

DRAFT

Minutes of the Tenth Meeting of U.K. Haemophilia Reference Centre Directors held on Tuesday 26th February 1980 at the Royal Free Hospital Haemophilia Centre.

Present:-

Professor A. Bloom (Chairman)

Professor E.K. Blackburn

Dr. C. Forbes

Dr. I. Delamore

Dr. P. Kernoff

Dr. E.G.D. Tuddenham

Dr. P. Hamilton,

Dr. C.R. Rizza

Dr. J.M. Matthews

Dr. G. Savidge

Dr. C. Ludlam

Dr. E. Preston

Miss R.J.D. Spooner

1. Apologies for Absence were received from Dr. P. Jones, Dr. J. Craske, Dr. R.T. Wensley and Dr. G. MacDonald.
2. The Minutes of the Ninth Meeting were approved and signed.
3. Matters arising from the Minutes
 - 3a) Trial of FEIBA

A Memorandum from Dr. Prentice was circulated and presented by Dr. Forbes. The possibility of a U.K. trial was discussed. There were thought to be several problems with organising such a trial. For example, financing of the trial and the small number of patients who could be included in the trial. The possibility of a trial being run under the

auspices of the Medical Research Council was raised as was the question of the use of a placebo, the number of patients treated each year for external bleeding and whether the study should be on open or closed bleeds. It was suggested that Dr. Prentice might consider circularising all Haemophilia Centres to find out how many Directors would be willing to join in a trial if one was organised.

It was suggested that Dr. Prentice should get advice from a Statistician concerning the number of patients which would be required for such a trial to give clear cut answers. With regard to cost, Dr. Forbes said that it was not likely that FEIBA would be provided free of charge by the manufacturers for use in a U.K. trial. Dr. Delamore suggested that more should be done to evaluate Factor VIII treatment as a base line before a trial of FEIBA and FEIBA-like materials was embarked upon. Professor Bloom suggested that the matter should be referred back to the Inhibitor Working Party for the Working Party to look at the present methods of treatment of patients with Factor VIII antibodies and for the possibility of a trial of Factor VIII concentrates to be looked into. It was agreed that at the present time a U.K. trial of FEIBA should not go ahead. Dr. Rizza mentioned that an International trial on methods of assaying factor VIII inhibitors was at present underway under the Chairmanship of Dr. Lechner of Vienna.

3b) Pain Relief

This item had been raised at the last meeting by Professor Ingram and was deferred for consideration by the Reference Centre Directors until all the Reference Centre

Directors had had an opportunity of reading the article to which Professor Ingram referred. Dr. Forbes mentioned that a trial was being organised in Glasgow supported by an MRC grant to study pain relief in haemophilia. There was no further discussion of the subject.

3c) Haematuria Working Party

No response had been received from the Haemophilia Centre Directors following the meeting in November 1979. Therefore it must be assumed that there is little interest in the setting up of a Working Party on Haematuria. A collaborative study which had been organised between Glasgow and Birmingham on renal abnormalities was mentioned and a similar study had also taken place in Cardiff. The results of these studies were currently in press.

4. Reports of Working Party Chairmen:

a) Hepatitis Working Party

In the absence of the Working Party Chairman, Dr. Craske, the report from the Hepatitis Working Party was given by Dr. Peter Kernoff. Dr. Kernoff said that at a recent meeting of the Working Party three possible further lines of study had been considered by the Working Party.

1. Chronic liver disease survey on a National basis,
2. Results of liver biopsies to be collected,
3. Preventive and other treatment of hepatitis.

1. Regarding the study of chronic liver disease

Dr. Kernoff said that there were three items to be considered:-

- a) what is the prevalence of chronic liver disease
- b) what are the main features of chronic liver disease

and c) what are the likely causes of chronic liver disease.

Dr. Kernoff presented a protocol which had been drawn up at the Royal Free Hospital for consideration by the Working Party.

2. Regarding liver biopsies.

Reference was made to a study in the United States. The Working Party had agreed that it would be better for the U.K. Directors to do their own study and not to join the study currently under way in the United States:

3. Therapeutic Trials.

- a) Possibility of hyper-immune globulin being given to carriers and other high risk patients and
- b) A trial of steroid treatment.

Professor Bloom said that all Haemophilia Centre Directors should be asked if they would be willing to collaborate with the Working Party in the trials. Dr. Hamilton suggested that the problems of alcoholism should be looked into. Dr. Preston said that if a study on chronic liver disease was undertaken the results of liver biopsies must be available, since it would otherwise be very difficult to be sure of the diagnosis. Professor Bloom summarised the aims of the Chronic Hepatitis Study as falling into two parts:-

1. To establish the incidence of Chronic Liver Disease and
2. To establish the pathology and prognosis in the affected patients.

