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MINUTES OF THE TENTH MEETING OF THE U.K. HAEMOPHILIA CENTRE DIRECTORS

Held in Oxford on Tuesday and Wednesday, 20th and 21st November, 1979

Prof. A.L. Bloom (Chairman - Day One)

Prof. E.K. Blackburn (Chairman - Day Two)

Present

Both Days:-

Dr. A. Aronstam,
Treloar Haemophilia Centre, Alton.

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

Prof. E.K. Blackburn,
Hallamshire Hospital, Sheffield.

Dr. David Bevan,
St. George's Hospital, London.

Dr. B.T. Colvin,
The London Hospital.

Dr. J. Craske,
Withington Hospital, Manchester.

Dr. A.A. Dawson,
Aberdeen.

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

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

Prof. R.M. Hardisty,
Great Ormond Street Hospital.

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

Dr. J.P.L.A. Hayes,
All Saints Hospital, Chatham.

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

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

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

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

Dr. P. Jones,
Royal Victoria Infirmary, Newcastle.

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

Dr. R.S. Lane,
B.P.L., Elstree.

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

Dr. C.A. Ludlam,
University Hospital of Wales.

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

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

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

Dr. V.E. Mitchell,
Leicester Royal Infirmary.

Dr. M.J. O'Shea,
Shrewsbury Hospital, Shrewsbury.

Dr. L. Parapia,
Bradford Royal Infirmary.

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

Dr. F.E. Preston,
Hallamshire Hospital, Sheffield.

Mr. J.L. Prothero,
Haemophilia Society.

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

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

Dr. H. Sterndale,
Margate.

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

Prof. J. Stuart,
Queen Elizabeth Hospital, Birmingham.

Dr. E. Thompson,
Taunton.

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

Dr. D. Walford,
DHSS, London.

Dr. R. Wensley,
Royal Manchester Children's Hospital.

Day One Only:-

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

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

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

Dr. D.M. Samson,
Northwick Park Hospital, Harrow.

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

Rev. A. Tanner,
Haemophilia Society.

Dr. Joan Trowell,
John Radcliffe Hospital, Oxford.

Dr. D.N. Whitmore,
Lewisham Hospital.

Apologies for Absence:-

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

Dr. B. Attock,
North Devon District Hospital, Barnstaple.

Dr. A.M. Barlow,
Huddersfield Royal Infirmary.

Dr. O.H.A. Baugh (rep. by Sister A. George),
Chelmsford & Essex Hospital, Chelmsford.

Dr. C.J.T. Bateman,
St. Richard's Hospital, Chichester.

Dr. A. Black,
Norfolk & Norwich Hospital, Norwich.

Dr. R.P. Britt, (rep. by Dr. Najam),
Hillingdon Hospital.

Dr. T.A. Blecher,
Queen's Medical Centre, Nottingham.

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

Dr. M. Chisholm,
Southampton General Hospital.

Dr. J. Cash,
Scottish National Blood Transfusion Service, Edinburgh.

Dr. Iain Cook,
Raigmore Hospital, Inverness.

Dr. T.J. Deeble,
Cumberland Infirmary, Carlisle.

Dr. D.I.K. Evans (Rep. by Dr. R. Wensley),
Royal Manchester Children's Hospital.

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

Dr. E.A. French,
Queen's Medical Centre, Nottingham.

Dr. C. Giles (rep. by Dr. R.M. Ibbotson),
Central Pathology Laboratory, Stoke-on-Trent.

Prof. R.H. Girdwood,
Royal Infirmary of Edinburgh.

Dr. H. Greenburgh,
Plymouth General Hospital.

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Dr. C.D. Forbes,
Glasgow Royal Infirmary.

Dr. C.A. Holman,
Lewisham.

Mr. K.R. Polton,
Haemophilia Society.

Dr. G. Savidge,
St. Thomas's Hospital, London.

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

Day Two only:-

Dr. T. Barrowcliffe,
NIBSC, London.

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

Dr. P.E. Crome,
Queen Mary's Hospital, Roehampton.

