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(Revised 29.3.1977)

Minutes of the Meeting of Haemophilia Centre Directors of the United Kingdom held on 13.1.77 at the Middlesex Hospital, London.

Those present were:-

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

Dr. S. Ardeman,
Edgware General Hospital.

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

Dr. T. Barrowcliffe,
National Institute for Biological Standards and Control.

Dr. O.H.A. Baugh,
Chelmsford & Essex Hospital.

Dr. E. Bidwell,
Plasma Fractionation Laboratory,
Oxford Haemophilia Centre.

Dr. Rosemary Biggs,
Oxford Haemophilia Centre.

Professor E.K. Blackburn,
The Royal Infirmary, Sheffield.

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

Dr. A.L. Bloom,
University Hospital of Wales.

Dr. J.M. Bridges,
Royal Victoria Hospital, Belfast.

Dr. Morag Chisholm,
Royal South Hants Hospital, Southampton.

Dr. B. Colvin,
The London Hospital.

Dr. J. Craske,
Withington Hospital, Manchester.

Dr. G. Crawford,
Hammersmith Hospital, London.

Dr. D.S. Dane,

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

Dr. Katharine Dormandy,
The Royal Free Hospital.

Dr. H. Dodsworth,
St. Mary's, Paddington.

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

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

Dr. Henry Ekert,
Oxford Haemophilia Centre.

Dr. D. Ellis,
Blood Products Laboratory, Elstree.

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

Professor P.T. Flute,
St. George's Hospital, London.

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

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

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

Professor R.M. Hardisty,
The Hospital for Sick Children, London.

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

Dr. R.M. Ibbotson,
Central Pathology Laboratory, Stoke-on-Trent.

Dr. A. Inglis,
Cumberland Infirmary, Carlisle.

Professor G.I.C. Ingram,
St. Thomas' Hospital, London.

Professor G.C. Jenkins,
The London Hospital.

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

Dr. Peter Kirk,
Treloar Haemophilia Centre, Hants.

Dr. J. Leslie,
Norfolk & Norwich Hospital,

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

Dr. Elizabeth Mayne,
Royal Victoria Hospital, Belfast.

Dr. W.O. Mavor,
Royal Hampshire County Hospital, Hants.

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

Dr. B. Murphy,
Torbay Hospital, Torquay.

Dr. A.E.S. Mustafa,
Memorial Hospital, Darlington.

Dr. G.A. McDonald,
Royal Infirmary, Glasgow.

Dr. J.M. Nicholas,
Essex County Hospital.

Dr. J.S. Oakey,
Orsett Hospital, Essex.

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

Miss Moira Patterson,
Scottish National Blood Transfusion Service.

Dr. K. Potter,

Dr. R.E. Potts,
Middlesbrough General Hospital, Teesside.

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

Dr. F.E. Preston,
The Royal Infirmary, Sheffield.

Mr. J. Prothero,
The Haemophilia Society.

Dr. S.G. Rainsford,
Lord Mayor Treloar College, Hants.

Dr. E.G. Rees,
Shrewsbury Hospital.

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

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

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

Mr. T. Snape,
Plasma Fractionation Laboratory, Oxford.

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

Dr. D. Stern,
Royal Victoria Hospital, Bournemouth.

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

Professor J.W. Stewart,
The Middlesex Hospital Medical School,

Dr. J. Stuart,
Queen Elizabeth Medical Centre, Birmingham.

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

Rev. Alan Tanner,
The Haemophilia Society.

Dr. Duncan P. Thomas,
National Institute for Biological Standards and Control.

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

Dr. G.R. Tudhope,
Ninewells Hospital, Dundee.

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

Dr. H.J. Voss,
Kettering & District General Hospital.

Dr. Sheila Waiter,
D.H.S.S.

Dr. D.N. Whitmore,

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

Dr. Williams,
Chelmsford & Essex Hospital.

Dr. D.A. Winfield,
Royal Infirmary, Derby.

Sister Davis,
Haemophilia Co-Ordinator.

Dr. F.E. Boulton,

Apologies for Absence from:-

Dr. R.P. Britt,
Hillington Hospital.

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

Dr. I.A. Cook,
Regional Blood Transfusion Centre, Inverness.

