Minutes of the Twenty-third Meeting of Haemophilia Reference Centre Directors held at St. Thomas's Hospital on 14th April 1986

Present:

Dr. C.D. Forbes (Chairman)
Dr. C.R. Rizza (Secretary)
Prof. A. Bloom
Dr. J. Davison
Dr. I. Delamore
Dr. M. Greaves
Dr. P. Jones
Dr. P. Kernoff
Dr. C. Ludlam
Dr. E. Mayne
Dr. F.E. Preston
Dr. A. Aronstam
Dr. J. Craske
Miss R.J.D. Spooner
Prof. I. Temperley (Observer)

1. Apologies for absence were received from:-

Dr. G. Savidge.

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

3. Matters arising from the Minutes

a) Regional Organisation of Haemophilia Care

The Chairman said he thought that the Extraordinary Meeting of all Haemophilia Centre Directors held on 17th March went very well but it was too early to know what the decision taken at the meeting would mean in terms of funding etc. In discussion several Reference Centre Directors said they thought there might be problems in some Regions and also that it would result in financial implications for the DHSS, e.g. what would happen to the £45,000 allocated to each of the Reference Centres in England? The position of the Reference Centre Directors was discussed and it was pointed out that any change in the title of Reference Centres was dependant on the DHSS agreeing to the change. The Chairman had written to Dr. Smithies and was awaiting her reply. The Reference Centre Directors asked the Chairman to seek a decision from the Department as a matter of urgency, to ask if they wanted HC(76)4 revised and to suggest that the DHSS's Advisory Group on Haemophilia should be re-convened. The Reference Centre Directors were at present the "Expert Body on Haemophilia" and they should put down in detail how they wanted HC(76)4 to be revised. Several directors said that they had already had informal discussions with colleagues in their supraregion concerning Regional organisation of haemophilia care. The Chairman thought there would be Regional implications regarding funding for AIDS counselling and Dr. Delamore pointed out that it would be very difficult if the allocations already made to Reference Centres were cut as some of the money had already been used to employ staff.

After further discussion it was agreed:-

a) The Chairman would write to Dr. Smithies stressing the need for a decision from the DHSS.

b) The Reference Centre Directors' future activities would depend on the DHSS's decision.

b) Supraregional Funding

Dr. Rizza said that no progress had been made since January, when the Working Party set up by the Royal College of Physicians and Royal College of Pathologists had agreed that Oxford and the Royal Free should be given extra funding. More information was still awaited from the other Reference Centres before a decision could be made about their funding.

4. Current Situation Regarding AIDS

a) Dr. Craske said he had information about 101 Haemophilia A patients with HTLV-III related illness. There were at present 18 AIDS cases, 20 ARC cases, 28 with thrombocytopenia, 25 with PGL and 10 with Glandular Fever Syndrome. 11 AIDS and 3 ARC cases were now dead. There was also 1 consort with AIDS, not included in the figures given above. Most of those who had died were older patients.

Regarding Haemophilia B, there were 20 patients HTLVIII+ and 3 with AIDS. 1 with AIDS had died.

Prof. Temperley said that in Eire he had found 60% of the severely affected Haemophilia A patients were anti-HTLVIII+.

Dr. Craske asked all the Reference Centre Directors to send completed AIDS/3 forms to Dr. Rizza as soon as new cases of AIDS or ARC were detected.

Dr. Jones said that he had informed the AIDS Group several months ago that he would not send details of his AIDS/ARC cases to Dr. Craske but would send the information directly to Colindale. He was looking very carefully at all his cases with Dr. Marion McEvoy and Dr. McEvoy would let Dr. Craske have the data.

Dr. Craske said he had no knowledge of Dr. Jones's arrangement with Dr. McEvoy. He had discussed the problem with her and CDSC's view was that they were limited to seeing whether there was a distinct cluster of lymphomas among haemophiliacs in Newcastle. There was no arrangement with Dr. Jones to study HIV infection in Newcastle haemophiliacs other than this.

Dr. Jones said he had two cases of definite lymphomas. He also reported that the female consort with AIDS, reported in the BMJ in November 1985, was still alive. Dr. McEvoy would be looking at the lymphoma group separately; Dr. Jones was trying with the help of Dr. McEvoy to find out why his experience was different from that reported by other Centres.

b) Dr. Jones said that the pro-rata system for the allocation of 8Y concentrate by BPL meant that he was getting reduced supplies of NHS F.VIII and he suggested that 8Y should be reserved for sero-negative patients.

Dr. Kernoff said he was concerned about the stock-pile of plasma at BPL which had not been tested for anti-HTLVIII and which might be used as a source of factor VIII/IX concentrate. The Chairman said that BPL were well aware of the problem and were considering what to do.

