

Minutes of the Eleventh Meeting of the AIDS GROUP of Haemophilia Centre  
Directors, held at the Royal Free Hospital on Monday 22nd September, 1986.

Present:

Dr. C.D. Forbes (Chairman)  
Dr. C.R. Rizza (Secretary)  
Dr. A. Aronstam  
Prof. A. Bloom  
Dr. I. Delamore  
Dr. P. Kernoff  
Dr. C. Ludlam  
Dr. E.E. Mayne  
Dr. P. Mortimer  
Prof. F.E. Preston  
Dr. A. Smithies  
Miss R.J.D. Spooner  
Prof. I. Temperley

1. Apologies for absence:

Dr. J. Craske, Dr. P. Jones, Dr. G. Savidge and Dr. R. Tedder.

2. Minutes of the Tenth Meeting:

The Minutes were approved and signed.

3. Matters arising from the Minutes:

a) Heterosexual Transmission of HTLVIII:

The Chairman said that this project had come to a halt because of concern regarding confidentiality. He thought the project was important and that it might be possible for the project to be undertaken collaboratively by a limited number of Centres; Dr. Craske was going to look into this possibility. If the project did go ahead it would need to be done within a tight time span as the scene was constantly changing.

b) Proposed Counselling Course for Centre Staff

The Chairman said that the course would be held at St. Thomas's Hospital on Friday, 7th November. The response to the initial circular to Centres had indicated that there was considerable interest in the proposed course. Full details regarding the course would be sent to Directors as soon as possible.

The cost of organising and attending the meeting were discussed. It was suggested that The Haemophilia Society should ask for help with travelling expenses for Centre Staff if the normal District Health Authority travel funds could not cover the expenses. It was agreed that the course would be for Haemophilia Centre Staff only and that patients would not be permitted to attend.

c) Confidentiality

Dr. Rizza presented a document he had written in response to the

request at the previous meeting. The first part of the document reviewed the data forms sent to Oxford by Haemophilia Centre Directors and the second section concerned the Data Protection Act. Dr. Rizza stressed that the information regarding patients given on Form AIDS/3 was handled in strict confidence in Oxford and that the information was not entered into any computer system, either in Oxford or in Manchester. Dr. Craske had assured Dr. Rizza that his computer system in Manchester did not contain the names of individual patients. Dr. Rizza stressed that the information collated in Oxford was used for statistical and research purposes only. The Chairman said he was very concerned that one or two large Centres were not sending information to Oxford for inclusion in the National Statistics but were independently publishing their data in the Medical Press. He thought it essential that all Centres should collaborate with Oxford, thus ensuring that the National statistics were complete. After further discussion, it was agreed that Dr. Rizza's document should be circulated to all Haemophilia Centre Directors and discussed at the A.G.M.

d) Data on outcome of pregnancies in haemophilic families - Report on WFH Project

Dr. Jones was not present, so there was no report on the WFH Project with which he was involved.

Dr. Rizza said that he understood that someone at the Great Ormond Street Hospital for Sick Children was liaising with Dr. Craske regarding an EEC Survey led by Dr. Peckham and they hoped to collaborate with the U.K. Haemophilia Centre Directors. The Chairman thought that the Directors would not want to go ahead with the EEC project at present. Concern was expressed regarding the confidentiality of information submitted to the Survey as very few patients would be involved so they would be very easily identified from reports even if not named.

After further discussion, it was agreed that the AIDS Group would themselves collect the information informally and exchange experiences but would not go ahead with a formal collaborative project involving all Centres, the WFH and the EEC. Dr. Smithies suggested that the AIDS Group should invite Dr. Peckham to one of their meetings to hear what she had to say about the EEC Survey.

e) Experience with CAT Scanning

The Chairman said that at the last meeting Dr. Jones had briefly reported on the experience in Newcastle with CAT scanning haemophiliacs and had invited other members of the AIDS Group to supply data and collaborate with him as a joint publication of their experiences. The Chairman did not know how far Dr. Jones had got with this proposal.