Dr. K.P. Cotter,
Coventry & Warwickshire Hospital.

Dr. A.A. Dawson,
Haematology Unit, Aberdeen.

Dr. B.E. Gilliver,
County Laboratory, Dorset.

Professor R.H. Girdwood,
The Royal Infirmary, Edinburgh.

Dr. H. Greenburgh,
Plymouth General Hospital.

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

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

Dr. W. d'A Maycock,
Blood Products Laboratory, Elstree.

Professor P.L. Mollison,
St. Mary's Hospital, Paddington.

Professor M.G. Nelson,
Royal Victoria Hospital, Belfast.

Dr. R.W. Payne,
The Royal Infirmary, Worcester.

Dr. M.J. Phillips,
Musgrove Park Hospital, Somerset.

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

Prof. T.A.J.Prankerd,
University College Hospital, London.

Dr. J. Stafford,
Plymouth General Hospital, Devon.

Dr. H.T. Swan,
The Royal Infirmary, Sheffield.

Dr. J.C. Watt,
Scottish National Blood Service.

Professor J.M. White,
King's College Hospital.

Prof. Blackburn: Welcomed everyone to the meeting, especially the Directors of newly-designated Centres and Associate Centres, and thanked Prof. Stewart for his hospitality. Prof. Blackburn announced that Dr. Biggs was retiring and that Dr. Rizza had agreed to take over as Secretary General for the Haemophilia Centre Directors.

Prof. Blackburn announced with regret the death of Col. Jeffrey: the meeting stood in silence in respect.

1. Minutes of the Last Meeting: Were approved and signed.

2. Matters arising from the Minutes:

a) Trial of prophylactic treatment of haemophilic patients at Alton (Dr. P. Kirk): Dr. Kirk reported on the third trial of prophylactic treatment at Alton the aim of which was to see if prophylactic treatment reduces the incidence of bleeds in severely affected haemophilic boys. All patients in the study already had bad joints. They were treated with cryoprecipitate, Kryobulin and Hemofil. All but 1 had a fairly substantial reduction in the number of bleeds. The estimated cost of prophylaxis was £4 - £18 per day above

the cost of previous "on demand" therapy.

In answer to questions, Dr. Kirk said that prophylactic doses were given on alternate days and that each prophylactic dose was calculated to give a rise of 30% in factor VIII. "On demand" doses for haemarthroses aimed to raise the patient's factor VIII to 20%. Dr. Prentice asked how much factor VIII would be needed to treat a patient on prophylaxis. Dr. Kirk said that the amount was of the order of 100,000 units a year. Dr. Kirk said that it should be emphasised that the patients selected for prophylaxis were all very severely affected haemophiliacs who consumed much more than the average amount of factor VIII when they received "on demand" treatment. Dr. Blecher asked which regime the boys prefered - on demand or prophylaxis. Dr. Kirk replied that the 2 boys with the best results (reduced number of bleeds) wanted to stop prophylactic treatment; the others wanted to go on. Possibly the 2 boys with good results had forgotten what a bad bleed was like. Prof. Stewart felt that prophylactic treatment for haemophiliacs should not be entered into on a large scale until there was sufficient evidence that it was beneficial to the patients. Dr. Rainsford said that the prophylactic trial was aimed to provide information for the future and not with the intention of immediate implementation.

b) Study of Hepatitis in Haemophilic Patients (Dr. J. Craske): Dr. Craske presented a written report to the meeting and outlined the findings detailed therein. 371 patients receiving Hemofil had been followed up. Only 1 death was possibly attributable to Hepatitis B. Dr. Craske suggested a special study of patients with factor VIII antibodies who may receive large doses of concentrates. Dr. Craske said he would

like to continue with his study over the next two years. "This continued study would include a follow up of patients who had had Hemofil associated hepatitis to study the incidence of chronic sequelae, and a comparison of jaundice associated with NHS Factor VIII and commercial products". Prof. Stewart said that jaundice would always occur and there were difficulties in specific identification of the causal agents. Dr. Dane said there were problems with the sub-typing. This was possible with samples from patients but was difficult with the concentrates because of the very small amounts of virus present in the samples. Tests for HB_sAg could not pick up trace amounts of antigen. Hepatitis B was uncommon in the general population in patients under 14 years of age. Dr. Mibashan asked Dr. Craske to clarify how he distinguished between Hepatitis B and non-B types and Dr. Craske said he looked at each individual case. Dr. Mibashan asked if a patient who had recently received treatment with an infected batch of Hemofil might not be excluded because he got jaundice too early and Dr. Craske said he thought it was very unlikely that this had occurred.