After further discussion, it was agreed that the Secretary should write to Dr. Lane about the stock-pile of plasma held at Elstree to find out what BPL's policy will be. He would also write to the Medicines Division at the DHSS requesting assurance that all the commercial products supplied to the U.K. were manufactured from HTLVIII-tested plasma. Dr. Smithies would be sent a copy of the letters.

c) Dr. Rizza said that the report on the Survey of HTLVIII Positivity in UK Haemophiliacs had been submitted to the BMJ. The BMJ wanted to publish it but had asked for it to be shortened so it could appear as a "Short Report". This had been done and it would appear in the BMJ soon in the same issue as a paper from Richard Tedder. Concern was expressed by the Reference Centre Directors that the BMJ had asked for the report to be shortened so drastically and it was suggested that the Chief Medical Officer at the DHSS should be informed that this had happened.

d) The Chairman said that the May 1986 Survey of anti-HTLVIII prevalence in UK Haemophiliacs would go ahead as planned. Dr. Craske stressed the importance of relating the results of the new survey to the type of blood products the individual patients used.

e) The Chairman said it was important for all the Reference Centre Directors to agree to report the AIDS/ARC and related data centrally, i.e. to Oxford. Dr. Jones said he would only send his data to Dr. McEvoy at CPHLS and she would pass information on to Dr. Craske. Dr. Craske felt strongly that this arrangement was not satisfactory and would lead to loss of important data as well as confusion.

f) Dr. Craske said that his funding for the Haemophilia Centre Directors' AIDS Projects would run out at the end of the year and he would need to put in a new grant application for continued funding. He wondered if this new grant application should include a request for funding to assist with the data collection in Oxford and if it should be submitted with a supporting letter from the Chairman. Dr. Rizza said that the Oxford Regional Health Authority were pressing the DHSS for special funding for the Data Collection and he did not want the Chairman to write about it.

5. Reports from Working Party Chairmen

a) Hepatitis

Dr. Craske gave a brief verbal report on the current situation.

Dr. Preston gave some information regarding the Sheffield liver biopsy studies. He said that no association between anti-HTLVIII positivity and hepatitis was evident on liver biopsies. Dr. Preston thought it was very important that the hepatitis studies continue.

Dr. Craske said he would like to propose 2 new hepatitis-related studies to be undertaken Nationally

i) A survey to find out the incidence of Hepatitis B carriers in the haemophilic population

ii) A survey to find out to what extent Hepatitis B immunisation of haemophiliacs in the U.K. was carried out and what the response rate was.

He would shortly be calling a meeting of the Hepatitis Working Party to discuss his proposals.

5b) Factor VIII Antibodies Working Party

Dr. Kernoff distributed a brief written report on the results of the questionnaire he had sent to 11 large Haemophilia Centres regarding the proposed national inhibitor study and his recommendations, which included 3 projects:-

i) A pilot study of heat-treated NHS (Elstree) Factor IX

ii) A study of "desensitizing" regimes

iii) An enquiry (in collaboration with the Secretariat in Oxford) to find out why only half the patients recorded as having Factor VIII antibodies were treated each year.

After discussion regarding the feasibility of the pilot study and the types of products to be used it was agreed that Dr. Kernoff should go ahead and approach likely collaborators. Directors who had used the Edinburgh heat-treated Factor IX to treat haemophiliacs with inhibitors felt that it was not as effective as the non-heated product. Dr. Kernoff said he would not require extra funding to enable him to organise the study. He would need to get BPL's approval of the study before it went ahead.

It was also agreed that Dr. Kernoff would go ahead with the enquiry regarding the Haemophilia A patients with Factor VIII antibodies who had not received treatment. Dr. Kernoff and Miss Spooner would discuss the details regarding the enquiry and would aim at writing to Directors in July.

5c) von Willebrand's Disease

No report had been sent in by the Chairman (Dr. Tuddenham) who was not present.

5d) Congenital Platelet Disorders

Dr. Preston said that the Working Party had drawn up a document (P2) giving the Minimal Diagnostic Criteria and had agreed on the format of the Registration Form (Form P1). He would let Miss Spooner have both documents (P1 and P2) for distribution to all Haemophilia Centre Directors as soon as possible.

It was suggested that it might be appropriate for the documents to be sent to all Haematologists in the U.K. as many patients with Platelet Defects were seen by Haematologists not working in Haemophilia Centres. The suggestion was discussed and it was agreed that the documents should only be sent to Haemophilia Centres in the first instance but that the survey could possibly be extended to other Haematologists at a later date.

After discussion it was agreed that the title of the Working Party should be "Congenital Platelet Disorders Working Party".

5e) Data Collection

Dr. Rizza said that the Working Party had met twice. Members of the Working Party were Dr. Rizza (Chairman), Miss Spooner, Dr. Kernoff and Dr. Ludlam. The aim of the Working Party was to review all the forms currently in use and the information currently collected, and to consider whether any changes could be made profitably to the kind of data collected and the way in which they were collected. The Chairman would report back to the Reference Centre Directors at a later date the Working Party's recommendations. It was suggested that all new proposals for collection of data from Haemophilia Centres should be reviewed in the first instance by the Data Collection Working Party but that there should be as little 'bureaucratic' delay as possible in this process.

