

Minutes of the Twenty-sixth Meeting of Haemophilia Reference Centre  
Directors held at the Royal Free Hospital on Monday 11th May, 1987

Present:

Dr. C.D. Forbes (Chairman)  
Dr. C.R. Rizza (Secretary)  
Prof. A.L. Bloom  
Dr. I. Delamore  
Dr. P. Jones  
Dr. P. Kernoff  
Dr. G.D.O. Lowe  
Dr. C. Ludlam  
Dr. E.E. Mayne  
Prof. F.E. Preston  
Dr. G. Savidge  
Dr. J. Craske  
Prof. I. Temperley (Observer)

1. Apologies for absence were received from:-

Dr. M. Greaves, Dr. P. Hamilton, Dr. G. McDonald and Miss R.J.D. Spooner.

2. Minutes of the Twenty-fifth Meeting were approved and signed by the Chairman.

3. Matters arising from the Minutes

a) Regional Organisation of Haemophilia Care

Dr. Savidge gave a report of the Meeting held at St. Thomas' Hospital on 16th March, 1987. He made it clear that the Committee which had been set up with him as Chairman had been given the go-ahead to update the yellow booklet "List of Haemophilia Centres in the United Kingdom". It was not concerned with rewriting HC76(4). The Committee had discussed the need to reduce the large number of Centres listed and it was suggested that in line with the World Federation of Haemophilia policy any Centre treating less than 10 severely affected haemophiliacs should not be included in the list. In general the Committee agreed to this step although Dr. Rizza had been concerned about the consequences of such a move in particular 60 Centres would be removed from the list and there might be loss of valuable statistical information from these Centres.

Dr. Savidge's report was discussed in some detail. Professor Bloom felt that some compromise was required and suggested that the new reduced list should perhaps have a statement "Treatment is available also at the following Centres" followed by a list of hospitals treating less than 10 severely affected haemophiliacs. It was agreed that the yellow booklet should be updated listing Centres which treat more than 10 severely affected patients. It was also agreed that Directors of 'Centres' not on the list should continue to be invited to the Directors Meetings and to receive minutes of meetings and statistical reports.

### 3b) Revised Special Medical Card

Dr. Rizza reported that the revised Medical Card with the modification suggested at the previous meeting had been sent to the DHSS for printing. He did not know how long it would be before the cards became available. He agreed to find this out from the DHSS.

### 4. Current situation regarding AIDS

The Chairman said most of this item would be discussed in the afternoon. The role and activities of the Expert Advisory Group on AIDS (EAGA) and the MRC Working Party on AIDS were discussed. The Directors were unhappy that there was no official representative of the Haemophilia Centre Directors on the EAGA. Professor Bloom sits on the Committee as a nominee of the Welsh Office although he answers questions related to HIV in haemophilia. It was agreed that the Chairman should write to Sir Donald Acheson, the Chairman of the EAGA, expressing concern at the lack of an official representative on the EAGA of the Haemophilia Centre Directors Organization. It was also agreed that Professor Bloom should write to Sir Donald Acheson suggesting that the matter of compensation for haemophiliacs was a topic which might be discussed by the EAGA.

The question of compensation was further discussed and Dr. Jones said the Haemophilia Society was planning to lobby all MP's on the subject of AIDS in haemophilia drawing attention to the physical, mental and economic suffering caused by HIV infection. There was concern that benefits in general are going to be reduced by the Government and that the Government will probably calculate individual 'recompense' for affected families. It was agreed that Dr. Jones should inform the Haemophilia Society that the Reference Centre Directors fully support the Society's attempts to obtain some compensation for haemophiliacs infected with HIV as a consequence of transfusion therapy.

### 5. Reports from Working Party Chairmen:

#### 5a) Hepatitis

The Working Party had held no meetings recently and there was no report. Dr. Craske said there had been some delay in licensing of the hepatitis B recombinant vaccine. He did not know the reason for this. New recommendations for vaccination with hepatitis B vaccine had been drawn up and would soon be published.

The factor VIII concentrate manufactured by Behring has been shown by clinical trial to be safe from transmitting hepatitis and HIV. The results have been recently published. These observations raise important ethical and practical questions concerning the choice of materials to be used in treating previously untransfused haemophiliacs. The suggestion was made that there should be a Working Party to look at safety of blood products or that the present Hepatitis Working Party should review safety of blood products. It was agreed that this and the safety of blood products should be discussed in more detail at the next meeting.

