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Minutes of the FOURTEENTH MEETING OF HAEMOPHILIA REFERENCE CENTRE DIRECTORS held at the Royal Free Hospital on MONDAY 1st MARCH, 1982.

Present:-

Prof. A. Bloom (Chairman)
Dr. C.R. Rizza
Dr. P. Hamilton
Dr. P. Jones
Dr. P. Kernoff
Dr. C. Ludlam
Dr. J.M. Matthews
Dr. Elizabeth Mayne
Dr. C. Prentice
Dr. F.E. Preston
Dr. G. Savidge
Dr. E. Tuddenham
Dr. R.T. Wensley
Dr. J. Craske
Dr. A. Aronstam
Miss R.J.D. Spooner

1. Apologies for Absence were received from Dr. I. Delamore and Dr. C. Forbes. Professor Bloom welcomed Dr. Aronstam to the meeting and said that he felt sure that the Reference Centre Directors would benefit from Dr. Aronstam's special experience of managing adolescent haemophilic boys.

2. The Minutes of the last meeting of the Reference Centre Directors were approved and signed.

3. Matters arising from the Minutes

(a) Scotland

Dr. Ludlam said that he had received a letter from the Scottish Home and Health Department saying that the Department recognised that Edinburgh was acting as a Haemophilia Reference Centre but that the Home and Health

Department was not prepared to "designate" the Centre as a Reference Centre. Dr. Ludlam was not happy about this and said that no additional services or resources had been requested from the Home and Health Department. He had written to the Scottish Home and Health Department and pointed out that the Edinburgh Haemophilia Centre already satisfied requirements for a Haemophilia Reference Centre as set out in the 1976 circular (No. HC(76)4). Dr. Ludlam asked Professor Bloom to write again to the Scottish Home and Health Department pointing out that there had already been a lengthy delay in the official recognition of the Haemophilia Centres in Edinburgh and Glasgow as Haemophilia Reference Centre.

b) Criteria for the designation of Haemophilia Centres/ Associate Centres

The draft document prepared and circulated to all the Reference Centre Directors by Dr. Peter Jones was discussed at length. There were detailed comments regarding the functions of the Reference Centres. Dr. Ludlam suggested that all elective surgery should be done by Reference Centres and should not be undertaken by other Centres. Dr. Wensley said that he thought this would create difficulties, especially with the larger Haemophilia Centres. Professor Bloom agreed that this would be very difficult to implement.

The issuing of Haemophilia Cards (P.2 (iii))

Dr. Preston thought that Haemophilia Cards should only be issued by Reference Centres but Dr. Wensley thought that this could be difficult. He pointed out that all the assays would have to be done at the Reference Centre if the Reference Centre was to undertake the responsibility for

the issuing of the cards. Dr. Savidge thought that it was important that all patients were seen at some time by the Haemophilia Reference Centre responsible for the Centre at which the patient's diagnosis had been made and for the assay to be checked by a Reference Centre. Professor Bloom suggested that the Department of Health might arrange for the green cards to be supplied only to the Reference Centres and for the Reference Centres to pass the green cards on only to the Haemophilia Centres in their Supraregions that they regarded as suitable to have the responsibility for issuing of Haemophilia Cards. It was agreed that the Reference Centre Directors should have the responsibility for the issuing of Haemophilia green cards.

It was suggested that the Haemophilia Reference Centres should not only have responsibility for the overall management of the Centres but also for the individual treatment of the patients registered at the Centres in the Supraregion. Dr. Preston thought that there would be difficulties in organising this at some Centres and referred to the problems he was having with a new Haemophilia Centre in his Supraregion. The meaning of item 9, page 3 of Dr. Jones's draft was queried and discussed. Miss Spooner said that she felt that this paragraph which had been in the original 1976 memorandum gave Oxford the authority to provide Haemophilia Reference Centre Directors with information about the patients treated at Haemophilia Centres in their Supraregions without the specific permission of the individual Haemophilia Centres on each occasion.

Staffing of Reference Centres (P.3, item 4)

Dr. Jones pointed out that the list of staff suggested in the draft was a minimum recommendation and that not all the members of staff listed needed necessarily to be full-time members of staff, for example the two consultants recommended in his draft document need not necessarily both be full-time. Dr. Ludlam suggested that a statement should be included saying that the Director of the Haemophilia Centre should have responsibility for the clinical and laboratory resources at the Haemophilia Reference Centre. After discussion, it was agreed that in addition to the staffing recommended by Dr. Jones, a junior hospital doctor (S.H.O. or above) should be added to the list.