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

Sister Ann George,
BTC, Brentwood.

Dr. Goldman,
Royal Free Hospital, London.

Dr. S. Ghosh,
Oxford Haemophilia Centre.

Dr. R.C. Hallam,
Bedford General Hospital.

Dr. P.A. Lilley,
Royal Free Hospital, London.

Dr. J.W. McHugh,
Kingston upon Thames, Surrey.

Dr. Najam,
Hillingdon Hospital.

Dr. J.R. O'Brien,
St. Mary's General Hospital, Portsmouth.

Dr. Jennifer Orchard,
University Hospital of Wales,

Dr. I. Peake,
University Hospital of Wales.

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

Dr. C.L. Rist,
Worthing Hospital.

Dr. P. Hamilton,
Royal Victoria Infirmary, Newcastle.

Dr. J. Howard Jones,
Royal Gwent Hospital, Newport.

Prof. G.C. Jenkins (rep. by Dr. B.T. Colvin),
The London Hospital, Whitechapel.

Dr. T. Korn,
Caernarvon & Anglesey Hospital, Bangor.

Dr. J.J. Kramer,
Hereford County Hospital.

Dr. J. Leslie,
Norfolk & Norwich Hospital.

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

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

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

Dr. S. Mayne,
Derby City Hospital.

Dr. B. Murphy (rep. by Dr. J. Edgcumbe),
Torbay Hospital, Torquay.

Dr. A. MacKenzie,
Sunderland Royal Infirmary.

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

Dr. M.J. Phillips (rep. by Dr. Thompson),
Musgrove Park Hospital, Taunton.

Dr. E.G. Rees, (rep. by Dr. O'Shea),
Shrewsbury Hospital.

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

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

Dr. H.T. Swan,
Hallamshire Hospital, Sheffield.

Dr. L.M. Swinburne,
St. James's Hospital, Leeds.

Dr. C.C. Thomas,
Frimley Park Hospital, Camberley.

Dr. G.R. Tudhope (rep. by Dr. A. Todd),
Ninewells Hospital, Dundee.

Prof. R.L. Turner (rep. by Dr. L. Parapia),
Bradford Royal Infirmary.

Dr. S. Varadi,
Epsom District Hospital.

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

Dr. H.J.H. Williams,
Lister Hospital, Stevenage.

Dr. M.L.N. Willoughby,
Royal Hospital for Sick Children, Glasgow.

Dr. C.R.R. Wylie,
York District Hospital, York.

Sister M. Fearns,
Royal Victoria Infirmary, Newcastle.

Dr. T.B.L. Kirkwood,
NIBSC, London.

Mr. T. Snape,
P.F.L., Oxford.

Day 1 - Business Session

1. Opening Address

Professor Bloom welcomed those present to the Meeting. This was his first meeting as Chairman of the Haemophilia Centre Directors. Professor Bloom thanked Professor Blackburn, the previous Chairman, for the ten years hard work which Professor Blackburn had undertaken on behalf of the Directors. He also thanked Professor Ingram who had been Co-Chairman for the last twelve months prior to his retirement in September 1979. Professor Bloom said that regrettably he would not be able to be present at the meeting on Wednesday 21st November.

3. Minutes of the Ninth Meeting

The Minutes were read and approved.

4. Matters Arising from the Minutes

There were no matters arising from the Minutes.

5. Report on the 1978 Annual Returns from Haemophilia Centre Directors

Dr. Rizza presented the report (Appendix A) which was circulated at the Meeting. He drew the Directors attention to various items in the report, in particular to the graphs which indicated that there was a slight levelling off of the

amount of materials used to treat the Haemophilia A patients and a decrease in the amount of Factor IX used to treat Christmas disease patients. Dr. Bidwell said that she had calculated the amount of Factor IX, which would be used during 1979, on the basis of the usage during the first ten months of the year and this indicated that there was likely to be a decrease in the amount of Factor IX used during 1979, compared with 1978. It was noted that there had been a decrease in the amount of cryoprecipitate used at Centres and it was pointed out that if cryoprecipitate was not made available to the Directors the short fall in this material would have to be made up in Commercial Factor VIII concentrates. Professor Bloom wondered how the usage of materials varied from Centre to Centre and whether some Centres were having difficulties in obtaining Commercial materials. There was some discussion regarding the number of young patients who had died, who had antibodies to factor VIII.