c) Staffing of Haemophilia Centres and rotation of staff at Haemophilia Centres: Dr. Biggs reported on a survey which had been undertaken on the staffing of the Reference Centres. The major difficulty was that the Centres were so different one from another. No standard staffing arrangements could be proposed. The main problem was rapid rotation of staff at all levels so that experienced staff were seldom available. The Reference Centre Directors were agreed that nursing staff were essential to the running of any Haemophilia Centre which catered for 25 or more regularly attending

patients a year.

Dr. Dormandy reported that she was now finding that the Medical Social Workers and Physiotherapists were rotating. She had spoken to Administrators about the problems caused by inexperienced staff but was informed that the rotation system was the result of the NHS reorganisation. Ancilliary staffs were expected to change their posts frequently to gain wide experience. This was most unsatisfactory for the Haemophilia Centre. Prof. Bloom mentioned the discontinuity caused by rotating registrars.

Prof. Stewart pointed out that it was possible for senior nursing staff (Staff Nurse or Sister) to be appointed to a Department on a permanent basis. Physiotherapists and Social Workers must be shared with other departments and there must be some rotation of staff since otherwise the various types of workers could not be trained.

Dr. Jones said that in Newcastle he had 2 nurses for the Haemophilia Centre (Sister and Staff Nurse), a senior physiotherapist who also dealt with children but did not rotate and two permanent part time senior social workers. Dr. Stern emphasised that it was only the senior grades of staff who did not have to rotate.

ACTION

Prof. Ingram said he thought it would be helpful if a memorandum went from the Meeting to the DHSS recommending that all Haematology Departments should have nursing staff who could help the Haemophilia Centre. He thought this would be particularly helpful to small Haemophilia Centres where the appointment of a nurse was difficult to justify.

Dr. Prentice pointed out that the decisions would be

taken by the local Area or District Teams. Maybe a local approach should be made as well? Prof. Ingram agreed but suggested that the central DHSS and Welsh Office should also be approached, regarding Social Workers, Medical Staff, Physiotherapists and Nursing Staff.

d) Collection of Statistics by Haemophilia Centre Directors.

Dr. Biggs referred to the written report prepared by herself and Miss Spooner on the Annual Returns received from Haemophilia Centres. She said the main points of interest were: a) the number of known Haemophilia A patients in the U.K. had now exceeded 3,000; b) the incidence of jaundice in 1975 was down in comparison to 1974.

ACTIONS

(i) Dr. Biggs suggested that the report should be prepared for publication as a short note to the British Journal of Haematology and that similar reports should be submitted to the Journal for publication each year.

(ii) Dr. Biggs also asked for permission to pass on to Dr. Maycock details of the numbers of patients treated at individual Centres so that Dr. Maycock could use this information when considering the allocation of NHS Factor VIII concentrate to Centres.

There was some general discussion about the criteria for the allocation of factor VIII to various Haemophilia Centres. It was generally agreed that all methods had disadvantages. For example the number of doses given might reflect the usage most accurately, but this information is not at present collected. The number of units of factor VIII used might preclude excessive allocation of factor VIII to

centres where short stay visitors expanded the number of patients treated, but would give advantage to Centres where extravagant doses of factor VIII were used. A vote was finally taken and it was agreed by 54 votes to 6 that Dr. Maycock should receive a note of the number of patients treated at each Centre and should base the allocation of NHS factor VIII on these figures.

ACTION

Prof. Bloom asked that returns be made for von Willebrand's disease patients. This suggestion received general support and Dr. Biggs agreed to include these in the data collected from 1976 onwards.