Designation as a Haemophilia Centre (Page 4, item 5)

It was suggested and agreed that Dr. Jones should spell out the responsibilities of a Haemophilia Centre in the same way as the responsibilities were spelt out for the Reference Centres. There was some discussion regarding the minimum number of patients required for a Haemophilia Centre to be officially designated and a graph was presented showing the number of patients treated by individual Haemophilia Centres during 1980. This showed clearly that there were a large number (36) of Haemophilia Centres that treated less than 10 patients during 1980.. It was suggested that Centres treating less than 10 patients with coagulation defects during any one year should be excluded from the list of Haemophilia Centres. It was agreed that the term "Associate Centre" was no longer desirable and also that the reference to Special Centres (page 5 of the draft) should be deleted.

It was agreed that Dr. Jones should circulate a revised draft to the Reference Centre Directors during the next 2-3 weeks and that a final draft should be prepared for consideration by the Reference Centre Directors at their next meeting and subsequently by all the Directors at the A.G.M. in September. The involvement of the Haemophilia Society in the preparation of the draft was discussed and it was agreed that the Society should not receive a draft until the papers for the A.G.M. in September were circulated. The Department of Health would also not get a copy of the draft until the final version for consideration by all Haemophilia Centre Directors had been prepared. It was agreed that a special meeting should be convened to take place in late June or early July at which the revised draft circular could be discussed by the Reference Centre Directors.

4. Haemophilia Centre Directors' Annual Returns

Dr. Rizza reported that the Annual Returns from Haemophilia Centres were coming in slowly. He and Miss Spooner were preparing a 5-year report on the Haemophilia Centre Directors returns for 1976-80 and hoped to be able to circulate a draft of the report to the Reference Centre Directors in a few weeks time. He said that there was a large amount of data available from the Haemophilia Centre Directors returns to Oxford and he did not think it would be possible to include all the data in the paper which was to be submitted for publication. He was therefore proposing to prepare two reports, one a detailed report which would be circulated to all the Haemophilia Centre Directors when finalised and a shorter report which would be submitted for

publication. The suggestion was approved by the Reference Centre Directors.

5. Reports from Working Party Chairmen

a) Hepatitis Working Party

Dr. Craske said that he had encountered problems with the MRC regarding financial support for the hepatitis survey but he was hoping to obtain some grants from other sources to enable the work to continue. He hoped to be able to present to the Directors, at their next meeting, the results of the researches so far which were showing very promising results. He said that he would like to know the total number of batches that patients received annually because he thought that this might be relevant to the incidence of hepatitis, and that ideally he would like to know the number of batches received by individual patients who had been treated since 1974. It was thought that it would be rather difficult for the majority of the Centres to provide this data to Dr. Craske. He said that the incidence of hepatitis B remained fairly constant. Dr. Wensley asked Dr. Craske if the Working Party was looking at the "Hepatitis-free" concentrates and Dr. Craske said that he was keeping an eye on the situation. Dr. Craske said that the two year surveillance programme which had been supported by the DHSS grant had now been completed but would continue for at least two more years supported by local funds available to Dr. Rizza. He hoped that the surveillance programme would continue for a longer period of time.

b) Home Treatment Working Party

Dr. Jones said that the members of the Home Treatment

Working Party felt that the Working Party could now be disbanded. The Working Party would continue to supply the Home Therapy booklets which had been printed. Disbandment of the Home Therapy Working Party was agreed subject to ratification at the A.G.M. in September.

c) The treatment of patients having factor VIII antibodies

Dr. Prentice said that a meeting had been held on the 11th February with Travenol to discuss the possibility of a trial of Hemofil concentrate versus Autoplex for the treatment of patients who had factor VIII antibodies. Drs. Preston, Prentice, Wensley, Hill, Mayne and Savidge had been present at the meeting. These Directors between them had just over 40 patients with inhibitors and they felt that a trial would be possible with this number of patients. If any other Reference Centre Directors or Haemophilia Centre Directors were interested in participating in the trial, Dr. Prentice would be very pleased to hear from them. A protocol for the trial had been drawn up by Travenol and copies were available for consideration by any interested parties. Only patients having joint bleeds would be included in the trial which would be a double blind trial. The patients would receive type-A material first, followed by type-B material. Inhibitor assays would be done locally and also in Glasgow. Factor VIII levels would not be monitored. Consent forms were being drawn up by Dr. Prentice for use at the Centres participating in the trial and each Centre would apply for consent from the Ethical Committee at their hospital before the trial commenced. It was hoped that the trial would start in about six weeks time, i.e. April-May