6. Future arrangements for collection and analysis of National Data

Professor Bloom described how the collection of National data had started in 1969, and had been modified over the years to meet the changing requirements of the Haemophilia Centre Directors. Some of the Directors had grumbled about completing the forms for the Annual Returns, as they involved a large amount of work at Centres, but the data had proved very valuable. The Reference Centre Directors had had detailed discussions in February, April and November 1979 about the collection of data, the type of data which should be collected and the

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methods of collection and had decided that the time had now come for the whole situation to be reviewed and discussed with all the U.K. Haemophilia Centre Directors. Dr. Peter Jones had been asked to review the methods of collecting data from the Centres. Professor Bloom said that the data collected fell into two broad categories: 1. A reference base of patient data consisting of a register of permanent and variable data regarding individual patients. 2. Data on the treatment received by the patients, usage of materials, etc., the development of inhibitors, the incidence of hepatitis and other information of value to Working Party projects. Dr. Peter Jones was invited to outline the proposed plans for future collection of data from U.K. Haemophilia Centres.

Dr. Jones said that in February 1979 he had been asked to look at the present methods of data collecting. He had no doubt whatsoever that the data were valuable and that collection of data should be continued. There were two questions however which should now be asked:
1. How could the collection of data from Centres be simplified and 2. What data should be collected?

Dr. Jones presented the Directors with a summary of a possible revised scheme for collecting data in the U.K. He said that with the forms that had been used for the last three or four years, the most difficult forms for Directors to complete were those asking for lists of the names of patients treated annually with details of their inhibitor status, date of birth and the types of materials that they had received during the year. Dr. Jones wondered whether it was

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necessary for the Directors to continue to provide this detailed information about the individual patients on an annual basis. He outlined the proposals for a new scheme which could start in 1980 and which would be based on the computer file which had been set up in Oxford with the help of the Oxford Regional Computer Unit. The data which was in the Computer file did not give the names of individual patients or the names of Haemophilia Centres; these were identified by code numbers only, to preserve confidentiality. Dr. Jones said that he and his colleagues in Newcastle would be quite happy for the names of their patients to go into the computer, except for the names of Carriers which he felt should not be held on a computer file, and this was one of the matters which should be discussed by the Haemophilia Centre Directors.

Dr. Jones presented some slides illustrating the type of data which was currently available in the Oxford Computer File and which could be made available to Haemophilia Centre Directors and Reference Centre Directors annually if they wished. Dr. Jones also showed a computer print-out giving the type of information which he had available on a computer file in Newcastle for the Newcastle Region patients.

Dr. Rizza presented a short document which he and Miss Spooner had prepared comparing the type of information at present available with the information which would be available if the new scheme described by Dr. Jones were implemented. This was discussed at some length.

Professor Bloom said that one of the problems with collecting data from the Centres was that there was no uniform

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system used by Centres to collect data and many Centres had problems with their record keeping methods. He wondered whether a system could be drawn up which could be used by all Centres to help with their record keeping. Dr. Jones said that he had looked into the question of record keeping at Haemophilia Centres and had found that the methods of record keeping varied considerably from place to place to fit in with the ways in which the Haemophilia Centres ran their clinical practices. He thought that it would be very difficult to find one system of record keeping which would suit all Centres.

There was much discussion about the type of information which might be deleted from the Annual Returns. Several Directors felt that it was the wrong time to cut back on collection of data on patients with Factor VIII or Factor IX antibodies or on patients who developed hepatitis since those were two outstanding problems in haemophilia today. The suggestion that the details of the types of materials used to treat individual patients should no longer be collected, was discussed.