3. Activities of Reference Centre Directors and the Supply of Factor VIII

Prof. Blackburn reported that there had been several meetings of the Reference Centre Directors. Two major items of importance which the Reference Centre Directors had considered were:-

1) Supplies of factor VIII concentrate: It was established that the Blood Transfusion Service could supply sufficient plasma for fractionation to provide a minimum of 40,000,000 units of factor VIII per annum.

2) There was a hold-up in the expansion of fractionation in the U.K. Prof. Blackburn was planning to organise a meeting to look into ways of expanding the facilities for fractionating. Dr. Holman commented that the Directors had for years said that they wanted concentrate instead of cryoprecipitate. Was it true that the DHSS were making no provisions for expansion? Dr. Jones declared his interest in this item as he was a paid Consultant to Hyland Laboratories until the end of February

1977 and he volunteered to withdraw from the meeting while the question of supplies were being discussed. It was agreed that he could stay. Dr. Waiter said that the target of factor VIII requirements had shifted over the years. The DHSS had understood that the capacity at Liberton, Elstree and Oxford was adequate. With the stated capacity of these centres a target of 50 m. units could be met. Dr. Biggs said that the target had not shifted. The first estimate given in recent years was 40-50 million units (Biggs, 1974). She did not know where the lower targets had come from; they certainly had not come from either the Expert Group on Haemophilia or from the Haemophilia Centre Directors. Dr. Barkhan asked if the figures covered total needs at Centres and meant that cryoprecipitate and commercial concentrates would be obsolete.

Dr. Biggs said that if the supply were unlimited and neither patient nor doctor had to pay for the factor VIII it was difficult to forecast how much factor VIII might be used. Doses could be increased and prophylaxis could become popular. The estimate of 40-50 million units per year made by the Haemophilia Centre Directors and the MRC Working Party concerned a minimum reasonable need. This amount would in their opinion supply enough factor VIII to cover for surgery and emergencies and ~~to~~ give on-demand and home therapy sufficient to prevent crippling and to permit a reasonably active life. The amount would thus render the U.K. independent of supplies of plasma collected in other countries and included the present supplies of cryoprecipitate.

The question about the maximum amount of material that could be made at the present Fractionation Units was raised.

Dr. Ellis said that 14-15 m. units was the maximum capacity for Elstree with the present plant and buildings. This included a proportion made in Oxford and was a final figure after current expansion was completed. Dr. Macdonald gave a talk about supplies of factor VIII concentrate in the West of Scotland. Cryoprecipitate was originally made at the Glasgow Royal Infirmary and later by the West Scotland Blood Transfusion Centre. Dr. Macdonald referred to the costs of building the Protein Fractionation Centre (PFC) at Liberton and showed figures illustrating the amount of plasma which had been sent to Liberton from the West of Scotland for fractionation. Dr. Macdonald said that the PFC at Liberton had the capacity to make 60 million units of factor VIII per year. To reach this target the Centre would need about £25,000 for new capital equipment and money for extra running costs which would include payment for staff to operate a 24 hour shift system of working. Dr. Macdonald said that commercial factor VIII was at present used in the West of Scotland. In 1976, 14% of all factor VIII was commercial. The supply of NHS factor VIII was increasing and in 1976, 46% of all factor VIII used was freeze-dried NHS intermediate potency concentrate. Prof. Blackburn said that it seemed as if the PFC at Liberton had capacity to supply factor VIII for the whole U.K. Dr. Waiter said that the DHSS together with the SHHD were planning the supply of Factor VIII on a U.K. basis. Plans had been made to divert plasma from South of the Border to Liberton when Mr. Watt was ready to receive it. It was planned that the factor VIII made from this plasma would return to Centres south of the Border. Agreement in principle had already been reached between the DHSS in

London and the Scottish Home and Health Department. Dr. Prentice commented that there was a big difference between the target of 60 million units and what was actually available for use. Prof. Hardisty said that as the plasma for fractionation in Liberton would have to come from all over England, including the South, perhaps it would be better to look into the possibilities of expanding the fractionation facilities in Southern England where the largest number of blood donors were resident. Dr. Rainsford asked if England and Wales would be charged for the use of the fractionation facilities in Scotland. If so, might it not be as well to continue to buy commercial concentrates? Dr. Holman asked when the Liberton PFC would be fully operational. Dr. Waiter said that it was for the Scottish Home and Health Department and Mr. Watt would decide when production was adequate to fractionate additional plasma. Dr. Bidwell said that the reasons for the limitation of production varied from place to place. Plasma was the present limiting factor in Oxford. Next year the Oxford production would be doubled, then the capacity for the building would be reached and there was no possibility of extending on the present site.

