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Minutes of the Fourth Meeting of the AIDS GROUP of Haemophilia Centre Directors, held at the Royal Free Hospital on Monday 20th May, 1985.

Present: Dr. C.D. Forbes (Chairman)
Prof. A.L. Bloom
Sister M. Fearns (representing Dr. P. Jones)
Dr. P. Kernoff
Dr. C. Ludlam
Dr. P. Mortimer
Dr. E. Preston
Dr. C.R. Rizza (Secretary)
Dr. G. Savidge
Dr. Alison Smithies (DHSS)
Miss R.J.D. Spooner

1. Apologies for absence:

Dr. A. Aronstam, Dr. J. Craske, Dr. I. Delamore, Dr. P. Jones (rep. by Sister M. Fearns), Dr. E. Mayne and Dr. R. Tedder.

2. Minutes of the Second Meeting:

The Minutes were approved and signed by the Chairman.

3. Matters arising from the Minutes:

a) CDSC Form 30c: The decision (recorded on P.3 of the Minutes) that Directors should send details of HTLVIIIAb+ results to CDSC on Form 30c was queried but confirmed.

b) Reservations were expressed about the use of the Phonetic Alpha-Numeric Coding suggested by CDSC as a means of identifying individual patients. The Chairman emphasised that CDSC did not mind what coding system was used by Directors to identify their patients and it was agreed that Centres could use their own coding system.

c) Confidentiality: Concern was expressed regarding the

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identification of HTLVIIIAb+ve patients. The need for confidentiality was recognized as was the risk to confidentiality arising from patient data being passed between London and Manchester on computer discs etc. It was emphasised that the AIDS Group had agreed to collaborate with the PHLS and that the PHLS laboratory staff handling patient samples needed to know the identity of the patients as problems might arise if duplicated samples or repeat samples could not be identified. Concern was also expressed regarding the difficulty of maintaining confidentiality in hospitals and there was discussion about the recording of HTLVIII Ab status in patients' hospital notes, the security of lists giving the names of patients who were HTLVIIIAb+ve and the labelling of samples sent to hospital laboratories via portering systems. It was agreed that Centres should try to ensure that the identity of patients who were HTLVIIIAb+ was kept confidential by the staff.

d) Dr. Craske: The Chairman said he had received a letter from Dr. Craske saying that he was despondent at the lack of co-operation from Haemophilia Centre Directors and was considering giving up the AIDS work he was doing on their behalf. The Chairman said that many people outside the Haemophilia Centre Directors organisation were taking an interest in the AIDS problem with haemophiliacs and it was important for the Haemophilia Centre Directors to collaborate with bodies such as CDSC but for the Directors AIDS Group to retain control of the haemophilia studies. Some bodies were sending out to Haemophilia Centres study protocols without prior reference to, and approval

from, the Directors AIDS Group. Reference was made to a letter dated 10th May from Dr. Galbraith to Prof. Bloom suggesting that CDSC undertake family studies in the haemophilic population. It was felt that Dr. Galbraith did not have the background knowledge of haemophilia that Dr. Craske possessed and that Dr. Craske should continue to coordinate the haemophilia studies, and make the appropriate data available to Dr. Galbraith for the overall UK AIDS picture. The possible reasons as to why Dr. Craske was not getting full cooperation from Haemophilia Centre Directors were discussed. Some Directors felt that the main problem lay with the complex data collecting forms sent out by Dr. Craske It was suggested that it might be helpful to Dr. Craske if a Reference Centre Director were nominated to assist Dr. Craske when protocols and forms were being drawn up and that all forms should be approved by the AIDS Group before they were distributed to Haemophilia Centres. Dr. Smithies was asked if the DHSS would consider providing financial support to Centres to enable them to employ staff to complete Dr. Craske's forms and Dr. Smithies pointed out that Dr. Craske was funded by the MRC for the Directors' AIDS Project. If additional financial help was required grant applications should be sent to the MRC/DHSS/SHHD giving details of the project to be undertaken. It appeared that the forms which gave rise to most problems at Centres were the ones designed to follow up patients who had received batches of concentrate with suspected high risk of AIDS contamination. Another problem in collaboration arose because of

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the lack of "feed back" from Dr. Craske.

