necessary from me at the Public Health Laboratory, Withington Hospital.

J. Craske.
22.9.77.

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TABLE 1

FACTOR VIII ASSOCIATED HEPATITIS 1973-6

YEAR	BRAND	TOTAL PATIENTS TRANSFUSED	HEPATITIS B	HEPATITIS NON-B
1973-5	HEMOFIL	371	30 (8.0)	48 (13.0)
	KRYOBULIN		NOT KNOWN	
1976	HEMOFIL	183	3 (1.6)	5 (2.7)*
	KRYOBULIN	101	6 (5.9)	8 (7.9)
1973-6 TOTAL TRANSFUSED		512		

2 CASES NON-B HEPATITIS EXCLUDED AS BRAND IMPLICATED DOUBTFUL

Figures in brackets indicate percentages.

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TABLE 2

FACTOR VIII - ASSOCIATED
NON-B HEPATITIS : PROTECTION CONFERRED
BY TRANSFUSION OF INFECTED BATCH

BATCH	TOTAL PATIENTS TRANSFUSED WITH BATCH	PATIENTS RECEIVING HEMOFIL FOR FIRST TIME WITH THIS BATCH	NON-B HEPATITIS PREVIOUS TRANSFUSION* NO	YES
P	30	30	NIL	NIL
Q	85	53	6 (11.3)	NIL
R	55	38	3 (7.8)	NIL
S	117	74	10 (13.5)	NIL
T	116	66	13 (19.6)	NIL
U	75	37	9 (23.6)	NIL
V	79	33	3 (9.0)	NIL
W	86	20	3 (15.0)	NIL
X	52	17	1	1 (2.0)
TOTAL		371	48	1

*PREVIOUS TRANSFUSION OF INFECTED BATCH OF HEMOFIL MORE THAN 60 DAYS BEFORE FIRST TRANSFUSION OF CURRENT BATCH.

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TABLE 3

MULTIPLE ATTACKS FACTOR VIII

ASSOCIATED HEPATITIS

HEPATITIS	NO. PATIENTS		TOTAL
	TWO ATTACKS	THREE ATTACKS	
HEMOFIL ASSOCIATED NON-B + HEPATITIS B	11		11
NHS FACTOR VIII NON-B + HEMOFIL NON-B	1		1
HEMOFIL NON-B + HEMOFIL HEPATITIS B + KRYOBULIN NON-B		1	1
HEMOFIL NON-B + KRYOBULIN NON-B	1		1
	13	1	14

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Haemophilia Centre Directors

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. W.S.A. Allan,
Wolverhampton.

Dr. A.M. Barlow,
Huddersfield.

Dr. D.L. Barnard,
Leeds.

Dr. O.H.A. Baugh,
Chelmsford.

Dr. Ethel Bidwell,
P.F.L., Oxford.

Dr. Rosemary Biggs,
Oxford.

Dr. G. Birchall,
Lancaster.

Prof. A.L. Bloom,
Cardiff.

Dr. F.E. Boulton,
Liverpool R.I.

Dr. Morag Chisholm,
Southampton.

Dr. V.M. Collins,
DHSS, London.

Dr. B. Colvin,
London Hospital.

Dr. S.H. Davies,
Edinburgh.

Sister G.S. Davis,
N.E. Thames Co-ordinator.

Dr. I.W. Delamore,
Manchester, R.I.

Dr. Helen Dodsworth,
St. Mary's Hosp., London.

Dr. J.A. Easton,
Wexham Park Hospital, Slough.

Dr. J.O.P. Edgcumbe,
Exeter.

Dr. D. Ellis,
B.P.L., Elstree.

Dr. D.I.K. Evans,
Manchester Children's Hospital.

Prof. P. Flute,
St. George's Hospital, London.

Dr. E.A. French,
Nottingham.

Dr. H. Greenburgh,
Plymouth.

Prof. R.M. Hardisty,
The Hospital for Sick Children,
Great Ormond Street, London.

Dr. N.E.M. Harker,
Middlesbrough.

Dr. J.P.L.A. Hayes,
Chatham.

Dr. F. Hill,
Birmingham Children's Hospital.

Dr. C.A. Holman,
Lewisham.

Dr. J.F. Horley,
Brighton.

Dr. Kay M. Hunt,
Bradford.

Dr. R.M. Ibbotson,
Stoke-on-Trent.

Dr. A. Inglis,
Carlisle.

Prof. G.I.C. Ingram,
St. Thomas's, London.

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Dr. P. Jones,
Newcastle.

Dr. P. Kirk,
Bristol.

Dr. T. Korn,
Bangor.

Dr. D. Lee,
Lancaster.

Dr. J. Leslie,
Norwich.

Dr. J.S. Lilleyman,
Sheffield Children's Hospital.

Dr. J.M. Matthews,
Oxford.

Dr. R.S. Mibashan,
King's College Hospital.

Dr. J. Murrell,
Truro.

Dr. G.A. McDonald,
Glasgow.

Dr. N.M. Naik,
Maidstone.

Prof. M.G. Nelson,
Belfast.

Dr. D.A. Newsome,
Blackburn.

Dr. E. Ntekim,
Hillingdon.

Dr. J.S. Oakey,
Grays, Essex.

Dr. M.J. Painter,
L.M.T. College, Alton.