Questions were asked about the potency of NHS concentrate which had until recently been made up at a concentration of about 5 u/ml. It was felt that more concentrated preparations were more convenient. It was stated that at Liberton, Elstree and Oxford a solution containing between 10 and 15 u/ml was now being produced as a product for administration to patients.

Prof. Ingram raised a technical point regarding the Elstree factor VIII concentrate and the expiry date given on

the bottles. After the date was there loss of factor VIII activity or was something toxic happening to the material? Dr. Ellis said that the expiry date was based on the expected loss of activity, which was about 10% in a year at +4°C, possibly there would be better stability at lower temperatures. No toxic products developed in the material after storage. Prof. Stewart said that there was a problem at present in finding sterile distilled water to dissolve the NHS concentrate. The commercial concentrates were supplied with water for solution which was an advantage. Dr. Ellis said that Elstree was looking into this problem and might in the future supply the water with the concentrate.

4. Organisation of Haemophilia Care

Dr. Dormandy reported on the findings of the North East Thames Working Party on Haemophilia, which was convened 2 years ago to study the care of haemophiliacs in the area and to promote home treatment wherever possible. The Working Party considered that the care of haemophiliacs would be improved by the appointment of a Nursing Sister who would act as co-ordinator for the Region and Mrs. Cheryl Aston was appointed. The Haemophilia Society provided funds to cover Mrs. Aston's appointment for the first year and she started work in February, 1976. Mrs. Aston was based at the North East Thames Blood Transfusion Centre at Brentwood. Mrs. Aston had been able to identify the hospitals at which haemophilic patients were treated which was very useful in planning the designation of Haemophilia Centres. When Mrs. Aston left, the Regional Health Authority had agreed to take over the financial responsibility for the appointment from April 1977. The co-ordinator's duties included: the care of

the patient and his family; promoting co-operation between Haemophilia Centres and between patients and the Haemophilia Centre and between General Practitioners and Haemophilia Centres; visiting schools, dental services; assessing patients for their suitability to receive home treatment and arranging for the training of patients; the collection of statistical information about supplies of factor VIII and the number of patients. The co-ordinator gets on well with everyone and plays a very useful role in providing a service for patients. Dr. Dormandy said that it was convenient for the co-ordinator to work at the Transfusion Centre and that a nursing sister was well qualified for the post.

Mr. Prothero said that the Society had been asked to fund the appointment of a Co-ordinator in the North East Thames Region and they were delighted with the results. The Society felt that the treatment of many haemophiliacs had been much improved. The Society would like other Regions to make similar appointments. Prof. Ingram said that he admired the North East Thames Region's system and would like to initiate a similar system in his own Region.

Dr. Jones said that he thought the North East Thames system was a good idea; he had a similar system in the Northern Region, but more than one person was involved there.

ACTION

Prof. Ingram suggested that a letter be written to the DHSS to recommend the encouragement of the appointment of Regional Co-ordinators for the promotion of Haemophilia Treatment. Prof. Bloom asked that a copy of any letter sent to the DHSS in London about a Regional Co-ordinators should also be sent to the Welsh Office. Prof. Bloom stressed that

all communications on any topic sent to the DHSS should also be sent to the Welsh Office.

5. The Expectation of Haemophilic Patients to take part in normal activities

Mr. Prothero said that the older haemophiliacs had low expectations and were often content to sit and vegetate. The Haemophilia Society aimed to encourage haemophiliacs to lead a full life within a reasonable range of activities.

A haemophiliac expected to be able to attend a local school according to his ability without any pressure to go to a selected school because of haemophilia. Employment should be based on the particular ability of the haemophiliac without considering the handicap of haemophilia and without having to travel a long distance to obtain treatment. As treatment improved the haemophiliac's expectations widen. It was not now unreasonable for them to participate in sports, within limits (e.g. perhaps to play squash if treatment was readily available if required;) money spent on treatment required as a result of sporting activities would be well spent. A haemophiliac who had muscles developed by regular exercise had less bleeding than a sedentary patient.

