

Witness Name: Alice Mackie

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INFECTED BLOOD INQUIRY

EXHIBIT WITN2189010

H176

→ Dr Moore (for information)

WITN2189010

DRAFT

Minutes of the Sixteenth Meeting of the AIDS GROUP of Haemophilia Centre Directors, held St. Thomas' Hospital on Monday 5th September, 1988

Present: Dr. C.R. Rizza (Chairman)
Dr. A. Aronstam
Dr. J. Craske
Dr. P. Jones
Dr. P. Kernoff
Dr. G. Lowe
Dr. C. Ludlam
Dr. E.E. Mayne
Dr. H. Pickles
Dr. G. Savidge
Dr. I. Walker
Dr. R. Wensley

1. Apologies for absence:

Dr. Mortimer, Professor A. Bloom, Dr. P. Hamilton,
Professor F.E. Preston, Miss R. Spooner,
Professor I. Temperley.

2. The Minutes of the Fifteenth Meeting were approved and signed.

3. Matters arising from the Minutes:

a) Counselling Courses for Haemophilia Centre Staff

Dr. Jones reported that the next AIDS counselling course meeting seemed to have been well received with 51 applicants to date. He asked colleagues to encourage their staff to attend on 27th October in Newcastle.

b) Proposed Studies of AZT in Haemophiliacs

Dr. Rizza reported that he had written to Dr. Yeo of the Wellcome Foundation drawing her attention to the Directors misgivings about some aspects of the Wellcome Study as requested at the previous meeting. He had received no reply.

Dr. Savidge reported that the Wellcome AZT trial on asymptomatic patients had started on 1st June, 1988. The trial was intended to be multi-national with 360 patients enrolled in total. To date he was aware of 10 or 15 patients who were on the trial. A meeting had been held in London with colleagues from Italy, Germany, Austria, Spain, France and Australia. Wellcome were providing £1500 per patient for the trial, which was scheduled to run for two years with independent statistical analysis. No guarantee of free drug had been given by Wellcome following the trial, which was a double blind placebo controlled study with stratification according to CD4 count.

Dr. Aronstam said that he was opposed to both this and the MRC study because he feared it would deprive people in the placebo group of AZT for two or three years. He wished to start patients on active drug following individual assessment of their clinical and immunological status. He felt that it would be too late to await the results of either study. After discussion it was agreed that there was no evidence of the efficacy of Zidovudine in

asymptomatic patients and most of them were preparing to enter patients into the MRC study rather than the Wellcome on, although none entering patients into both trials.

4. a) Seroprevalence Studies

Dr. Rizza reported that the seroprevalence study had provoked a good response.

To date only one very questionable sero-conversion only had been reported and at the time of the meeting it appeared that this was due to a transcription error. Further details would be made available after investigation. The question of counselling people before performing antibody tests was raised by Dr. Ludlam. Members agreed that this was mandatory and usually took about half an hour.

Members agreed that the figures obtained from the sero-prevalence study could be more available to the Macfarlane Trust.

b) Dr. Rizza reported that Sir Richard Doll had given a preliminary report suggesting that from the time they were first found antibody positive 13% of patients had developed AIDS after four years. There was no significant difference between those with haemophilia A and those with haemophilia B but a very

significant difference with age. The chances of developing overt disease within four years were 6% for those under 25 years of age, 15% for those between 25 and 44 years of age and 35% for those above 44 years of age. The full report would be sent to the Reference Centre Directors when it was available.

5. Sexual Questionnaire

Dr Rizza tabled the proposals for the Sexual Questionnaire which he had again discussed with Dr. Anne Johnson of the MRC.

Dr. Kernoff wondered whether the question of a case control study had been considered or whether the questionnaire was just for HIV antibody positive haemophiliacs and their wives. Dr. Rizza said that the study was intended for the HIV antibody positive men. He said that Sir Richard Doll did not feel that it would be fruitful to study HIV antibody positive female partners retrospectively and that more information would be available from a prospective study. Dr. Rizza reported that some 30 patients at Oxford had so far completed the form without difficulty whilst acknowledging that the questionnaire on page 4 relating to contraception was difficult. Dr. Kernoff again raised the question of studying people who are antibody negative which he felt could contribute to the debate on whether testing contributed to a change in behaviour. The question of whether AZT modified the risk of transmission was also raised.

6 Strategies for Surveillance of HIV

Dr. Craske asked that this item rested.

7 Any Other business

Dr. Jones reported that the Macfarlane Trust had appointed an Administrator, Wing Commander John Williams. A Statement of the Trust's intentions with regard to allocation of monies was to be issued shortly. It had been decided that people wishing to apply for substantial sums of money to cover mortgages and insurance should first approach their usual financial advisers so that risk assessment had already been undertaken before their application to the Trust. The major problem presently faced by the Trustees was the lack of information about how many dependants were likely to require help now or in the future. The directors were shortly to be asked to help collect this information from families known to them. Directors were also asked to encourage people to register with the Trust. To date some 700 of the estimated 1200 haemophiliacs who were known to be infected had registered and the Trustees were grateful for all the help they had received.

Dr. Jones asked for the views of members with regard to the Trustees' attitude to applications for finance for artificial insemination by donor. Several applications for help had already been received. There was general agreement that where National

Health Service facilities could not be provided the Trust should be asked for help.

One of the questions that had been raised with regard to insemination was whether it was possible to use the infected husband's sperm separated from the semen. To members' knowledge this was still experimental and there was doubt whether sperm themselves carried HIV.

Dr. Jones raised the escalating problem of legal action being taken against Directors by their patients. No-one present had yet been summonsed but most members had received requests for notes and 5 had been asked to comment of medical records from other hospitals. There was a general agreement that Directors should pool information on cases that came to their notice. Difficulties were expected for patients who were suing the Health Authority and therefore the Doctor and yet still continuing to be treated by him or her. Difficulties were also expected in having both supply and reply to legal questions relating to past treatment of haemophiliacs.

It was decided that Dr. Rizza should write to the defence organisations to see whether they would release the numbers of cases presently under review. Dr. Pickles agreed to ask the Department if it would release figures relating to cases known to them.

Dr. Rizza agreed to circulate the historical schedule of events to all Directors. This schedule sets out the dates for the introduction of antibody testing and putative viral inactivation of the different blood products.

Dr. Ludlam raised the question of lymphoma occurring in the infected haemophilic population and said that he was interested in knowing of cases. Dr. Savidge wondered whether Hodgkins Disease was a direct result of HIV infection and Dr. Wensley reported a case of chronic lymphatic lymphoma in one of his patients. Dr. Ludlam asked members to let him know their views on treatment.

8 Date of Next Meeting

The date of the next meeting was provisionally fixed for Monday 13th February, 1989 at the Royal Free Hospital.