

Minutes of the Eighth Meeting of the AIDS GROUP of Haemophilia Centre Directors, held at St. Thomas's Hospital on Monday 27th January, 1986.

Present: Dr. C.D. Forbes (Chairman)
Dr. A. Aronstam
Prof. A. Bloom
Prof. D. Barker
Dr. I. Delamore
Dr. C. Ludlam
Dr. P. Mortimer
Dr. F.E. Preston
Dr. C.R. Rizza (Secretary)
Dr. G. Savidge
Miss R.J.D. Spooner

The Chairman welcomed Professor Barker to the meeting and thanked him for agreeing to help the Group with the statistical and epidemiological aspects of their studies.

1. Apologies for absence:

Dr. J. Craske, Dr. P. Jones, Dr. P. Kernoff, Dr. E. Mayne and Dr. A. Smithies.

2. Minutes of the Seventh Meeting:

The Minutes were approved and signed by the Chairman.

3. Matters arising from the Minutes:

a) Heterosexual Transmission of HTLVIII:

The Chairman distributed the detailed project protocol and summary of the aims of the study which Drs. Ludlam and Craske had prepared as agreed at the previous meeting. The Chairman recommended that the National project went ahead as quickly as possible. Dr. Rizza said that information received by Oxford and Dr. Craske at present identified only 4 or 5 anti-HTLVIII positive wives in the U.K. The proposal was that every Haemophilia Centre would see an anti-HTLVIII test as many of the sexual contacts of haemophiliacs as possible, and try to find out the duration of the relationship, the type of sex, etc. The sexual contacts of anti-HTLVIII negative haemophiliacs would be included in the study, as well as the sexual contacts of anti-HTLVIII+ haemophiliacs. The patients would be seen in the first instance by the Centre Director personally or his/her deputy and would be asked to identify their partner(s). There would be difficulties if Directors aimed to trace all sexual partners and it was suggested that the study should be mainly concerned with regular contacts. Participation in the study would be entirely voluntary, both from the point of view of the Haemophilia Centre and the patient. Professor Bloom queried the need for the sexual partners of anti-HTLVIII negative patients being included in the study. He felt that patients might worry if they were asked to participate in the study after being re-assured that their result was negative. He wondered if the negative patients and their partners would be a valid control group for the positive patients, and felt that the study would be biased anyway as it relied on volunteers. Since there seemed to be some confusion in the minds of directors about the

aims of the study those were discussed in some detail. Professor Barker said that he could understand why the Directors wanted a National study and why they were interested in the sexual partner of anti-HTLVIII haemophiliacs but he did not think that including anti-HTLVIII negative partners of negative haemophiliacs would be helpful, nor did he think that information regarding sexual patterns would be useful. He suggested that the serology be studied in the first instance and questions regarding sexual practices put to a sample group of patients and partners at a later date. The Chairman felt it was important to find out what proportion of sexual partners of anti-HTLVIII +ve and anti-HTLVIII -ve haemophiliacs were positive. It was felt by some that the study was addressing several separate issues:

- a) Infectivity rate of haemophiliacs receiving blood products
- b) Can haemophiliacs who are anti-HTLVIII +ve transmit the infection to their sexual partner(s)?
- c) Are seronegative haemophiliacs infectious?

Professor Barker thought that the first part of the project would be to investigate serologically the sexual partners of anti-HTLVIII haemophiliacs. Problems were foreseen by some Directors if the wives of HTLVIII Ab- haemophiliacs were tested and found to be HTLVIII Ab+, the fidelity of the wives might be in doubt. Dr. Savidge asked if HTLVIII Ab- patients could transmit the virus to their sexual partners. Dr. Mortimer thought this would be very difficult to demonstrate. But because of this very question it was important to test regularly all the haemophiliacs and their wives.

Professor Barker was again asked to advise regarding control groups for any studies which went ahead. With regard to controls for the studies it was felt that controls should be drawn from the same local population as the patients under study. Other details such as age, social group etc. would need careful consideration. The Chairman thanked Professor Barker for his advice and reflected that the proposed study was more complex than the AIDS Group had initially envisaged. After further discussion it was agreed that the National study of the sexual partners of anti-HTLVIII haemophiliacs should go ahead in the first instance, followed where appropriate by the detailed questionnaire regarding sexual practices to see if there were any differences between any wives who were HTLVIII Ab+ and those who were HTLVIII Ab-.