Some haemophiliacs have unreasonable expectations. For example, prophylactic treatment might be an ultimate goal but it was not at present practicable. One haemophiliac wanted to take up motor racing but Mr. Prothero thought this unreasonable.

Mr. Prothero said that Haemophilia Centre Directors differed a good deal in their opinions about reasonable activity for haemophiliacs; some for example thought that dancing was an unreasonable activity.

Mr. Prothero said that home therapy had helped a great deal. In particular it permitted patients to go on holiday away from their Centre and to travel on business if necessary.

Prof. Blackburn said that he agreed with Mr. Prothero's approach. He tried to encourage his patients to develop activities in which they could excel and to do what they could within their limitations. Dr. Evans asked about getting married and having families; what was the Society's policy about this? Mr. Prothero said that the Society had no policy. Many haemophiliacs marry nurses. Haemophiliacs were no different than anyone else emotionally. He had met a few who did not think that they should be on the marriage market, but the majority of haemophiliacs had no problems. Children were another matter. Dr. Colvin asked about patients with inhibitors. Mr. Prothero said that he hoped that haemophiliacs with inhibitors would be more careful but he also hoped that the medical people would come up with an answer to this problem soon. Dr. Rizza said that in the end it is the patient who decides what he will or will not do. His impression is that haemophiliacs with inhibitors do not behave any differently than any other haemophiliacs. This comment was agreed by all the other Directors. Dr. Sterndale said that attending normal schools depended on the Local Education Authority and the local Head Master. Sometimes they would not allow a haemophilic boy to go to an ordinary school. Mr. Prothero said he did not think that the majority of haemophiliacs were now barred from attending ordinary schools. Prof. Stewart said that it was possible for haemophiliacs to achieve very high levels of achievement. One of his patients had hoped to row in the last Olympics but unfortunately this had not been

possible due to an accident at a party just beforehand. Dr. Rainsford pointed out that the advantages of Lord Mayor Treloar College for selected boys were that the physiotherapy and hydrotherapy was on the spot. There was a minimum of interruption of education in obtaining treatment and physical education.

The Haemophilia Society provided literature on human rights and on the deliberations of the Genetics Committee of the World Federation of Haemophilia.

6. The Supply of Factor IX

Dr. Bidwell said that in 1972 as a result of a questionnaire to the Directors she estimated the factor IX requirements of Haemophilia Centres at about 5,000 bottles a year and she had arranged to be able to make 7,500 bottles a year. By 1976 in fact nearly 10,000 bottles were used. In 1976 Dr. Bidwell asked those Haemophilia Centre Directors whose requirement had increased considerably if they had changed their policy. In this letter Dr. Bidwell had said that present arrangements for production of factor IX and level of funding did not allow for prophylactic treatment except for occasional short periods of time. Since writing this letter she had discovered that a few very severely affected patients were in fact on prophylaxis in Oxford and she thus felt that she should inform Directors that prophylaxis for severely affected patients may not be excluded if it were shown not to result in substantial increased usage.

Prof. Blackburn thanked Dr. Bidwell for the good supplies of factor IX she had made available over the years. Dr. Rizza said that 13 severely affected Christmas Disease patients who were regular attenders at the Oxford Centre had

been put onto home treatment and regular prophylactic doses of factor IX concentrate. They had been receiving prophylactic treatment at the Centre before commencing home treatment. The dose given was one bottle of concentrate every fortnight or every week, depending on the size of the patient. Two of the patients were young twin brothers who now never missed school. Dr. Rizza said treatment was very effective and the patients did not use much more material than for "on demand" treatment. Dr. Bidwell said that she had been enabled to increase supplies of factor IX concentrate during 1976 only by the excellent co-operation from Dr. Ellis. She would like to know what the Directors' present requirements were. Prof. Stewart said he thought that it was important to get figures on the advantages of prophylactic treatment of Christmas disease patients. Dr. Bidwell said she would also like to have an estimate of the number of patients likely to need prophylactic treatment. Dr. Rainsford said in fact patients at the College on prophylactic treatment did not use more factor IX than those who received "on demand" treatment.