f) Stock-pile of Plasma at Elstree

The Chairman gave a brief report on the meeting which had been held at Hannibal House on 15th September 1986 to discuss the problem and asked Dr. Smithies to give the up-to-date situation. Dr. Smithies said that all the plasma used at Elstree since June had been screened. The DHSS had agreed that the stock-pile of plasma (51,000 litres) held at Elstree would not be used at present. Donors who had contributed to the stock-pile of

plasma were being tested. Once all the data have been collected the Department would have a meeting with the Reference Centre Directors, GSM and other interested bodies to decide what to do with the stock-pile. 2,000 vials of heat-treated Factor VIII made from untested donors had not been issued for use. It was suggested to Dr. Smithies that the vials of concentrate should be held up in the same way as the stock-pile of plasma, although some Directors said they would use NHS concentrate made from unscreened plasma in preference to commercial concentrates.

#### 4. Seroprevalence Study

Dr. Rizza presented a brief report giving results of the 1986 HIV Seroprevalence Study; a more detailed report would be circulated, in confidence, to all Directors before the A.G.M. It was agreed that the results of the Survey should be regarded as confidential and should not be disclosed to anyone outside the Haemophilia Centre Directors Organisation for the time being. Professor Preston mentioned that he was not happy about the 1985 HIV data being published anonymously and it was pointed out that the data had in fact been published by the AIDS Group although the members of the Group were not identified by name.

#### 5. Progress Reports on Dr. Craske's Projects

- a) New AIDS cases/ARC cases (Appendix A) and b) Study of seroconversions following treatment with NHS Factors VIII and IX (Appendix B)

The Chairman presented the two written reports received from Dr. Craske (Appendix A and Appendix B) and it was agreed that these should be circulated to all Directors for discussion at the A.G.M. Dr. Ludlam was asked to give Dr. Craske an up-date on the Edinburgh patients so that the figures on Page 1 of Appendix B could be corrected. The Chairman said that he found Dr. Craske's reports very interesting. He wondered why some of the patients who received infected batches had not seroconverted and Dr. Ludlam said he thought this might be due to individual variation in immune response. Dr. Mortimer said he queried Dr. Craske's choice of controls in the retrospective study and would have preferred a wider range of controls. He would discuss the matter with Dr. Craske. He thought it would be helpful to have data on patients who did not receive the implicated batches.

- c) Family/Social Contacts Studies

Discussion was deferred as Dr. Craske was not present.

#### 6. Seroconversions following treatment with commercial concentrates

The Chairman said that the rumours were rife regarding seroconversions following treatment with commercial concentrates and he was not sure how strong the evidence was. Dr. Kernoff said he thought it was going a little too far to say the seroconversions were undoubtedly due to commercial concentrates as some of the data were not clear cut.

#### 7. HIV Antigen Assay

The Chairman had received a letter from Dr. J.P. Allain concerning a

kit test for assay of HIV antigen and suggested that any Directors who were interested in collaborating with Dr. Allain should contact Dr. Allain direct.

#### 8. Information Exchange

The Chairman drew the Group's attention to the following publications:-

- i) AIDS: a Guide to Survival. Peter Tatchell. GMP Publishers Ltd., 1986.
- ii) Clinical Aspects of AIDS and ARC. Eds: M. Staquet, R. Hemmes and A. Baert. O.U.P., 1986.
- iii) CDC AIDS Bulletins, published in the USA.

The Chairman also mentioned that an International AIDS Meeting would be held in Washington in June 1987.

#### 9. A.O.B.

- i) Litigation on behalf of selected haemophiliacs had been reported in the National Press (Mail on Sunday). Apparently the Haemophilia Society was pressing the case.
- ii) Insurance for haemophiliacs: Prof. Temperley reported that some Insurance Companies were now asking for HIV results. One of his von Willebrand's disease patients could not get insurance. The Chairman said that this important matter would be discussed fully at the Counselling Day on 7th November.
- iii) The Chairman had just received a letter from Mrs. Jean Lovie enclosing a Job Description for Social Workers at Haemophilia Centres which had been drawn up by BASW/HSIG who hoped that it would be approved by the AIDS Group. It was agreed that the Job Description would be circulated to all AIDS Group members and would be discussed at the next AIDS Group meeting.

#### 10. Date and Place of Next Meeting

Monday afternoon, 19th January 1987 at St. Thomas's Hospital, starting at 2.15 p.m.

The meeting closed at 12 noon.