Dr. Mortimer thought it was important for the partners of anti-HTLVIII ^{negative} haemophiliacs to be looked at as they might be infected already and might have been infected by the HTLVIII Ab- haemophiliacs. He thought several Centres would want to participate in a study of this type and it would be a check if the seronegativity meant what the virologists thought it did. He would not like to see this part of the original project shelved. The Chairman suggested that Group members should think about the issues raised and discuss them again at the next AIDS Group meeting. It was agreed that two new protocols would be prepared and pre-circulated to members before the next AIDS Group meeting. There would be proposals for two separate studies and Drs. Forbes, Ludlam and Craske would draft the protocols in the first instance.

b) Proposed Counselling Day for Haemophilia Society and Centre Staff

The Chairman said he was waiting to hear from the Society about the proposals he had put forward, which included the draft programme for the first meeting. He would contact the Society again and hoped to have a date and place for the first meeting agreed with the Society before the next AIDS Group meeting.

4. Progress Reports on Dr. Craske's Projects

Dr. Craske was unable to be present because of a family bereavement.

a) New Cases of AIDS/ARC

The Chairman was concerned about the lack of information being received from Centres. Miss Spooner said that supplies of the revised Form AIDS/3 had been sent to Directors with the Annual Returns form. After discussion, it was agreed that at the next meeting of all Directors on 17th March Directors should be reminded about the importance of reporting the AIDS/ARC cases to Dr. Rizza and supplies of both the reporting form (AIDS/3) and the paper giving the criteria for diagnosis of AIDS/ARC cases (AIDS/2) would be available at the meeting.

b) Study of Seroconversions following treatment with "suspect" batches of NHS factor VIII and IX

Discussion was deferred until the next meeting.

c) Family/Social Contacts Studies

i) Dr. Craske had pre-circulated a written report (Appendix A). Discussion was deferred until the next meeting.

ii) Dr. Forbes suggested that a new project should be set up to investigate the possible transmission of HTLVIII from children to their parents who were giving home treatments. It would be appropriate for a paediatrician to be involved with this project if it was undertaken by the AIDS Group. After discussion it was agreed that the Secretary would write to Dr. Peter Jones to ask him if he would be willing to draw up a protocol along the lines suggested by the Chairman. The protocol would be pre-circulated for discussion at the next AIDS Group meeting.

5. a) Data on outcome of pregnancies in haemophilic families

The Chairman said that the suggestion that this new project be undertaken had been raised by Dr. Mortimer. The proposal was that Directors should study the anti-HTLVIII status of children fathered by haemophiliacs since 1980. This would entail testing stored serum samples to ascertain the HTLVIII status of the fathers at the time the children were conceived and ideally, though not necessarily, serial samples taken since that time. It was agreed that Dr. Forbes and Dr. Mortimer would write a simple protocol for this proposed project for pre-circulation and discussion at the next AIDS Group meeting.

6. Information Exchange

The Chairman presented to each Group member a package containing various documents concerning AIDS.

7. A.O.B.

a) Dr. Aronstam said he had spoken to Dr. Breederveld in Amsterdam as agreed regarding the verbal reports that a Dutch patient had developed a glandular fever like illness and had seroconverted to anti-HTLVIII positive after receiving commercial heat-treated factor VIII. The reports were true and details would be published shortly in The Lancet. The patient had received non-heated material 15 months before receiving the heated material.

b) Dr. Rizza asked what advice Group members gave regarding possible pregnancy to the anti-HTLVIII negative wives of anti-HTLVIII negative patients. It was agreed by most Directors that the wives should be advised to wait for the time being before conceiving children.

c) Dr. Rizza suggested that there should be more time available at AIDS Group meetings for the Directors to discuss and compare their views and patients. This was agreed.

8. Date and Place of Next Meetings

- 1) MONDAY 10th MARCH at Royal Free Hospital.
- 2) To be arranged by the Chairman and Secretariat.

The Chairman thanked Dr. Savidge for his hospitality and the meeting closed at 1.15 p.m.

GRO-C