

Witness Name: Glenn Wilkinson

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**INFECTED BLOOD INQUIRY**

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**EXHIBIT WITN2050038**

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MONEY FROM DRUG  
COMPANIES TO DIRECTORS  
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Minutes of the Ninth Meeting of the United Kingdom Haemophilia  
Centre Directors held in Oxford on Monday 13th November, 1978.

Present:-

Dr. A. Aronstam,  
Treloar Haemophilia Centre.

Dr. P. Barkhan,  
Guy's Hospital, London.

Dr. A.J. Barrett,  
Westminster Hospital, London.

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

Dr. D. Bevan,  
St. George's Hospital, Tooting.

Dr. Ethel Bidwell,  
Plasma Fractionation Laboratory.

Dr. G. Birchall,  
Royal Infirmary, Lancaster.

Prof. E.K. Blackburn,  
Sheffield Royal Infirmary.

Dr. T.E. Blecher,  
The General Hospital,  
Nottingham.

Prof. A.L. Bloom,  
University of Wales, Cardiff.

Dr. F.E. Boulton,  
Liverpool Royal Infirmary.

Dr. D.G. Chalmers,  
Addenbrooke's Hospital,  
Cambridge.

Dr. M. Chisholm,  
Southampton.

Dr. Mary Collins,  
Dept. of Health & Social Sec.

Dr. B. Colvin,  
The London Hospital.

Dr. J. Craske,  
Manchester.

Dr. S.H. Davies,  
The Royal Infirmary, Edinburgh.

Dr. I.W. Delamore,  
The Royal Infirmary,  
Manchester.

Miss Sheila Dykes,  
St. Thomas's Hospital, London.

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

Dr. J.O.P. Edgcumbe,  
Royal Devon & Exeter Hospital.

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

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

Dr. E.A. French,  
General Hospital, Nottingham.

Dr. D.K. Goff,  
Sunderland.

Dr. P. Hilgard,  
Hammersmith Hospital, London.

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

Dr. C.A. Holman,  
Lewisham Hospital, London.

Dr. R.L. Holman,  
Royal United Hospital, Bath.

Dr. J.F. Horley,  
Royal Sussex County Hospital,  
Brighton.

Dr. J. Howard Jones,  
Newport.

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

Dr. R.M. Ibbotson,  
Central Pathology Laboratory,  
Hartshill.

Dr. P. Jones,  
Newcastle-upon-Tyne.

Dr. M.W. Kenny,  
Queen Elizabeth Hospital,  
Birmingham.

Dr. P.B.A. Kernoff,  
Royal Free Hospital, London.

Dr. D. Lee,  
B.T.C., Lancaster.

Dr. J. Leslie,  
Norfolk and Norwich Hospital.

Dr. G. Lowe,  
Glasgow.

Dr. J.M. Martindale,  
Walton Hospital, Liverpool.

Dr. J.M. Matthews,  
Oxford Haemophilia Centre.

Dr. E. Mayne,  
Royal Victoria Hospital,  
Belfast.

Dr. S. Mayne,  
Royal Infirmary, Derby.

Dr. K. McGrath,  
Sheffield Children's Hospital.

Dr. B.A. McVerry,  
University College Hospital,  
London.

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

Dr. T.R. Mitchell,  
Charing Cross Hospital, London.

Dr. B. Murphy,  
Torbay Hospital, Torquay.

Dr. D.A. Newsome,  
Blackburn Royal Infirmary.

Dr. J.R. O'Brien,  
Portsmouth.

Dr. J.R.M. Pinkerton,  
General Hospital, Salisbury.

Mr. K. Polton,  
The Haemophilia Society.

Dr. C. Prentice,  
Royal Infirmary, Glasgow.

Dr. F. Preston,  
Sheffield Royal Infirmary.

Mr. J. Prothero,  
The Haemophilia Society.

Dr. E.G. Rees,  
Shrewsbury Hospital, Shrewsbury.

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

Dr. C.R. Rizza,  
Oxford Haemophilia Centre.

Dr. G.L. Scott,  
Bristol Royal Infirmary.

Mrs. A. Shaw,  
Royal Manchester Children's  
Hospital.

Dr. D. Shaw,  
Ninewells Hospital, Dundee.