The main projects currently being undertaken by Dr. Craske were:

a) Identification of AIDS cases

b) Identification of ARC cases

c) Family contacts studies

d) Social contacts studies

e) Study of Seroconversion following treatment with "suspect" batches of Factor VIII and IX

After discussion it was agreed that:

1. Dr. Craske should continue to coordinate the Haemophilia Centre Directors AIDS Projects.

2. The AIDS Group should define clearly what they expected from Dr. Craske.

3. AIDS case reports should be sent to CDSC via Dr. Craske.

4. Form 30c should be sent direct to CDSC by Directors, using their own coding system to identify individual patients.

5. The Reference Centre Directors should complete and return to Dr. Craske as soon as possible any outstanding forms, especially Form AIDS/3 (revised) notifying AIDS and ARC cases. If thought necessary, Directors should apply to the DHSS/SHHD for funds for secretarial assistance.

6. The follow up forms should be revised by Dr. Craske, with Dr. Ludlam's help, for approval at the next AIDS Group meeting.

7. Dr. Craske should circulate brief reports to Centres at approximately monthly intervals as this would stimulate a response from Directors.

8. Dr. Craske should ask Directors to send in NIL returns if they had no cases of AIDS/ARC.

9. Dr. Craske should ask individual Directors for the detailed information he required when he heard "via the grape-vine" of new AIDS/ARC cases.

10. The situation would be reviewed again in 3 months' time.

4. Report of the Atlanta AIDS Meeting

The Chairman presented copies of some detailed statistics he had obtained in Atlanta and some notes prepared by Dr. Jones on a visit to New York. Proceeding of the Atlanta meeting would be published later in the year. Prof. Bloom said that the work of Gallo's group had been particularly interesting. Of particular concern was the risk that AIDS might spread from the recognized high risk groups into the general population. Dr. Mortimer said he felt that the UK was not facing up to the potentially large problem of AIDS. ARC was much more multifaceted than previously thought. Sero+ individuals seemed to have a 5% chance of developing AIDS and 25% chance of developing ARC. Cerebral infection with the HTLVIII virus was a very important and worrying feature which might result in neurological and mental deterioration in the long term. The suggestion was made that perhaps haemophilia patients should be CAT scanned for evidence of cerebral involvement.

5. HTLVIII Antibody Tests Update and Results

Dr. Mortimer said that at a recent meeting the Director of the PHLS had informed them that funds should be available soon

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for setting up diagnostic tests at all PHLS Laboratories. At present and for the next 3 months only 6 PHLS laboratories would regularly be doing the tests. Commercial kits were currently being evaluated. For the time being, Directors should continue to send samples to Drs. Tedder and Mortimer. Concern was expressed regarding the reliability of the test systems at present used. Dr. Mortimer said in cases of doubt repeat testing was carried out on a further sample from the patient. He thought the situation would change; when the new test systems were implimented the quality of screening would improve. Dr. Mortimer did not believe that the passive transfer of antibody was the explanation of some of the variable results obtained.

The Chairman gave a brief report he had received from Dr. Tedder. A Research Scientist had been appointed to work with Dr. Tedder and there was now little delay in providing results. Dr. Tedder was keen to get family studies underway, in collaboration with Dr. Craske.

Some commercial laboratories were now undertaking Ab. tests and the question of quality control was raised. Dr. Mortimer said that the PHLS was taking active steps for controlling the work in the PHLS laboratories but this would not cover commercial laboratories.

6. New AIDS/ARC Cases

A new AIDS case had apparently been reported to CDSC but details were not yet known. Dr. Ludlam presented a copy of a paper he had submitted for publication in The Lancet entitled "HTLVIII Infections in Seronegative Haemophiliacs Following

Transfusion of Factor VIII" and Sister Fearns circulated copies of information regarding Newcastle patients which was to be published in the BMJ in June.

7. Nursing Problems and AIDS

In collaboration with the Haemophilia Nurses Association, Sister Fearns was preparing a document to cover the specific problems that nurses dealing with haemophiliacs encountered and which were not adequately dealt with in the RCN document. Sister Fearns would send to the Chairman a copy of the draft document as soon as possible and hoped that it would be approved by the AIDS Group for circulation to all Nurses dealilng with haemophilic patients. It was agreed that Sister Fearns should go ahead with drafting a document for approval by the AIDS Group.