7. A Handbook for Haemophiliacs

Dr. Jones said that the Directors of the Reference Centres had asked him to draft a handbook. He had made such a draft and hoped that the handbook would become available for patients on home therapy. Dr. Jones said that he had made a survey on home treatment and he was proposing to write to Haemophilia Centre Directors again, with a new survey form, to obtain up-to-date information. He would then publish the results of his survey.

Prof. Blackburn asked Mr. Prothero how the Haemophilia Society's book was coming along. Mr. Prothero said that

Mrs. Stopford had drafted a book and found financial support for it. A further draft was being made and he hoped to have this available soon. Prof. Blackburn asked if the Society had co-operated with the DHSS in drafting the book. Also, was it the feeling of the meeting that there should be only one handbook for haemophiliacs or that there should be two? Dr. Biggs said she did not think there would be any clash between Dr. Jones's book and the Haemophilia Society's book. Mr. Prothero mentioned that the Handbook for Travelling Haemophiliacs published by Abbotts was soon to be re-printed and revised and Dr. Biggs said that the DHSS booklet called "Notes on the Care of Patients with Haemophilia and Christmas disease" was also being re-written and she hoped it would be ready soon.

8. Transport for Haemophiliacs

Mr. Prothero said that the Haemophilia Society planned to circulate to all Haemophilia Centres a summary of the present situation. Under the new arrangements severely disabled persons were paid a mobility allowance and were not being provided with a vehicle. He had heard of several haemophiliacs spending their allowance on high-powered motor bicycles. The situation was unsatisfactory but that at present there was nothing that could be done. The cash allowance was not equivalent to the supply of a vehicle.

ACTION

Prof. Blackburn said he would write to the DHSS recommending that severely disabled haemophiliacs should be provided with suitably adapted cars. Dr. Colvin said that he had a patient who apparently did not qualify for a mobility allowance but who was asked at a medical examination to do

things he thought might cause damage to his joints. Mr. Prothero said that there were apparently very wide variations in the criteria for making a mobility allowance. Dr. Colvin suggested that a Haematologist should be present at every medical examination to decide about a mobility allowance. Dr. Jones said that this was possible and would be done if requested.

9. Repair of Telephones for Haemophiliacs

Prof. Ingram said that haemophilic patients should have a telephone at home, especially when on home treatment. He suggested that haemophiliacs should be included in the category of "E" subscribers on the Post Office's lists so that repairs would be carried out urgently and asked that a recommendation to this effect should be sent to the Post Office from the Meeting.

ACTION

Prof. Blackburn agreed to write to the Post Office to see how this could be arranged.

10. Working Parties to study problems of interest to Haemophilia Centre Directors and patients

Dr. Rizza said he felt that some means should be found to streamline the proceedings at the Annual General Meetings of Haemophilia Centre Directors. Originally the purpose of the meetings was to discuss and plan collaborative research, and arrange for this to be carried out. Many projects had been proposed and reports were included on the Agenda for the meetings which made these meetings very long and discursive. He suggested that a small number of Working Parties should be set up to discuss, plan and arrange for the projects to be undertaken. The Working Parties would give only brief reports

at the Annual Meetings; all business discussions would take place at the Working Parties' own meetings. Dr. Delamore supported Dr. Rizza's suggestion. He said the meetings had become too unwieldy. Dr. Craske said that Working Parties should be constantly reviewed as to their usefulness. Prof. Stewart said he thought that Working Parties should be set up for a limited time with limited objectives. Prof. Bloom suggested that 2-3 Working Parties should be set up in the first instance. Prof. Blackburn put forward the following suggestions:-

Working Party	Chairman
Hepatitis	Dr. Craske
Treatment of Patients with Factor VIII Inhibitors	Dr. Prentice
Reagents - Standardisation	Prof. Stewart

It was suggested that the meeting should have had prior warning of this proposal and an opportunity to form views before being asked to approve the setting up of the Working Parties. It was proposed that Dr. Rizza's recommendations should be circulated to the Directors for comments and nominations regarding membership of the proposed Working Parties.