Dr. N.K. Shinton,  
Coventry & Warwickshire  
Hospital, Coventry.

Dr. C.A. Sieff,  
Great Ormond Street, London.

Miss R.J.D. Spooner,  
Oxford Haemophilia Centre.

Prof. J. Stewart,  
Middlesex Hospital, London.

Dr. L.M. Swinburne,  
Leeds.

Rev. A. Tanner,  
The Haemophilia Society.

Dr. C.C. Thomas,  
Camberley, Surrey.

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

Dr. E. Thompson,  
Taunton, Somerset.

Dr. E.C.D. Tuddenham,  
Royal Free Hospital,  
London.

Prof. R.L. Turner,  
The Royal Infirmary, Bradford.

Dr. R. Vaughan Jones,  
St. Peter's Hospital, Chertsey.

Dr. V. Vignarajah,  
Roehampton.

Dr. R. Warwick,  
Hillingdon Hospital, London.

Dr. R.T. Wensley,  
Manchester Royal Infirmary.

Dr. P.J. Whitehead,  
Whitehaven, Cumbria.

Dr. D.N. Whitmore,  
Lewisham Hospital, London.

Dr. D.A. Winfield,  
Derby.

Present at Scientific Session Only:-

Dr. T. Barrowcliffe,  
N.I.B.S.C.

Sister Maureen Fearn,  
Newcastle.

Dr. S. Ghosh,  
Oxford.

Dr. Peter Hamilton,  
Newcastle.

Mr. T. Kirkwood,  
N.I.B.S.C.

Dr. I. Peake,  
Cardiff.

Mr. I.L. Rhymes,  
Oxford.

Dr. M.J. Seghatchian,  
North London Blood Transfusion  
Centre

Mr. T. Snape,  
Oxford.

Dr. J. Trowell,  
Oxford.

1. Apologies for Absence:-

Dr. W.S.A. Allan,  
Wolverhampton.

Dr. S. Ardeman,  
Edgware, Middlesex.

Dr. B. Attock,  
Barnstaple.

Dr. A.M. Barlow,  
Huddersfield.

Dr. C.J.T. Bateman,  
Chichester.

Prof. A.J. Bellingham,  
(rep. by Dr. F. Boulton),  
Liverpool.

Dr. J.M. Bridges,  
Belfast.

Dr. R.P. Britt,  
Hillingdon.

Dr. D. Burman,  
Bristol.

Dr. I. Cook,  
Inverness.

Dr. K.P. Cotter,  
Coventry.

Dr. P. Crome,  
(rep. by Dr. V. Vignarajh),  
Roehampton.

Dr. A.A. Dawson,  
Aberdeen.

Dr. T.J. Deeble,  
Carlisle.

Prof. P.T. Flute,  
(rep. by Dr. D. Bevan),  
St. George's, Tooting.

Dr. C. Forbes,  
Glasgow.

Prof. R.H. Girdwood,  
Edinburgh.

Dr. P.A. Gover,  
Eastbourne, Sussex.

Dr. P. Green,  
Bournemouth.

Prof. R.M. Hardisty,  
(rep. by Dr. C.A. Sieff),  
Great Ormond Street, London.

Dr. Harker,  
Middlesbrough.

Dr. J. Howard Jones,  
Newport, Gwent.

Prof. J.G. Humble,  
(rep. by Dr. A.J. Barrett),  
Westminster Hospital, London.

Dr. A.D.F. Hurdle,  
Epsom, Surrey.

Prof. G.I.C. Ingram,  
(rep. by Miss S. Dykes),  
St. Thomas's Hospital, London.

Dr. T. Korn,  
Bangor, Wales.

Dr. R.S. Lane,  
(rep. by Dr. D. Ellis),  
B.P.L., Elstree.

Dr. J.S. Lilleyman,  
(rep. by Dr. K. McGrath),  
Sheffield Children's Hospital.

Dr. A. MacKenzie,  
Sunderland.

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

Dr. J. Martin,  
Alder Hey Children's Hospital,  
Liverpool.

Dr. G.A. McDonald,  
(rep. by Dr. C.R.M. Prentice),  
Glasgow.

Prof. P.L. Mollison,  
St. Mary's Hospital, London.

Prof. M.G. Nelson,  
Belfast.

Dr. R.A.M. Oliver,  
Thornton Heath, Surrey.

