

Minutes of the Seventeenth Meeting of the AIDS GROUP of Haemophilia
Centre Directors, held the Royal Free Hospital on Monday 13th
February, 1989.

Present: Dr. C.R. Rizza (Chairman)
Professor A.L. Bloom
Dr. J. Craske
Dr. P.B.A. Kernoff
Dr. G.D.O. Lowe
Dr. C.A. Ludlam
Dr. E.E. Mayne
Professor F.E. Preston
Dr. G. Savidge
Dr. R. Wensley

1. Apologies for absence:

Dr. P. Mortimer, Dr. R. Tedder, Dr. H. Pickles,
Dr. I.W. Delamore, Dr. P. Jones and Miss R.J.D. Spooner.

2. The Minutes of the Sixteenth Meeting have been circulated and
there were no amendments

3. Matters arising from the Minutes:

Professor Bloom raised the topic of the previous sexual
questionnaire. He asked whether it could be reactivated or was
it now in limbo and was it still possible to have a
peripatetic counsellor for case control studies of heterosexual
transmission. Dr. Rizza commented that it might be appropriate
to return and consult with Professor Sir Richard Doll or re-
consult Dr. Anne Johnston as to how to proceed. It was
commented that 10% of the normal population are homosexuals,
therefore the number of spouses or contacts which develop HIV
positivity may only equal 10% of the haemophiliacs which are
positive for more than one high-risk group. The previous number
of contacts which had seroconverted was 18 and it is now known
that 26 have in fact seroconverted.

Discussion was held regarding what type of counsellor was the
best person to help fill in the questionnaire with the
patients. Dr Rizza suggested that a woman asking a woman
evoked a good response, whereas when men were asked, the
response was not so good.

Finally it was agreed that the Chairman would go back again
and consult with Sir Richard Doll and will communicate with
members by letter as soon as possible.

3a. Counselling Courses for Staff

Discussion was held whether there was a need at the present time for more such courses. It was noted that the Newcastle meeting, held in October 1988, comprised a day of lectures and it was discussed whether there was a need for a more practical course with establishment of small discussion groups. It was agreed that no more meetings should be held for at least six months.

3b. AZT Trials

Dr Rizza reported that by 12th January 1989, 146 patients had been entered into the MRC Concorde Trial and it had incorporated 44 Haemophiliacs at 7 Centres. Dr. Savidge indicated that the two Wellcome Trials were 007 and 009. The first study carried by Wellcome has been completed and was called 007. It was a trial of AZT versus AZT and prophylactic Acyclovir. To date there is information on 25 patients. The second ongoing 009 Trial has some 30-35 patients enrolled incorporating some from Austria, France, Germany, Italy and a few in Australia. The difficulties in recruitment were discussed and it appeared that most patients were worried about loss of time from work and the travelling at frequent intervals to the hospital. The provision of travel expenses was not deemed helpful.

It was felt that it was probably going to be difficult to achieve the proposed number of patients for both trials. The Chairman volunteered to write to Dr. Gelmon to propose the possible amalgamation of both trials.

3c. Development of Lymphoma in Haemophilic patients

Dr. Ludlam presented the information to the Committee regarding facilities available in Edinburgh for helping to classify and diagnose lymphoma in haemophiliac patients. The Chariman thanked Dr. Ludlam and members agreed to participate.

4. Progression to AIDS in Haemophiliacs

The Chairman intimated that the article based on the Haemophilia Centre Directors Data had been submitted to the BMJ and was going ahead for publication.

5. Litigation

The Chairman reported that he had written to the Medical Defence Union to find out the magnitude of the problem and he had only received a vague reply concerning number of patients taking legal action. Some discussion was held regarding the minutes of the Special meeting of Hameophilia Reference Centre Directors which was held in the Royal Free Hospital on 13th May 1988, when Dr. Katherine Allsopp of the Medical Defence Union presented some information and guidelines

for members of the committee. The Chairman said that it was agreed at the special meeting that no minutes of the meeting should be kept. Subsequent to that meeting, Dr. Ludlam had produced a history of chronological events relating to HIV seroconversion and infection. Copies of the historical document were presented at the meeting. The Chairman went round the table and asked members for the numbers of cases that they were aware were proceeding to litigation. A total from the members present indicated 56 cases which are proceeding. Dr. Ludlam indicated that his document was merely a draft. He felt that additions were welcome and he requested that everyone should write to him as soon as possible with any proposed amendments or for the inclusion of any references or documents which were not included.

Dr. Mayne indicated that she had been contacted by a firm of solicitors in Merseyside regarding her treatment policy using commercial concentrate and the low number of HIV positive patients that existed in Northern Ireland. It seemed apparent that the firm concerned were trying to obtain information to help in litigation cases. It was suggested that, in some instances, patients have received concentrate when the legal profession seemed to believe that cryoprecipitate would have been a more appropriate treatment. In response to this, Dr. Savidge indicated that he had a patient who received only two bags of cryoprecipitate in 1982, and seroconverted. Dr. Lowe suggested that the Haemophilia Society booklet, "AIDS and the Blood", written by Dr. Peter Jones, should be included in Dr. Ludlam's list of chronological events.

At the conclusion of the discussion, the Chairman urged that all comments should be written in to Dr. Ludlam within four weeks.

Dr. Rizza suggested that members should all obtain a copy of HM54(32) which deals with litigation in the NHS. Dr. Allsopp had mentioned the document while attending the Reference Centre Directors' Special meeting in May 1988. Dr. Kernoff asked if a query could be placed to the legal authorities regarding the ownership of social workers' notes. No one was aware of the exact procedure and Dr. Kernoff agreed to pursue the matter.

6. Any Other Business

There was a letter from Dr. Philip Mortimer to Dr. Rizza indicating that he would provide a secure confidential store of any old sera from haemophiliacs. Members were asked to contact Dr. Mortimer if they had storage difficulties.

The Chairman indicated that a letter had been received from Dr. Gibb who was a lecturer in infectious disease, working with Dr. Ian Hann, the Haemophilia Centre Director at Great Ormond St. Dr. Gibb was seeking the numbers of HIV positive children that were being looked after in the Centres. She

wanted this information so that the surveillance of HIV in children could be co-ordinated. The members agreed that no such disclosure could be made by the Reference Centre Directors and suggested that Dr. Gibb contact Haemophilia Centre Directors individually. Dr. Rizza agreed to write to Dr. Gibb advising her accordingly. Attention was drawn to the forthcoming meeting in Glasgow on HIV infection in childhood.

The meeting ended and the date and place of the next meeting was decided to be in St. Thomas's Hospital, London on Monday 11th September 1989 at 2.15pm.

GRO-C: C Rizza

11/9/89