Professor Bloom suggested that regarding the survey of the incidence of chronic liver disease it should be left to the Working Party to decide who should be asked to participate. He felt that the detailed study on patients undergoing liver

biopsies should perhaps be dealt with by collaboration between a few selected Centres. Some Centres were already collaborating with Dr. Craske in this matter. Dr. Hamilton suggested that in the Autumn a Symposium should be held on Hepatitis with experts in liver disease discussing the advisability of biopsies and the advantages and disadvantages of steroid treatment.

After further discussion it was agreed that a trial of hyper-immune globulin in haemophilia carriers and other patients at high risk of contracting hepatitis was desirable. It was thought that this trial would need to be a multi-centre study and it was suggested that the Working Party should draw up a protocol for a trial and submit this to the Reference Centre Directors.

4b) Home Treatment Working Party

A written report from Dr. Peter Jones was presented by Dr. Forbes. Arising from this was a suggestion from Professor Bloom that it would be very useful if people planning to publish booklets, etc. could let the Reference Centre Directors know. This was agreed.

4c) Factor VIII Antibodies

In the absence of Dr. Prentice there was no report from the Factor VIII Antibodies Working Party.

4d) Factor VIII Assay

Dr. Rizza said that there was nothing further to report from his Working Party since the November Meeting.

4e) Von Willebrand's Disease Working Party

Dr. Tuddenham reported that the first meeting of the Von Willebrand's disease Working Party had been held on the

1st February 1980. The Minutes would be circulated to the Reference Centre Directors with the Minutes of this Meeting. The Working Party was drafting a new protocol for the study of von Willebrand's disease patients, which would form the base for a possible National Register of von Willebrand's disease patients.

5. Haemophilia Reference Centres in Scotland and Northern Ireland

Professor Blackburn said that patients had raised with him the question of Haemophilia Reference Centres in Scotland and Northern Ireland. There were at present no official Reference Centres in either Scotland or Northern Ireland and some patients were very worried about this. Professor Bloom referred to the DHSS leaflet published in 1976. Professor Bloom said that in 1975-76, it had been agreed in Scotland that there should not be any officially designated Reference Centres in Scotland although unofficially the Centres in Edinburgh and Glasgow acted as Reference Centres. Northern Ireland was included in the Oxford supra-region and Belfast was the only Haemophilia Centre in Northern Ireland. After some discussion it was suggested that Belfast should be regarded as the Reference Centre for Northern Ireland and that Dr. Rizza should write to Dr. Mayne asking if she would approve of this idea and if she would like to attend future Reference Centre Directors Meetings. This was agreed. It was also agreed that the Department of Health should be asked to put Edinburgh and Glasgow as the Scottish Reference Centres and Belfast as the Northern Ireland Reference Centre,

in the list of U.K. Haemophilia Centres when this was reprinted. Dr. Ludlam asked that the Lothian Health Board should receive a copy of the letter to the Department of Health as this would help him in his negotiations with the Board.

6. Prescriptions for Factor VIII

Professor Bloom said that he had received a letter from the Haemophilia Society raising the matter of prescriptions for Factor VIII. Apparently some haemophilic patients were receiving prescriptions from their General Practitioners for Factor VIII which they took along to local chemists. The patients have to pay the normal prescription charges on these prescriptions for Factor VIII and are not happy about the situation. Dr. Savidge said that Professor Ingram had thought it was a good idea for patients to receive their factor VIII supplies via their General Practitioners and local chemists, to get round some of the difficulties over financing through hospital budgets. There was one Centre in the South-east which had approximately eight patients on home therapy who were obtaining factor VIII from local chemists. The Director and the patients seemed very happy with the arrangements and Dr. Savidge felt that there might be strong resistance from the patients and the Director concerned if attempts were made to alter this practice. After discussion in which all the Reference Centre Directors expressed strong views regarding the inadvisability of patients receiving their Factor VIII supplies from any source other than a Haemophilia Centre, it was agreed that Professor Bloom should write to the Haemophilia Society saying that the Reference Directors felt the best

method for supplying Factor VIII was through a Haemophilia Centre and that they could not support a policy whereby Factor VIII was supplied by local chemists on prescriptions issued by the General Practitioner. It would be pointed out that there would be increased costs to the National Health Service in the long run by using this method of supplying Factor VIII to the patients and if this practice escalated it might seriously disrupt the management of patients. It was also felt by the Reference Centre Directors that there were medical disadvantages in prescribing factor VIII in this way, as it would not be easy for proper records to be kept on the batches of materials the patients received.

7. Authorship of Working Party Reports

Dr. Forbes said that he thought it would be desirable for the names of all Working Party members to appear on all reports presented by Working Party Chairmen. It was agreed that this would be a good policy.