Dr. R.W. Payne,  
Worcester.

Dr. M.J. Phillips,  
(rep. by Dr. E. Thompson),  
Taunton, Somerset.

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Prof. T.A.J. Prankerd,  
(rep. by Dr. J.D.M. Richards),  
University College Hospital,  
London.

Dr. P.M. Robb,  
(rep. by Dr. J.M. Martindale),  
Walton Hospital, Liverpool.

Dr. K.S. Rodan,  
Worthing Hospital, Sussex.

Dr. Diana M. Samson,  
(rep. by Dr. C.D.L. Reid),  
Northwick Park Hospital.

Dr. R.F. Sheppard,  
Northampton General Hospital.

Dr. J. Stafford,  
(rep. by Dr. Greenburgh),  
Plymouth General Hospital.

Dr. H. Sterndale,  
Margate, Kent.

Dr. J. Stuart,  
(rep. by Dr. M.W. Kenny),  
Queen Elizabeth Hospital,  
Birmingham.

Dr. J. Thomas,  
Kingston-upon-Thames, Surrey.

Dr. G.R. Tudhope,  
(rep. by Dr. D. Shaw),  
Ninewells Hospital, Dundee.

Dr. Varadi,  
Epsom, Surrey.

Dr. Sheila Waiter,  
(rep. by Dr. Mary Collins),  
Department of Health & Social  
Security.

Mr. J. Watt,  
F.F.C., Edinburgh.

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

Dr. M.L.N. Willoughby,  
Glasgow Children's Hospital.

Dr. S.G.F. Wilson,  
Ninewells Hospital, Dundee.

Dr. J.K. Wood,  
Leicester.

Dr. C.R.R. Wylie,  
York.

## 2. Opening Address:-

Professor Blackburn said that he would be retiring as Chairman of The Haemophilia Centre Directors after the present meeting. The Reference Centre Directors had invited Professor A. Bloom to take over as Chairman and Professor Bloom had said he would be willing to do so, after the summer of 1979 until when he was too heavily committed with other things, if all the Haemophilia Directors were in agreement. In the meantime, Professor G.I.C. Ingram had agreed to act as Co-Chairman with Professor Blackburn.

It was agreed that Professor Blackburn and Professor

should be Co-Chairman until the Autumn of 1979, when Professor Bloom would take over as Chairman.

3. Minutes of the Eighth Meeting

The Minutes of the Eighth Meeting held in 1977 were approved and signed.

4. Matters arising from the Minutes

a) Staffing of Haemophilia Centres

Professor Blackburn mentioned that several Directors were still unhappy with their staffing situations and invited Directors to comment further on this matter. Dr. Shinton said that there appeared to be local resistance to the appointment of nurses to haemophilia centres. Dr. Rizza said that some Centres had got a nurse after stating that the Haemophilia Centre Directors had officially passed a motion stating that they regarded it as an essential for any Haemophilia Centre which treated twenty-five or more patients during a year to have a nurse on the establishment of the Centre.

Professor Bloom referred to the book edited by Dr. Rosemary Biggs (The Treatment of Haemophilia A, Haemophilia B and von Willebrand's Disease). He said that this book contained much information which was of value when dealing with Administrators. The question of staffing was one of the matters dealt with in the book.

b) Handbook for Home Therapy

Dr. Peter Jones said that the handbook had been published and distributed to all Directors. He asked

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Directors to let him have any comments they wished to make. Dr. Jones said that he would like to thank the Haemophilia Society for their generous financial support in paying for the cost of publishing the Handbook.

c) Transport for Haemophiliacs

Mr. Polton of the Haemophilia Society handed out a leaflet written by the Society which outlined the types of help which were available to the disabled. The Society was of the opinion that some people were refused mobility allowances because the doctors assessing them did not have sufficient knowledge about Haemophilia.

d) Analgesics in Haemophilia

Professor Blackburn said that there was nothing further to report on this matter.

e) Supplies of Factor VII

Dr. Bidwell said that in 1977 she had asked Directors to let her know if they had patients with Factor VII deficiency as the material was now available from the Plasma Fractionation Laboratory for use for named patients. Regular supplies were now available and three patients were at present known. She asked Directors to let her know if any further patients came to light.

f) Anti-A and Anti-B Agglutinins

In 1977 Dr. Rizza had asked Directors to let him know if they had any cases of haemolysis following replacement therapy with factor VIII or IX and so far only one case had



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been reported to him. Professor Bloom mentioned that he had had two cases but had not yet reported these and Dr. Tuddenham said they had also had two cases at the Royal Free Hospital.