Dr. Craske said that the Hepatitis Working Party was particularly interested in collecting the data on the types of materials which the individual patients had received and he felt that this information was very important to the work of his Working Party. He already had some evidence that there were different Non-A and Non-B viruses and that the presence of the different viruses in therapeutic material might be related to different methods of fractionation. If the Directors no longer provided information about the different

types of products used at the Centres, it would not be easy to continue with this line of work. The suggestion that the breakdown of the amount of the different types of commercial products used at Centres should be discontinued was also discussed and it was generally thought inadvisable to discontinue the collection of this data at present in view of the potential value of this information in the study of post-transfusion hepatitis.

Dr. Bidwell said that she would be very loath to see the Directors lose the detailed data on the use of materials for the patients with antibodies and for the von Willebrand's disease patients. Professor Bloom said that the von Willebrand's disease patients and the Carriers were a small number of patients but that they were a group of patients particularly susceptible to hepatitis and he felt this data should continue to be collected. It was suggested that the various Working Parties should establish exactly what type of information they wished to have collected and come to an agreement about this with the Reference Centre Directors and Oxford. Professor John Stuart asked if anyone objected to patients names going into the computer file and the question of access to the computer file was discussed. It was agreed that the Haemophilia Centre Directors should have access to the names of only their own patients but that Working Party Chairmen could have access to relevant data from the full computer files. The recent request by the BMA to G.P.'s that they should oppose the names of patients going into computer files, was raised and the Haemophilia Society representatives

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were asked how the Society would feel about patients names being put on a computer file. Mr. Polton said that he did not think that any of the Society's members would object to their names going on to a computer file. All haemophiliacs know that their names are held in files at Haemophilia Centres and this was something they accepted as being necessary and did not worry about. Professor Stewart was concerned about the confidentiality aspect of putting names into the computer file. He said that he would much prefer the present system, whereby the patients were identified in the computer file by number only, to be continued. One of the Directors asked whether there was any possibility that commercial firms could get hold of the data in the computer file. This was thought extremely unlikely; there would be no question of the commercial firms being allowed access to the files and there were strict checks on confidentiality at the Regional Computer Unit in Oxford.

Professor Bloom proposed that a vote should be taken on the proposal that the computer file should hold the patients identifications by code numbers only for the time being and the Directors should see how this worked out. He had the impression that the feeling of the Meeting was in favour of code only, but Dr. Forbes said that his impression was that the Meeting was in favour of names. After further discussion a vote was taken and it was agreed that the names of the patients should be put into the computer file.

The question of the annual collection of information concerning the therapeutic materials received by named patients

was discussed further. Professor Hardisty said that all Haemophilia Centres should keep a record of individual patients' usage of materials. He wondered whether it would be possible for all the totalling of the individual patients' usages to be done in Oxford. Dr. Kernoff felt that there were no problems in adding up the totals at Centres for the individual brands of materials and he felt that Dr. Craske had presented a convincing case for continuing to collect the information on the total amount of different brands of material used at Centres and of the different types of materials received by the individual patients.

With regard to collecting any additional or new types of data in the future it was agreed that this should be discussed by the Haemophilia Centre Directors before being embarked upon. In this way any tendency for 'mushrooming' of data collection should be controlled.

Dr. Sterndale suggested that the Directors should continue for 1980 at least to collect the detailed information for the benefit of the Hepatitis Working Party. Dr. Chalmers said that he was strongly opposed to the central computer doing the day to day totalling of materials used by patients etc. He felt that this could lead to errors and that this was the sort of work which should be done at individual Centres as only the people who were treating the patients could be aware of errors which might creep in. Dr. Sterndale put forward the proposal that the collection of data on the different types of materials used to treat patients at Centres in the U.K. and the types of materials received by the

individual patients should be collected for 1980 in the same way as it was currently being collected. The majority of Directors supported Dr. Sterndale's proposal and this was agreed. There was then discussion as to whether or not the collection of data on the Carriers of Haemophilia A or B and the von Willebrand's disease patients was necessary. It was agreed that the data on the Carriers and von Willebrand's disease patients treated each year, should continue to be collected.