8. Dr. Poller's Factor VIII Quality Control Study

Dr. Hamilton said that he was very worried about the study which Dr. Poller was carrying out. He was worried that the diagnosis of haemophilia would be made in all laboratories throughout the United Kingdom rather than in the Specialised Centres as at present and he wondered what the other Directors felt about this. He wondered whether other Directors had also been invited to join in Dr. Poller's study and if the Factor VIII Assay Working Party had been invited to collaborate with Dr. Poller. Dr. Rizza said that neither he nor NIBSC knew anything about this study, before receiving the communication

from Dr. Poller. Dr. Poller had asked NIBSC for their published papers regarding Factor VIII assays, etc. Dr. Hamilton said that he wondered whether Dr. Poller knew that the Directors had a Factor VIII assay Working Party and if his attention should be drawn to the existence of the Working Party. It was agreed that Dr. Rizza (in his capacity as Chairman of the Factor VIII Assay Working Party) should write to Dr. Poller, and that the other Reference Centre Directors should also write to Dr. Poller and mention the Working Party in their replies.

9. The Role of the Department of Health in Organising Haemophilia Care

Professor Bloom said that he had received a letter from Dr. French in which he suggested that it would be more appropriate for the Haemophilia Reference Centre Directors to handle the supplying of the booklet listing the Haemophilia Centres and the booklet "Notes on the Care of Patients with Haemophilia and Christmas disease" than for this function to be undertaken by the Department of Health. After discussion, it was agreed that Professor Bloom would write to Dr. French to say that he had discussed the matter with the Reference Centre Directors who did not feel that they could take over these tasks from the Department of Health.

10. Progress Report on the Haemophilia Centre Directors' Annual Returns

Dr. Rizza reported that all the 1978 Annual Returns had now been received and that the names of patients were now included in the Computer File. Miss Spooner hoped to be able to send all Directors a list of their patients for checking

early in the summer, and had drawn up an outline layout of the printout which could be sent to all Haemophilia Centre Directors in January 1981 to replace the forms currently used for recording details of the individual patients treated at Haemophilia Centres. The Reference Centre Directors were asked to let Miss Spooner have their comments on the draft printout within the next two weeks.

11. The Next Meeting of All Haemophilia Centre Directors

Dr. Forbes said that the Royal College of Physicians and Surgeons in Glasgow would be very happy to act as host to the Haemophilia Centre Directors at the 1980 Meeting. Funds were available from Travenol to assist in the running of a two-day meeting. The dates for the meeting would be 30th September and 1st October 1980 and the suggested title for the Meeting which would follow the Annual General Meeting of Haemophilia Centre Directors was "Unresolved Problems of Haemophilia". Dr. Forbes suggested that the programme should be as follows:-

Day 1 a.m. The Haemophilia Centre Directors Business Meeting
p.m. Reports from Working Party Chairmen. A Factor VIII Workshop, possibly with some International Speaker

Evening A dinner in the College

Day 2 Symposium on the following topics:-

Liver disease

Joint Problems - Suggested Speakers Dr. Hilgartner and Professor Duthie

Pain and Analgesics

Administration of Factor VIII by oral route - Suggested Speaker Dr. Hemker

The use of DDVAP in mild haemophiliacs

The use of Prothrombin Complex Concentrate for the
treatment of haemophiliacs with Factor VIII
antibodies

There was some discussion about this programme and it was agreed that Dr. Forbes, Dr. Rizza and Dr. Preston should finalise the details of the Meeting. Dr. Forbes said that the capacity of the Meeting would be approximately 200 people, so that more than one representative could come from each Haemophilia Centre.

12. Date and Place of Next Reference Centre Directors' Meeting

It was agreed that the next Meeting should take place on Monday 22nd September at St. Thomas' Hospital at 10.30 am.

13. Any Other Business

1. Dr. Forbes said that he was hoping to run a "camp" for haemophiliacs in the University Campus at Stirling at which in addition to the usual camp activities there would be lectures on haemophilia care, etc. The Haemophilia Society was very enthusiastic about the idea and Dr. Forbes was seeking the views and suggestions of the Reference Centre Directors on this matter. Dr. Tuddenham said that he was at present assisting with the organisation of a seaside holiday camp to which four haemophilic boys would be invited.

2. Dr. Kernoff said that the Royal Free's booklet on the treatment of haemophilia was now available and the Centre would be very pleased to send supplies to Haemophilia Centres.

3. Dr. Savidge said that the Computer system at St. Thomas'

Hospital was now running well and details of the system could be made available for a small fee to any Haemophilia Centre which would be interested in the St. Thomas's scheme.

The Meeting closed at 3.30 p.m.