It was agreed that Directors should continue to notify Dr. Rizza of cases of haemolysis.

#### 5. Funding of Working Parties

Professor Blackburn said that the matter had been discussed at the Reference Centre Directors Meeting. The Hepatitis Working Party had received a three year grant from the Department of Health and Social Security and the Home Treatment Working Party was receiving some financial support from Travenol Laboratories to cover the cost of the Employment Study which the Sub-committee of the Working Party was undertaking. The Haemophilia Society had been considering the matter put to them at the last Meeting and Professor Blackburn had recently received a reply from the Society. He invited Mr. Tanner of the Society to speak about this matter.

Mr. Tanner said that the Society had been asked to act as an agent to collect money for use by the Reference Centre Directors Working Parties. The Society had considered this matter and discussed it with their Medical Advisors and other persons, and it appeared that the Directors wanted to continue their personal links with the drug companies and the drug companies would not be happy to deal with the Directors via the Society. The administrative side of the

Society would need expansion to cope with this matter, and there were also problems about who would get the money. The Society would like to continue as they were doing at present giving support to Haemophilia Centres whenever possible.

Last year £20,000 had been given to support the work at different centres. The Society would be willing to consider the request for funds to support the work of the Directors' Working Parties.

Dr. Peter Jones said that he had raised this matter last year because his Working Party was concerned about the question of receiving funds directly from Drug Companies. He emphasised that it was the Employment Sub-committee who were receiving financial support from Travenol Laboratories to cover the cost of a survey they were at present undertaking and not the main Home Treatment Working Party.

#### 6. Council of Europe Questionnaire

Dr. Rizza said that a request had been received from the Council of Europe via Dr. Ian Temperley for data to be made available to the Council of Europe regarding the treatment of Haemophilia in the United Kingdom. The matter had been discussed with the Department of Health and by the Reference Centre Directors who had agreed that data which were available through the annual returns already submitted to Oxford by the Haemophilia Centre Directors could be given to the Council of Europe and that no additional data would be requested from Directors.

There then followed some discussion regarding the

large number of questionnaires which Directors had received in recent months from a variety of sources.

The matter had been discussed by the Reference Centre Directors at their meeting on 15th September, 1978 and the feeling then was that they should help whenever possible. This view was supported by the other Haemophilia Centre Directors.

It was agreed that the Secretariat in Oxford should be informed about all questionnaires received by Directors and the Directors as a whole should help when possible.

#### 7. Life Insurance for Haemophiliacs

Dr. Rizza referred to a letter which had been received from Mr. Rosenblatt of the Haemophilia Society asking if any statistical data was available regarding the ages and dates of death of haemophiliacs which would be helpful to the Insurance Co-ordination Group of the European Advisory Board, of the World Federation of Haemophilia. The matter had been discussed by the Reference Centre Directors who had agreed that data would be made available to the Society from the Directors' 1977 and 1978 Annual Returns. It was emphasised that patients' names would not be given to the Society.

Mr. Prothero said that he was now the European Liaison Officer on behalf of the British Haemophilia Society. He said that haemophiliacs did not have as much difficulty in the United Kingdom as they had in other countries in obtaining life insurances but in some countries this was a very major problem indeed. Life insurance problems would be greatly eased if the data was collected and co-ordinated and a

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report could be published from the European Society.

8. Management of Inherited Factor XIII (FSF) Deficiency

Professor Blackburn referred to a letter which Professor Losowsky of Leeds had circulated to Haemophilia Centre Directors concerning the numbers of patients with factor XIII deficiency in the United Kingdom. Five patients with congenital Factor XIII deficiency were known in Leeds. Professor Losowsky wanted to know if there were any other patients in the United Kingdom to find out how big the problem was so that some assessment could be made of the need for factor XIII concentrates for treating those patients. This information would be of great value to the Plasma Fractionation Laboratories.