ACTION

Dr. Rizza agreed to write to the Directors to obtain their views about subjects for Working Parties and people to be included on the Working Parties. It was suggested that memberships should be limited to a maximum of 3-4 persons per Working Party and that the Working Party's objectives should not overlap with ones at present in existance. Dr. Barkhan said the Chairman of each Working Party should be the person

to decide on the size of the Working Party.

11. Home Therapy

Prof. Ingram gave a brief report on the progress of the socio-economic study jointly being undertaken by St. Thomas's Hospital and Oxford Haemophilia Centres.

12. The treatment of haemophilic patients having anti-factor VIII antibodies

Dr. Prentice said that Dr. Bidwell had suggested that a survey should be undertaken to find out how these patients were treated. He had drawn up a protocol (previously circulated) which would provide the information. It was thought that there was no uniform policy throughout the U.K. Some Directors treated their patients by giving very large doses of factor VIII concentrate; others used activated Factor IX (FEIBA). There was possibly a risk of Disseminated Intravascular Coagulation (DIC) when activated factor IX concentrate was used but it seemed that if given in small doses it could be effective.

Dr. Prentice invited all Directors to fill in the Protocol Forms and return them to him. He asked them to do as many of the tests as possible. It was important to find out what people were using to treat these patients. Dr. Mayne enquired if Dr. Prentice wanted 1976 data or only 1977 onwards. She had an interesting case last year. Dr. Prentice indicated that he would like any interesting data which were available, but the plan was to start with patients treated during 1977. Dr. Stuart suggested that the name of the Centre and Director should be added to the forms, and suggested that data could also be collected on patients treated conservatively, e.g. with bed-rest only. Dr. Craske asked that data about treated

patients should be sent to him in connection with the study on hepatitis. Dr. Bidwell asked that Mr. Snape should be included as a Member of the Working Party if a Working Party on the treatment of patients who had anti-factor VIII antibodies was to be set up.

ACTION

It was agreed that a Working Party was to be set up, under Dr. Prentice's Chairmanship, and that Mr. Snape should be a Member. Dr. Mibashan said that it was to be left to the Directors to decide what type of treatment a patient should receive. He personally did not think that Factor Eight Inhibitor By-Passing Activity had been used to cover patients for surgery or dental extractions and recommended caution. Dr. Preston said that one of his patients had just undergone some dental extractions with FEIBA and they were awaiting the results. If successful, the patient would have a dental clearance. Dr. Bloom mentioned that he had given platelets to patients having factor VIII antibody as a last resort. He had tried FEIBA and was not convinced about its effectiveness. He warned that up till now Immuno had been supplying FEIBA free of charge, but he understood that they may start charging for it. Prof. Ingram mentioned that he had used vast quantities of Oxford factor IX concentrate to treat 2 patients having anti-factor VIII antibodies. He also was not convinced of its effectiveness. He had later used FEIBA with similarly inconclusive results. In one patient it looked as though the antibody level had risen after treatment.

13. Any other Business

Prof. Ingram raised the question of the timing of the Main Directors' Meeting. He felt that the Agenda for the

meeting should be circulated at least 2 months beforehand so that it could be discussed at Supraregional Meetings in advance of the main meeting. He suggested that the Reference Centre Directors' Meeting should be regarded as a Steering Committee for the Main Meeting. He said that it had been suggested that the Main Meeting should be open to non-Haemophilia Centre Haematologists who treated haemophiliacs. He realised that this might involve a problem over numbers but would like the meeting's view. It was mentioned from the floor that many new young haematologists who had had experience of treating haemophiliacs in the past would like to continue with this work and be able to attend the Directors Meetings. There was some discussion over the role of Associate Centres and Dr. Biggs said she did not see why haematologists who treated haemophiliacs should not have the status of Associate Centres. There was difficulty in having a full list of Centres which should be notified of the Annual Meeting.

Prof. Ingram said he thought that the Regional Haematology Subcommittees could send out information to appropriate Haematologists regarding the meetings.

There was some discussion about the purpose of inviting an ill-defined group of haematologists who did not wish to be classified as Associate Haemophilia Centre Directors. Dr. Stuart said that the specialist group meeting of Haemophilia Centre Directors was not the right place to undertake general education of Haematologists.