Miss Moira R. Patterson,
P.F.C., Edinburgh.

Dr. M.J. Phillips,
Taunton, Somerset.

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

Mr. K.R. Polton,
Haemophilia Society.

Dr. C.R.M. Prentice,
Glasgow.

Dr. F.E. Preston,
Sheffield.

Mr. J. Prothero,
Haemophilia Society.

Dr. S.G. Rainsford,
Alton.

Dr. J.D.M. Richards,
U.C.H., London.

Dr. C.R. Rizza,
Oxford.

Dr. Patricia Robb,
Liverpool.

Dr. Diana M. Samson,
Harrow.

Dr. Shahriarhi,
Westminster Hospital.

Dr. N.K. Shinton,
Coventry.

Prof. J.W. Stewart,
Middlesex Hospital, London.

Dr. J. Smith,
P.F.L., Oxford.

Miss R.J.D. Spooner,
Oxford.

Dr. J. Stuart,
Birmingham.

Rev. A. Tanner,
Haemophilia Society.

Dr. C.G. Taylor,
Pembury, Tunbridge Wells.

Dr. D.S. Thompson,
Luton.

Dr. J. Voke,
Royal Free Hospital, London.

Dr. H.J. Voss,
Kettering.

Dr. Sheila Waiter,
DHSS, London.

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Dr. R.T. Wensley,
Manchester.

Dr. P.J. Whitehead,
Whitehaven.

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

Dr. D.A. Winfield,
Derby.

Dr. D.N. Whitmore,
Lewisham.

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 Director's 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. Barkhan

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

Dr. T.A. Blecher,

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

Dr. D.S. Carmichael

Dr. D.G. Chalmers

Dr. I.A. Cook

Dr. K.P. Cotter

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

Dr. A.A. Dawson

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

Dr. C.D. Forbes

Dr. B.E. Gilliver

Prof. R.H. Girdwood

Dr. P.A. Gover

Dr. R.C. Hallam

Dr. K.M. Harrison

Prof. Humble (rep. by Dr. Shahrairhi)

Dr. R.M. Hutchinson

Dr. J. Kramer,

Dr. A. MacKenzie

Dr. J.R. Mann

Dr. J. Martin

Dr. Maycock (rep. by Dr. Ellis)

Dr. Mayne

Dr. T.R. Mitchell

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

Dr. M.W. McEvoy

Dr. J.W. Nicholas

Dr. J. O'Brien

Dr. M.J. O'Shea

Dr. R.W. Payne

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

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(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 400 L of fresh frozen plasma per week and was producing approximately 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 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. Should it become possible to transfer plasma from Transfusion Centres in England for fractionation in Scotland the transfer would be probably centralized through the Blood Products Laboratory at Elstree. 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.

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(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 Director's held in Oxford on the 23rd May, 1977.

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6. Future Arrangements for Haemophilia Centre Director's 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 meetingsshould 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 Transfusion Centres with factor VIII 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 questionaire 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

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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_sAg 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 was 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.

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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 was now available for use in 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 Director 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.

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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. W.S.A. Allan,
Wolverhampton.

Dr. A.M. Barlow,
Huddersfield.

Dr. D.L. Barnard,
Leeds.

Dr. O.H.A. Baugh,
Chelmsford.

Dr. Ethel Bidwell,
P.F.L., Oxford.

Dr. Rosemary Biggs,
Oxford.

Dr. G. Birchall,
Lancaster.

Prof. A.L. Bloom,
Cardiff.

Dr. F.E. Boulton,
Liverpool R.I.

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Dr. R.M. Ibbotson,
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Dr. A. Inglis,
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Prof. G.I.C. Ingram,
St. Thomas's, London.

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Dr. P. Jones,
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Bristol.

Dr. T. Korn,
Bangor.

Dr. D. Lee,
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Dr. J. Leslie,
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Haemophilia Society.

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Oxford.

Dr. Patricia Robb,
Liverpool.

Dr. Diana M. Samson,
Harrow.

Dr. Shahriarhi,
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Dr. N.K. Shinton,
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Prof. J.W. Stewart,
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Miss R.J.D. Spooner,
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Dr. J. Stuart,
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Dr. C.G. Taylor,
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Dr. D.S. Thompson,
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Dr. J. Voke,
Royal Free Hospital, London.

Dr. H.J. Voss,
Kettering.

Dr. Sheila Waiter,
DHSS, London.

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Dr. R.T. Wensley, Manchester.

Dr. P.J. Whitehead, Whitehaven.

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

Dr. D.A. Winfield, Derby.

Dr. D.N. Whitmore, Lewisham.

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.

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

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Dr. K.M. Harrison

Prof. Humble (rep. by Dr. Shahrairhi)

Dr. R.M. Hutchinson

Dr. J. Kramer,

Dr. A. MacKenzie

Dr. J.R. Mann

Dr. J. Martin

Dr. Maycock (rep. by Dr. Ellis)

Dr. Mayne

Dr. T.R. Mitchell

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

Dr. M.W. McEvoy

Dr. J.W. Nicholas

Dr. J. O'Brien

Dr. M.J. O'Shea

Dr. R.W. Payne

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

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(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.

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(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 questionaire 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_sAg 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.

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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 liklihood a reflection of the improvement in haemophilia treatment throughtout 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.