#### 5b) Factor VIII Antibodies

Dr. Kernoff had observed when reviewing the annual statistics that few patients with Factor VIII antibodies seemed to require treatment. Further studies with Miss Spooner showed that many patients do not present for treatment. This may be because they believe that treatment is not available to them because of their antibody. Furthermore many patients recorded as having antibodies now live abroad. With regard to the proposed study of FEIBA in patients with factor VIII antibodies Dr. Kernoff reported that there was an unanimous view that comparison should be between FEIBA v NHS IX if there is to be a study. Dr. Kernoff reported that Immuno were trying to carry out a study comparing FEIBA with Immuno Factor IX. Dr. Kernoff was looking into the possibility of a study in which Immuno and Elstree would participate. Dr. Eibl of Immuno and Dr. Lane of BPL have met to discuss the possibilities. The plan was to study at least 200 bleeding episodes involving knees, ankles and elbows in total. Collaborating Centres have been identified and a protocol is being produced by Immuno.

#### 5c) von Willebrand's Disease

Dr. Savidge reported that he had not to date been able to obtain all the Working Party's files and information from Dr. Tuddenham, the previous Chairman. A detailed report would be given as soon as they became available.

#### 5d) Inherited Platelet Disorders

Professor Preston gave a report on the last meeting. It was agreed that haematologists who requested forms for notifying cases of inherited platelet disorders should be sent them.

Professor Preston reported that a document had been produced in collaboration with the British Society for Thrombosis and Haemostasis. This would be circulated.

#### 5e) Data Collection

The Working Party had not met and there was nothing new to report.

#### 6. Clinical Trials of NHS Concentrates

Dr. Kernoff reported on the Protocol drawn up for the study of 8Y and which had been circulated. Apart from a modification to the admission criterion (5.3) - (all patients should be previously untransfused) - the protocol was now finalised. It was generally agreed that the study should go ahead although most Directors felt that fortnightly venepuncturing of children might prove difficult to justify and might be turned down by the local Ethical Committee. Dr. Kernoff wished the protocol to be presented to the AGM in the autumn by which time a clinical trials exemption certificate should have been obtained by BPL. It was agreed that the protocol should be circulated now, with a note to the effect that a clinical trials exemption certificate (CTX) has not yet been obtained. It was made clear that 8Y was issued for treatment on a named patient basis and that responsibility for its use and for any untoward side-effects lay with the treating physician until a CTX was obtained.

## 7. AIDS Counselling Courses

The next course to be held in Newcastle. To be organised by Dr. P. Jones. Dr. Jones suggested it should be concerned with HIV in children and not specifically in haemophiliacs. **This was agreed.** A date had not yet been fixed but Autumn 1987 was being considered.

## 8. NEQAS

Professor Preston said that he had been unable to attend the last meeting of NEQAS. Dr. Davidson wrote to Dr. Forbes asking for the collaboration of the Directors in obtaining plasma from mild haemophiliacs for quality control studies. Dr. Davidson's letter was to be circulated to Directors by the Secretariat.

## 9. Arrangements for the 1987 and 1988 meetings of all Haemophilia Centre Directors

The 1987 AGM is to be held on 25th September 1987 at the Royal Free Hospital Lecture Theatre I.

The 1988 AGM and Scientific meeting is to be held in Dublin and Dr. Mayne reported that plans for the meeting were progressing. Professor Temperley said he had approached Cutter Laboratories for assistance with funding for the meeting.

## 10. Next Meeting of Reference Centre Directors

Monday 7th September at 10.30 a.m. at St. Thomas' Hospital, London.

## 11. A.O.B.

Professor Hardisty wrote to say that Dr. Hann was taking up the post as Consultant Haematologist and would be taking over as Haemophilia Centre Director at Great Ormond Street. Dr. Hann also had written to say that he was leaving the Royal Hospital for Sick Children in Glasgow and proposed that Dr. Brenda Gibson be recognized as the Haemophilia Centre Director at that Centre. Dr. Forbes intimated that he was moving to Dundee to take up the Chair of Medicine and proposed that Dr. Gordon Lowe be recognized as the Director of the Glasgow Centre. All of the above recommendations were unanimously approved.

The Directors heard with sadness the death of Mr. Schnabel who died recently. **It was agreed** that a letter should go from the Directors to Mrs. Schnabel and to the World Federation of Haemophilia expressing sympathy.

Professor Preston spoke briefly about his protocol for a study of the value of interferon in haemophiliacs with chronic hepatitis. Dr. Kernoff said that he was planning a similar study but without the requirement for liver biopsy. He would be happy to send his protocol to those interested in participating in such a study.

The Meeting closed at 1.30 p.m.

GRO-C: Forbes