7. Report on Meetings of Reference Centre Directors

Dr. Rizza gave a brief outline of the matters which had been discussed at recent Haemophilia Reference Centre Directors Meetings:-

i) Haematuria Working Party

The question of the setting up of a Haematuria Working Party had been discussed by the Reference Centre Directors. The Reference Centre Directors felt that if a Working Party was set up it should have a much wider remit than was initially envisaged and they felt that this matter should be referred back to the main meeting of all Haemophilia Centre Directors to ask if there was anyone who would be willing to look into this problem with a view to setting up a Working Party. If anyone was willing to undertake this work they should draw up details of their proposals and submit them for consideration by the Reference Centre Directors.

ii) The Widening of Scientific Meetings

The possibility of the Scientific Meetings at the Annual Haemophilia Centre Directors Meeting being opened up so that technical staffs and other people with an interest in

haemophilia could attend had been discussed. It had been agreed that in 1980 it would be possible for this to be done.

iii) Von Willebrand's disease

The Reference Centre Directors had discussed the possibility of a von Willebrand's disease Working Party being set up and had agreed that a Working Party should be set up under the Chairmanship of Dr. E.G.D. Tuddenham subject to the approval of all the Haemophilia Centre Directors.

iv) The Working Party on Carrier Detection

This Working Party had been wound up. Professor Bloom said that the Carrier Detection Working Party had run into difficulties in defining its remit. They did not feel at the present time that there was any point in continuing to have a Working Party on Carrier Detection. Dr. Colvin mentioned that in London a multi-centre study was being undertaken on Carrier detection and he thought this might produce some useful information.

8. Von Willebrand's Disease Working Party

Dr. Tuddenham put forward his proposals for the work of this new Working Party for the approval of all the Haemophilia Centre Directors. The first problem for the Working Party would be to define what von Willebrand's disease was. Dr. Tuddenham referred to a survey which had been carried out by the Haemostasis Club several years before. Dr. Tuddenham felt that there would be some benefits in compiling a register of known von Willebrand's disease patients but here again the problems over the diagnosis of von Willebrand's disease would have to be looked into first. He reminded Directors that the

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computer file in Oxford had details only on treated von Willebrand's disease patients and not on known but untreated von Willebrand's disease patients. Dr. Tuddenham referred to the many variants of von Willebrand's disease which had been reported, in particular to the sixteen variants reported by Miller and Graham in July 1979 issue of Blood. He also referred to the ETRO Working Party which classified von Willebrand's disease into only four types but he felt that there were many patients who did not fit into any of those four categories.

Professor Bloom asked for the approval of the Meeting to the setting up of the von Willebrand's disease Working Party. This was unanimously agreed. Professor James Stewart asked if the Working Party would deal with methods of diagnosis of von Willebrand's disease. Professor Bloom suggested that Directors should write to Dr. Tuddenham with ideas about the matters which the Working Party should consider. This was agreed.

9. Provisional Date and Place of Next Meeting of Haemophilia Centre Directors.

Professor Bloom said that the 1980 Meeting of all Haemophilia Centre Directors would be held in Glasgow. No date had yet been decided upon.

10. Any Other Business

i) Dr. Colvin said that his Centre had been encountering problems with the Ambulance Services in that patients were refused transport to Haemophilia Centres and were frequently taken not to a Haemophilia Centre but to the nearest General

as Co-Chairman of the Haemophilia Centre Directors and presented Professor Ingram with a compass as a token of the Directors appreciation.

In the absence of Professor Bloom, Professor Blackburn then took the Chair.

Reports of the Working Party Chairmen:-

1. Hepatitis Working Party

Dr. Craske presented his report. He said that some corrections were required to Table 3 because of updating of information. The corrected version of this Table would be included in a written report to the Department of Health and any Directors who wished to have the corrected version of the Table should write to him. Dr. Craske said that the Working Party had drawn up a new form, Form C3, which they would like Directors to complete for patients who had chronic hepatitis. The Working Party felt that it was important for the incidence of chronic hepatitis in haemophilic patients to be assessed. There was much discussion regarding the incidence of chronic hepatitis in haemophilic patients, the possible value of liver biopsies and the type of information which Directors would be willing to give to the Working Party.