1982. Statisticians had been consulted and would decide on the length of the trial and how many bleeds were needed for significant results.

d) Factor VIII Assay

Dr. Rizza outlined the four projects which the Factor VIII Assay Working Party had been involved in.

a) Calibration of an International Reference Plasma. Dr. Barrowcliffe had presented data on this and there was now discussion about what the new reference plasma should be called.

b) Calibration of the Tenth British Standard.

c) Proposed study of factor VIII concentrates by users to see if there was any significant discrepancy between labelled content of vial factor VIII and content found by user's assays. Letters had been sent to several major Centres throughout the world to try to obtain information concerning any discrepancies between factor VIII content.

d) To look at the effect of different absorbing agents on the assay of factor VIII:C.

5e) von Willebrand's disease Working Party

Dr. Tuddenham said that all the Haemophilia Centres should now have supplies of the von Willebrand's disease registration forms which were to be completed and returned to Oxford for entry into the National Register. Miss Spooner said that approximately 200 forms had been received to date and Dr. Tuddenham said that he thought that the results of the analyses of the forms would prove most interesting.

6. Assays on commercial concentrates

Dr. Kernoff said that he thought NIBSC were responsible for checking factor VIII preparation for assaying the material before it was released for use in hospitals throughout the U.K. He had therefore been very surprised by the letter in the Lancet describing idscrepancies between the 'labelled' potency and the 'found' proteins. NIBSC allowed 20% leeway on the assay value of the material. He thought that NIBSC should have been the people to have known about the discrepancies and that it should not have been necessary for the discrepancies to have been brought to light by a Haemophilia Centre. There was some discussion about the functions of NIBSC. Professor Bloom suggested that the Reference Centre Directors should let Dr. Rizza know what their experience was with the commercial concentrate. He said that the British Society of Haematology were holding a meeting in Brighton in April at which Dr. Duncan Thomas would be saying how NIBSC went about assaying the commercial concentrates. He thought that this would be an interesting meeting for the Reference Centre Directors to attend. Dr. Ludlam said that he did not think that the NHS concentrate was allowed to have a 20% leeway on the assay results but Professor Bloom said that he thought that the NHS material was only sent to NIBSC voluntarily and that it was not compulsory for the NHS material to be assayed by NIBSC.

7. Arrangements for the 1982 meeting of all Haemophilia Centre Directors

Dr. Wensley said that it had not proved possible to find a suitable date at the end of September or early in

October on which the meeting could be held in Manchester. It had therefore been agreed that the meeting would be held in Manchester on the 13-14th September. The 13th September would be reserved for a Business Meeting and the 14th would be for Scientific Sessions with invited speakers. Dr. Wensley outlined the suggested programme for the meeting which was approved. He said that he was planning to arrange for the preliminary notices regarding the meeting to be sent out soon to all Haemophilia Centre Directors.

8. Date and Place of the next meeting of Reference Centre Directors

It was agreed that the next meeting of Reference Centre Directors should be held on Monday 6th September at St. Thomas' Hospital.

9. A.O.B.

Professor Bloom said that he had received a letter from Dr. Martin Inwood who said that he had very much enjoyed the 1981 A.G.M. to which he had beeninvited to attend and that he would like a representative to come from Canada each year to attend the U.K. Haemophilia Centre Directors Meetings. This request was discussed in some detail and it was felt that it would be very difficult to extend an invitation to Dr. Inwood or his colleagues to attend all future meetings of U.K. Haemophilia Centre Directors without making similar provisions for other interested people. The Directors meetings were essentially private meetings but it was agreed that Dr. Inwood could come to future meetings as an informal guest.

b) Dr. Preston asked if platelet disorders came within the aegis of Haemophilia Centre Directors and if so whether the

Reference Centre Directors should be collecting information on patients with platelet disorders. A discussion on this subject was deferred until the next meeting of the Reference Centre Directors.

Professor Bloom thanked Drs. Kernoff and Tuddenham for their hospitality and the meeting finished at 1.30 p.m.