Professor Blackburn asked any Directors who had not received Professor Losowsky's communication to let Professor Losowsky know if they had patients with Factor XIII deficiency. A check at the meeting showed that there were nine Factor XIII patients known to the Directors.

11. Report on the 1976 and 1977 Annual Returns from Haemophilia Centres (Appendix A)

Dr. Rizza presented the report which he and Miss Spooner had prepared on the 1976 and 1977 annual returns. He emphasised that the report was at present incomplete as there were still some replies outstanding from Directors.

It was clear from the returns so far received that an increasingly large amount of commercial factor VIII

concentrate was being used by Haemophilia Centres. Dr. Rizza wondered whether the Department of Health had any views on this matter, and whether the Department was making any progress towards the United Kingdom eventually becoming self-sufficient in British made Factor VIII concentrate.

Dr. Collins of the Department of Health said that there was no limit on the amount of commercial material which Haemophilia Centres could receive.

There was some discussion regarding the tables giving the causes of death of haemophiliacs and Christmas disease patients. Dr. O'Brien asked if in the subsequent report the age of death could be noted. Some of the Directors would have liked to have known much more information about the causes of death, but this information was not available to the Directors in the first instance so it could not be included in the report.

9(a) Supplies of Factor VIII Concentrates, the DHSS Contract and the Price of Commercial Factor VIII

Professor Blackburn asked Dr. Collins, representing the Department of Health, if she could give an outline of the Department's policy regarding the supply situation. Dr. Collins said that the DHSS's original target had been reached and exceeded by 1978 and they wonder now whether there was a revised target. Scotland could not produce any more factor VIII at the moment because of the continuing problems over shift work.

The Department's target figures included the cryo-

precipitate which was used throughout the United Kingdom. Professor Bloom said that he had a feeling that there was complacency in the Department of Health about the target situation. He appreciated that the DHSS had to have a target and wondered if the target should not now be set at 100 million units.

Dr. Collins said that the target of 100 million units had in fact already been thought about at the Department of Health. Professor Stewart said that a lot of cryoprecipitate was still used in the United Kingdom and Directors would prefer to use the concentrates rather than the cryoprecipitate. He wondered what the relevant cost was, between making cryoprecipitate and making the concentrates. In Eire the cost was thought to be about the same.

Dr. Wensley said that it should be possible to make cryoprecipitate averaging 125 units per pack. There were technical problems in making the concentrates and he would suggest that the Department should wait at the moment before embarking on a policy of turning over entirely to concentrates.

Dr. Ellis of the Blood Products Laboratory said that the programme for doubling production at Elstree was under-way. The limiting factor at the moment was in the amount of plasma which was coming into Elstree for fractionation and the way in which it was packaged. Elstree was not technically equipped at present to deal with the single donation packs.

Professor Bloom asked if the Blood Products Laboratory was sufficiently well funded, if not could the Directors help with this matter in any way. Dr. Ellis said that he would

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convey this comment to Dr. Lane. There then followed some discussion concerning the relative cost of freeze dried factor VIII.

Dr. Tuddenham said that the cost of cryoprecipitate to his Centre as purchased from Edgeware Blood Transfusion Centre and calculated on their assay of the factor VIII content worked out at 7.5 pence per unit. The cheapest price for commercial concentrate is close to this figure and occasionally below it. Dr. Wensley on the other hand estimated that the cost of making cryoprecipitate was about one-third of the cost of making concentrates.

Dr. Bidwell stressed these costs were quite nominal and not the true costs incurred in producing the materials. She thought it was very dangerous to quote these figures. The costs of making the concentrates had not been worked out fully and it was a very difficult thing to do.

Dr. Jones said that he felt strongly that the Directors should set a new target for factor VIII production for the Department of Health. 40 million units of factor VIII was the target set in 1973, almost 50 million units of factor VIII were used in 1977 according to the Directors' returns and only 17 million units of this material was British made concentrate. This meant that the Department of Health was not yet half way towards the earlier target which had been set. In view of the high cost of commercial material he felt sure that it was better to spend the money on the British Fractionation plants rather than to continue to spend large sums of money in purchasing the foreign made commercial concentrates.

Dr. Collins said that she hoped that it would

possible for Regions to divert the money which was at present being used to purchase commercial concentrates towards getting more plasma for fractionation. There would be a difficult period however. Dr. Jones and Professor Stewart both said that treatment could not stop while funds and plasma were being diverted.