Professor Stewart of the Middlesex Hospital suggested that samples of liver should be obtained from all haemophiliacs who went to post-mortem. The average attack rate of hepatitis in patients aged over 40 was six times that for those aged under 40. Age was a very relevant factor. Dr. Craske commented that most patients thought to have developed chronic liver disease had not previously had an overt attack of hepatitis. There were various possible causes of hepatitis

Hospital, he wondered if other Directors had met this problem and how they coped with it. Mr. Prothero said that the Haemophilia Society had taken up this problem on several occasions had written a note of instructions for Ambulance Personnel and patients. This was available from the Society. Several Directors said that they had in the past encountered similar problems to those which Dr. Colvin was describing and they recommended that the Haemophilia Centre Directors made direct contact with the Ambulance Service to discuss these difficulties.

ii) Factor IX Supplies

Dr. Bidwell asked Directors to make requests before the 30th November for Factor IX supplies sufficient to cover the anticipated needs to mid-January. Plasma Fractionation Laboratory would be closed all of Christmas week but open on New Year's Day.

The Business Session finished at 5.30 p.m.

DAY 2

Dr. Rizza said that he had a pleasant duty to perform before the official business of the day commenced. He wished on behalf of all the Haemophilia Centre Directors of the United Kingdom to thank Professor Blackburn for all the work he had done on their behalf over the last ten years when he was Chairman of the Group, and presented Professor Blackburn with a gift of a 'Mont Blanc' fountain pen from the Directors as an expression of their gratitude and thanks. Dr. Rizza also thanked, on behalf of the Directors, Professor Ingram for the work that he had done during the last twelve months

Treloar College. He said that there were difficulties for Directors in buying materials to use to treat patients prophylactically. Had there been any move to find out if prophylactic treatment really did any good? Dr. Jones said that for haemophilia A patients limited prophylaxis was very effective indeed but it must be for a very good reason. One could spend less on prophylactic treatment than on on demand treatment in some instances. Dr. Delamore from Manchester said that he would like to take up Professor Stewart's point about prophylaxis. He asked Dr. Jones if he could evaluate the benefits of prophylaxis and if the Working Party recommended it.

Several Directors felt that there were problems over the definition of prophylaxis. Dr. Jones said that he was intending to go back to the larger Haemophilia Centres who had patients on prophylactic therapy to ask them for further details.

Dr. Kernoff said that the Royal Free Hospital had problems over the money to purchase commercial materials, therefore they had adopted a deliberate policy of giving National Health concentrates for home therapy and purchasing commercial material for use at the Hospital.

3. Treatment of Patients Having Factor VIII Antibodies

Dr. Colin Prentice presented a brief report from the Factor VIII Inhibitor Working Party summarizing the work they had undertaken over the last year and their proposals for the future.

Dr. Prentice said that there were many difficulties over non-controlled studies of the type that the Working Party

and one should keep an open mind about it. There were two types of Non-A and Non-B hepatitis. It was very important to pool data for the whole of the U.K.; to look at data from only a few selected Centres would not be very useful. It was agreed that the Working Party would produce a new two-part form on which Haemophilia Centre Directors could report cases of chronic hepatitis. Part one of the form would be for the Directors to record brief details on the patient and Part two would be for much more detailed information, to be completed at those Centres where the information was available.

2. Home Treatment Working Party

Dr. Jones presented an interim report from the Home Therapy Working Party and outlined briefly the data which had been obtained to date on patients treated during 1978.

A book had been published under the sponsorship of Speywood Laboratories for mothers to read to haemophilic children. This would shortly be available.