8. Information Exchange

The Chairman distributed an updated information package to members of the Group.

9. Date and place for Next Meeting

Monday 17th June, in the Committee Room 2 at the Royal Free Hospial starting at 11.00 a.m.

10. A.O.B.

10a) Studies of Family and Household Contacts

The form designed by Dr. Craske was discussed and it was agreed that the form was too complex and modifications were required. Dr. Ludlam was asked to help Dr. Craske redesign the form, which should be precirculated to Group Members before the next meeting.

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The letter from Dr. Galbraith, mentioned earlier in the meeting, was discussed again and it was agreed that the Chairman would write to Dr. Galbraith to thank him for his offer of help but saying that the AIDS Group already had a study underway.

The Chairman had also received a letter from Professor Adler who had proposed a survey of the sexual partners of haemophiliacs. Dr. Acheson, Chief Medical Officer at the DHSS and Dr. Galbraith of CDSC were encouraging Professor Adler to undertake the study. Dr. Kernoff said he had attended a meeting with Drs. Acheson, Machin, Craske, Tedder and Savidge to discuss the proposals and a protocol had been drawn up. It was suggested that a simple survey of sexual contacts should be carried out in the first instance, Dr. Tedder was trying to identify samples of sexual contacts that he had already received from Centres. The results available so far had been tabulated by Dr. Tedder and were presented to the Group. After discussion it was agreed that the possibility of a more detailed study being undertaken should be deferred until a later date. Concern was expressed that Dr. Acheson had not contacted the AIDS Group in the first instance with his proposals and the Chairman agreed to write to Dr. Acheson to let him know that the Haemophilia Centre Directors' AIDS Group was arranging to set up a Survey on a National basis.

10b) Results of Professor Bloom's Questionnaire

Professor Bloom had precirculated to the AIDS Group analyses of the data he had obtained from the questionnaire sent to all UK Haemophilia Centres in April 1985. Since preparing the results for precirculation further replies had been received, the

response now being 80%. With reference to Table 1, Dr. Mortimer said he was concerned to see that a large number of Centres were still using non heat treated Factor VIII and suggested that all Directors be advised not to use non heat treated Factor VIII. Dr. Kernoff pointed out that such advice would need to be followed with recommendations regarding alternatives and such recommendations would need careful consideration as problems other than AIDS (e.g. hepatitis) had to be taKen into account. Dr. Savidge was concerned to see the apparent increase in the use of cryoprecipitate and wondered if this was the reason for the large number of Centres who said they had no financial problems. Dr. Ludlam suggested that Professor Bloom should try to get information from the Centres who had not yet replied as it was important to Know what these Centres used. Table 2 had been prepared for presentation at a recent meeting of the Health and Safety Committee. A copy had gone to the ACDP who were preparing new Guidelines. It was hoped that the new ACDP Guidelines would be published within 12 months. After further discussion it was agreed that Professor Bloom would prepare a letter for publication giving the results of his Survey and would circulate a draft of the letter to the AIDS Group Members for comment.

10c) Industrial Injuries Compensation

A letter and enclosure from Dr. Smithies was presented. Dr. Smithies said it was important that the DHSS was made aware of any people who lost their job as a consequence of their being

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HTLVIIIAb+. There could be problems for staff who contracted the infection outside work and it might prove very difficult for staff to prove that their work was the source of the infection. Concern was expressed by the Reference Centre Directors regarding the advice to be given to staff, e.g. should they have HTLVIII Ab tests, should they tell prospective employers if they were HTLVIIIAb+, should the career prospects of staff who were HTLVIIIAb+ be restricted? Some Centres were already encountering difficulties with recruiting and retaining staff. The Reference Centre Directors said that they would welcome advice from Dr. Smithies on this matter. Concern was also expressed about staff being included in HTLVIII studies and it was thought that local Ethical Committees should be asked to approve such studies.

The Chairman thanked Dr. Kernoff for his hospitality and the meeting closed at 3.30 p.m.