Professor Blackburn said that several Directors were concerned about Drug Companies who were not in the Department of Health's contract. The Directors wondered what the advantages of the Department of Health contract was and what were the regulations about this. Dr. Collins said that there were four firms at present holding contracts with the Department of Health. The Department could not stop firms from advertising the material outside Haemophilia Centres.

Professor Blackburn said that the worry of the Reference Centre Directors was that the concentrates might be used for non-haemophilic patients and the Directors felt very strongly that there should be some control over this.

It was suggested that an attempt should be made to cost the National Health Factor VIII concentrates. Perhaps it was cheaper to use commercial material. Dr. Ellis said that he thought that the NHS concentrates would be cheaper and he was doing a costing exercise already.

Dr. Chalmers said that he thought it was very dangerous to rely on the commercial concentrates. He thought that the United Kingdom should be self-sufficient and should not rely on foreign materials.



Discussion followed on the level at which the Department of Health's target for factor VIII production should now be set. It was agreed that the Department had improved its target but that it was still short. Dr. Holman suggested that the Department of Health should set their target now at 100 million units of factor VIII and Dr. Jones said that as the target of 50 million units had not yet been achieved he thought it would be a mistake to set the new target as high as 100 million.

Dr. Collins said that the Department of Health would like to know how much concentrate was being used for hip and knee replacements. Dr. Rizza asked why the Department of Health was asking for this and Dr. Collins said that it would simply be useful to know about it. Dr. Holman said that he had sent one hip replacement patient to Oxford for further treatment. The operation had been a success and more patients would ask for this operation.

Dr. Jones said the figures would only be meaningful if one took into account the amount of material required by the patients before they had the hip replacement operations.

Professor Bloom said that he would also like to know the Department of Health's reasons for asking for this information. Dr. Bidwell suggested that it would be useful to know the figures for the amount of materials used by patients in the various age groups.

Dr. Prentice said that he would be happy to give information on the hip and knee replacements undertaken during

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one year. There was then discussion about the amount of materials used for surgery generally and it was suggested that it might be useful for this figure to be collected once again.

Dr. Davies commented that hip replacement only represented a small amount of the material used for all operations. The target must be realistic to be of value. What the Directors wanted was 50 million units of factor VIII as freeze dried concentrates.

Professor Stewart said that he would like a statement to go from the meeting to the Department of Health stating that the forecast given by the Directors three years ago of the amount of factor VIII which would be required was correct and that the meeting viewed with concern the decreased proportion of factor VIII which was being supplied by the National Health Service. Attention of the Department of Health was drawn to the factor IX situation where the forecast had been accurate and 99.5% of the total demand for factor IX in the United Kingdom was met from the United Kingdom laboratories. It was suggested that the Department of Health should make every effort to reach the target figure for the factor VIII required for the treatment of Haemophilia A patients in the United Kingdom.

This motion was seconded by Dr. Jones and agreed. It was suggested that possibly a Working Party should be set up to look into the question of dosage levels. Dr. O'Brien commented that the emphasis from Directors was always towards giving lots of treatment and no credit was ever given to those

Directors who were economic in the use of the concentrates.

9(b) Factor IX Concentrates

Dr. Bidwell gave a brief report on the amount of factor IX which had been supplied to Centres during 1972-1977. She had asked Directors to let her know their estimated requirements for 1978 onwards and those estimates already showed a twenty per cent increase over the previous year. She stressed the importance of having accurate estimates since considerable capital investment on freeze drying and other equipment would be needed at the Plasma Fractionation Laboratory if the demand for factor IX concentrate continued to increase.

Dr. Bidwell then presented the reasons given by Directors for their increased usage of factor IX. Several Directors had commented that they were treating small children who were growing and therefore requiring more treatment but in general there was no clear-cut reason for the increase in usage.

13. Any Other Business

a) Working Party on Haematuria.

Dr. Evans raised this question. He wondered what the best treatment for haematuria was and whether a trial should be considered on a National scale to find the answer to this question.