Four prizes were to be awarded annually to haemophilic patients for academic achievement. One of £100 per annum was donated by Catherine Cookson, the authoress; £75 would go to a haemophiliac aged 12 years or over and £25 to a haemophiliac aged under 12 years. Brendon Foster and an anonymous person had also offered to put up two more prizes of similar value. The details of how the prizes were to be allocated would be decided by a panel of judges in collaboration with the Haemophilia Society.

Professor Stewart of the Middlesex Hospital raised the problem of prophylaxis and referred to the trial at Lord Mayor

Day 2 - Scientific Session

1. Supplies of NHS Factor VIII Concentrate

Dr. R.S. Lane of the Blood Products Laboratory at Elstree gave a most interesting talk about the position with regard to supplies of NHS Factor VIII concentrate, in which he outlined briefly the history of the Blood Products Laboratory, the present situation and the many problems which the BPL was encountering. He emphasised the need for closer co-operation between the users and producers of the blood products, and explained how the present NHS funding arrangements militated against this. Dr. Lane emphasised the importance of the Haemophilia Centre Directors keeping records to show how they were using the materials with which they were supplied. The aim of the Blood Products Laboratory was ultimately to achieve self-sufficiency in the supplying of NHS Factor VIII to meet the needs of the UK Haemophilia Centres.

2. Antenatal Diagnosis of Haemophilia

Mr. C.H. Rodeck outlined briefly the techniques of foetoscopy and showed a film illustrating the techniques. Dr. Mibashan presented the data on haemophilia A and haemophilia B Carriers. 15 Haemophilia A Carriers and 1 Haemophilia B Carrier had been tested so far. The size of the demand for the technique was not yet known. Dr. Mibashan had had 30-40 patients referred for possible foetoscopy and out of these only 16 had eventually had the tests done. Many of the referrals were from overseas. Assays were done by modified one-stage techniques for Factors VIII and IX and Factor VIII clotting antigen and related antigen assays were also done. Dr. Peake gave the results of the assays for factor VIII C:ag

had tried to undertake and the Working Party was considering the possibility of a prospective controlled trial being organised. There was considerable discussion about the possibility of the Working Party setting up a properly controlled study of activated prothrombin complex concentrates in the management of haemophiliacs with factor VIII antibodies. Many difficulties were seen over the setting up of such a trial; for example should FEIBA or some other preparation be used, and should the effectiveness of the preparation(s) be compared with a placebo, factor VIII concentrates or non-activated prothrombin complex concentrates. In addition much concern was expressed about the problem of assessing the clinical effectiveness of any form of therapy. Attention was drawn to the two studies which were currently being planned, one in Holland and one in the United States of America, and it was suggested that the UK Haemophilia Centre Directors might like to consider collaborating with the USA.

Dr. Walford from the Department of Health said that she felt obliged to bring in a word of caution to Dr. Prentice over planning a trial. She pointed out that a clinical trial certificate would be required because FEIBA and Autoplex were unlicenced materials. It was agreed that Dr. Prentice would look into the possibilities of a trial being organised and report back to the Directors at the 1980 Meeting.

4. Factor VIII Assay Working Party

Dr. Rizza presented the written report from the Working Party which had been precirculated and Dr. Barrowcliffe expanded further on the findings of the collaborative study, and the future plans of the Working Party.

undertaken in Cardiff on the samples sent from King's College Hospital.

3. Home Treatment Working Party's Employment Study

Professor John Stuart from Birmingham outlined the results of the study which was undertaken in the Autumn of 1978 by four Haemophilia Centres in which 502 questionnaires completed by Haemophilia A and Haemophilia B patients were analysed. A paper reporting the findings would shortly be submitted to the Medical Press.

The Employment Study Sub-Committee had also arranged for the printing of a small booklet which was aimed at helping haemophilic patients to obtain employment. Copies of this book were distributed to those present at the Meeting and supplies would shortly be sent to all Haemophilia Centre Directors. Further copies could be obtained from the Haemophilia Society.

4. Von Willebrand's Disease

Dr. Helen Armitage of Oxford presented the results of a study she had recently completed of 177 individuals from 42 families with von Willebrand's disease.

The Meeting closed at 5.30 p.m.