6. Counselling Workshop on AIDS

The Chairman said he had already had one meeting with Mr. Watters and Mr. Tanner of the Haemophilia Society and another meeting would be held soon. He would write to all Haemophilia Centre Directors as soon as possible with details about the Workshop. The date for the Workshop agreed with the Haemophilia Society was 27th June, but this might have to be changed to avoid a clash with a meeting the Haemophilia Special Interest Group were arranging. Sister Maureen Fearns, Mrs. Jean Lovie and Mrs. Riva Miller would help with organising the Workshop.

7. Proposed new title "Honorary Senior Member of Haemophilia Centre Directors Organisation"

The Chairman said he was putting forward the proposal for the creation of the new title as he felt that the Directors should acknowledge good service done by colleagues who were now retired. He suggested that the people selected for the honour could be invited to the Dinner to be held during the next meeting of all Haemophilia Centre Directors in Edinburgh where they would be thanked for their work and perhaps presented with a parchment of recognition. He had discussed his suggestion briefly with Dr. Rizza and the following names had come to mind: Prof. R.G. Macfarlane, Dr. Rosemary Biggs, Dr. Ethel Bidwell, Prof. A.S. Douglas, Dr. J. O'Brien, Prof. E. Blackburn, Dr. S.H. Davies, Prof. R.H. Girdwood, Prof. Wilkinson, Sir William Maycock, Prof. G.I.C. Ingram and Dr. S.G. Rainsford.

During discussion of the Chairman's suggestion it was agreed that in principal the idea was good but some reservations were expressed, especially regarding the presentation of a parchment and possible offence caused by errors of ommission of names. It was agreed that the senior retired people in the locality of the venue should be invited informally to AGM Dinners but no formal presentations would be made. In line with this decision Prof. Macfarlane, Dr. Bidwell, Prof. Douglas, Dr. Davies and Prof. Girdwood would be invited to the Dinner in Edinburgh as they all lived in Scotland.

8. NEQAS

Dr. Preston said that a separate analysis of the results from Haemophilia Centres had been carried but he had not yet received the information from Dr. Poller. The 1985 studies indicated that there had been a substantial improvement in Factor VIII assay performance throughout the country.

Dr. Davidson said that NEQAS was undergoing a major review. The Department had issued new guidelines to the Chairman who would be responsible to the Steering Committee. Dr. Poller had resigned as Chairman and Dr. Davidson had been appointed in his place. In the future NEQAS would get funding from the DHSS and work to a budget.

9. 1986 AGM

Dr. Ludlam confirmed that the plans for the Meeting on 9-10th October were well in hand. Several speakers from overseas were being invited and Alpha Pharmaceutical Co. had kindly agreed to provide funds. A block booking reservation had been made for hotel accommodation and the Dinner for Directors would be held at the College of Physicians. Only a limited number of people would be able to attend the Dinner. After discussion it was agreed that invitations for the senior retired people to attend the Dinner would be sent from the Chairman via the Secretariat in Oxford. The AGM on 9th October would be a private meeting attended only by the Haemophilia Centre Directors or their official representative and the usual invited Observers. The Scientific Meeting would be open to all involved in haemophilia care and Dr. Preston would circularise details to BSHT members.

10. Next Meeting of Reference Centre Directors

The date already agreed, MONDAY 22nd SEPTEMBER at Royal Free Hospital, was confirmed.

11. A.O.B.

a) The Chairman showed the draft of a new design for the Special Medical Card (green "haemophilia card") which he had prepared. It was suggested that it might be appropriate for the Data Collection Working Party to look at the card and the card was handed over to Dr. Rizza for consideration.

b) 1987 AGM: It was suggested that the 1987 AGM should be a One-Day meeting held in London early in October. Dr. Kernoff agreed to look into suitable dates for the meeting to be held at the Royal Free Hospital and to report back to the Reference Centre Directors at their next meeting.

c) The Chairman confirmed that the next Meeting of the AIDS Group would take place in Newcastle on 2nd July.

d) Dr. Delamore asked advice from the Reference Centre Directors regarding a problem that had arisen in Manchester. A Haematologist colleague in the Region who was not working in a Haemophilia Centre had sent a blood sample from a patient to the Manchester Royal Infirmary for diagnosis of a possible coagulation defect and requesting that the patient be registered with him. Staff at the Manchester Haemophilia Centre had sent an appointment for the patient to attend as an out-patient for diagnostic tests and the referring Haematologist had been unhappy about this. Dr. Delamore was of the opinion that the patient should be registered with the Manchester Reference Centre as well as with the referring Haematologist. The referring Haematologist would not agree to this and had sent the matter to the Regional Haematologist's Group for a decision. The problem was discussed by the Reference Centre Directors and it was agreed that Dr. Delamore should meet the Haematologist and draw his attention to the DHSS circular HC(76)4. It was also agreed that Directors could not give a diagnosis and issue Haemophilia Cards for patients they had not seen.

The Meeting closed at 3.30 p.m.

GRO-C: Forbes

2/9/86