Dr. Swinburne said that she would certainly support this idea. She had in fact first raised this point more than

three years ago. It was agreed that the possibility of a Working Party on Haematuria be set up and should be considered by the Reference Centre Directors at their next meeting.

b) Professor Bloom raised the question of other people attending the Scientific Section of the Directors' Meeting. He thought that other members of Haemophilia Centre staffs would benefit from discussions at the Scientific Session and that consideration should be given to the broadening of this meeting. At the present meeting members of the Directors Working Parties who were not Directors had been invited to attend and he thought that this was a very good move in the right direction.

Dr. Tuddenham said that he also would like the Scientific Sessions to be broadened out so that other people could attend then.

It was agreed that the suggestion of broadening the Scientific Meeting should be discussed further by the Reference Centre Directors.

c) Professor Bloom said that the Royal College of Pathologists had asked him to consider organising a workshop on the assay of coagulation factors and their standards. Professor Bloom wondered whether there was any demand for this and if there were any volunteers. He would like to suggest that if there was a need for this type of meeting it should be held in Oxford. Dr. Chalmers said it was not clear for whom this workshop was intended. Was this course to be for doctors to help them to pass their examinations or

was it for Senior Technical staff? Dr. Shinton thought that clearly the idea was for the meeting to be held for Pathologists only as it was being proposed by the Royal College of Pathologists.

Dr. Prentice suggested that if a workshop was to be held it should be for a defined purpose and for the people who were really doing the work. Professor Bloom said that he had already declined to organise such a meeting.

It was agreed that if further workshops were organised they should be for those actually involved in the work of coagulation laboratories.

The meeting adjourned for lunch at 1.00 p.m.

#### SCIENTIFIC SESSION

#### 14. Reports by Working Party Chairmen

##### i) Hepatitis

Dr. J. Craske presented the report which had been circulated with the Agenda (Appendix B) and outlined future plans.

##### ii) Home Treatment

Dr. R. Jones reported on the activities of the Working Party and its Sub-Committees.

##### iii) Treatment of Patients having Factor VIII Antibodies

Dr. C. Prentice gave a preliminary report on the information he had received from Haemophilia Centres and the aims of the Working Party.

iv) Factor VIII Assay

Dr. C. Rizza presented the report which was circulated at the meeting (Appendix E).

v) Detection of Carriers

Professor A. Bloom outlined the possible tasks which the Working Party could undertake and invited Directors to let him have further suggestions.

15. Recent Advances in the Treatment of Haemophilia

Dr. Brian Colvin gave a brief resumé of the current methods of treating haemophiliacs and the current problems. He circulated a list of useful references (Appendix F).

16. Report on the Haemostasis Club's von Willebrand's Disease Survey

Professor Bloom said that in 1975 the Haemostasis Club had arranged a survey. He gave the preliminary results, on some slides. The aims of the study were revised and further data collected in 1976. Detailed analysis was not really worth doing but some data were available. Dr. Tuddenham of the Royal Free Hospital had volunteered to do a further study of von Willebrand's disease if the Directors wished for this to be done. After discussion it was agreed that the matter would be discussed further at the next Reference Centre Directors meeting.

17. Proposal for a National Autopsy Study of von Willebrand's Disease

Dr. Peter Kernoff said that he had thought that such

a study might be a good idea but having looked into the matter further, he realised that there would be many problems.

After discussion, the decision of the meeting was that, at the moment, the idea of a National Autopsy Study for von Willebrand's disease was not feasible.

18. Computer System for Compiling Statistics

Sister Sheila Dykes set up a demonstration outlining the computer system used by St. Thomas's Hospital for listing the sites of bleeding in individual haemophiliacs, tracing batches of material thought to carry a hepatitis risk, and for compiling the Annual Returns statistics. The facilities could be made available to other Centres for a small fee.

19. Pre-Natal Diagnosis of Haemophilia

Professor Bloom reported on the work which had been undertaken recently in Cardiff on the pre-natal diagnosis of haemophilia.

There was some discussion about the techniques which were used in Cardiff and then Dr. Mibashan was invited to talk about the work which was being undertaken at King's College Hospital. He gave details of the results which had been obtained so far on 39 samples of foetal blood, and offered to carry out Factor VIII and Factor IX assays at King's for patients referred there from other Haemophilia Centres.

20. Professor Blackburn thanked the Directors for all the help that they had given him during the years in which he had been Chairman of the Directors.

The Meeting closed at approximately 5.30 p.m.