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Minutes of the Nineteenth Meeting of the AIDS Group of  
Haemophilia Centre Directors held at The Royal Free Hospital  
on 12th February 1990.

Present

Dr. C.R. Rizza (Chairman)  
Dr. A. Aronstam  
Prof. A.L. Bloom  
Dr. J. Craske  
Dr. F.G.H. Hill  
Dr. P.B.A. Kernoff  
Dr. R. Lee  
Dr. J. Leslie  
Dr. G.D.O. Lowe  
Dr. P. Mortimer  
Dr. B. McVerry  
Prof. F.E. Preston  
Dr. G. Savidge  
Dr. I. Simpson  
Dr. I. Temperley  
Dr. R.T. Wensley  
Dr. Rejman  
Miss R.J.D. Spooner

- 1a) Apologies: Dr. P. Jones and Dr. C.A. Ludlam.
- 1b) The Chairman welcomed Dr. Simpson, Joint Secretary of the 3 Defence Unions. In view of Dr. Simpson's attendance it was agreed that Item 6 (Litigation) should be taken first on the Agenda.

2. Minutes of the last meeting

The minutes were approved and signed.

6. Litigation

Dr. Savidge raised the point that one member of the AIDS Group was

acting as an expert on behalf of the Plaintiffs and wondered whether it was acceptable for him to take part in the Group's discussions on Litigation and the Defence of the main statement of Claim. Dr. Simpson said this was an awkward position. It would be less awkward if the expert was advising on the "generic" action. Dr. Aronstam said he was the person referred to. He had not been asked to be a medical expert witness for the plaintiffs. If the group felt it was awkward for him to be present he would leave the meeting. He pointed out that some other directors were in a similar position and more might be in the future. In reply to a question Dr. Simpson said he could see no reason for Dr. Aronstam to leave the meeting. Dr. Rejman said that the cases of Plaintiffs in the Wessex Region were being held back at present and would follow on after the lead cases had been considered. Dr. Aronstam said he knew of at least two cases involving his patients which were going ahead as lead cases; it was news to him that Wessex cases were being put back. In view of the feelings already expressed he thought he should leave the meeting for the time being while the matter was discussed. After Dr. Aronstam had left the room the situation was discussed further. Several Directors said they would feel nervous discussing details of their clinical practice with a representative of the plaintiffs in the room and some suggested that the Health Authorities' defence lawyers might be put in an embarrassing position. Prof. Bloom thought that the Health Service Solicitor's advice should be sought. Prof. Preston thought that the problem went beyond HIV and that discussion of liver disease in view of the Haemophilia Society's request for information might prove very awkward if an expert witness for the plaintiffs was present.

It was pointed out that Dr. Jones was acting for <sup>5</sup> the Plaintiffs in Scotland. After further discussion it was agreed that the Chairman would write for advice to the Consortium of Defence Lawyers and to the Central Legal Office in Scotland.

Barbara Simpson's letter of 7th February outlining the present situation was presented by the Chairmam and discussed. With regard to Health Authorities' Defence to the Re-amended Statement of Claim Dr. Savidge said that he had been using heat-treated Factor VIII as early as 1983 and he was trying to get the Defence's Statement amended as it said heat-treated factor VIII was not used until the end of 1984. Discussion followed as to how the lawyers would put together a generic defence in the light of the varied practices at Centres. It was agreed that Barbara Simpson's letter was helpful and that the Chairman would ask her to provide further reports of a similar nature. Dr. Hill asked Dr. Ian Simpson if it was clear that medical staff would not be sued. Dr. Simpson said yes, this was quite clear. Prof. Bloom asked if medical staff could be sued at a later date. Dr. Simpson said they could be sued, as individuals.

Dr. Lowe suggested that Dr. Simpson's advise should be sought regarding the Haemophilia Society's request for information on hepatitis. Was hepatitis likely to be another item for which haemophiliacs would seek litigation and was it advisable for the Haemophilia Centre Directors to continue to collect data? Dr. Simpson said it would not be advisable

for the Directors to stop collecting data as they had already started to do so. Dr. Hill pointed out that hepatitis was not a new thing; only the test was new. After further discussion, Dr. Simpson agreed that the Haemophilia Society should not be given hepatitis data. Dr. Hill expressed concern about Haemophilia Society representatives hearing Hepatitis Working Party reports at A.G.M.s. Dr. Lowe thought there was a difference between testing LFTs and testing for Hepatitis C and he wondered whether the patient's consent to testing should be sought. Dr. Mortimer said he thought that reliable Hepatitis C tests would be available in about a year. At the moment the tests were quite reliable, but it would soon be possible to do confirmatory tests. Prof. Bloom didn't see why permission needed to be asked for Hepatitis C tests as this was just another LFT. Dr. Savidge said that patients were now becoming more and more conscious of what tests were, so he would advise caution at present.

Dr. Aronstam returned to the meeting and intimated in view of the obvious concern of his colleagues that he would resign from the Group. The Chairman expressed his regret and asked Dr. Aronstam to consider the matter further before making a final decision. The Chairman would write to the Defence Lawyers to get their response to the situation and would let Dr. Aronstam know the reply. Dr. Lowe asked the Chairman to take advice from the Central Legal Office in Scotland regarding Dr. Peter Jones's involvement in the cases in Scotland. This was agreed.

Prof. Preston quoted results presented at a recent meeting on prevalence of anti HCV in spouses of haemophiliac. A figure of 20% was found which he thought was very worrying. Dr. Lowe proposed that all Regional Centre Directors should be included in the Hepatitis Working Party. After discussion it was agreed that the Chronic Hepatitis Working Party should be incorporated with the AIDS Group. Dr. Kernoff emphasised that all questionnaires might be raised in evidence at a later date and Dr. Rejman suggested that the Directors should check with their legal advisers what date was the cut-off for documents to be presented by defendants.

3a. Sexual Questionnaire

The Chairman said that the questionnaire (Appendix A) had been sent again to RCDs as requested and comments were invited. Dr. Hill was concerned about why the Study was being done and would like a clear idea of the purpose of the Study. He wondered if it would give people a false sense of security. Dr. Craske said he would support the Study, which he thought was essential to do. Dr. Hill thought many Centres had difficulties in getting co-operation from patients and wives. Dr. Rizza said there had been no problems with the 37 wives in Oxford who took part in a pilot study. Dr. Hill said that most Centres did not have the time or resources to take on the the Heterosexual Study. The questionnaire was discussed very briefly. No enthusiasm for the Study was shown and it was agreed not to proceed with it.

3b. BBC's Proposed Scientific Study on Heterosexual Transmission of HIV.

The Chairman said he had received a phone call from the BBC to say that they would like to do a scientific study on heterosexual transmission and would provide £20,000 to cover costs. The Chairman invited the Group's views on the project involving HCDs co-operating with the BBC.

4. Progression to AIDS in haemophiliacs

The Chairman presented tables showing the numbers of AIDS and ARC cases currently known. The AIDS figures were comparable with the figures published by CDSC as there were regular exchange of information between Oxford and CDSC.

4b. Reporting to CDSC of deaths in anti-HIV+ patients

The Chairman had received a letter from Dr. B. Evans (Consultant Epidemiologist, AIDS Unit, CDSC) asking if Directors would agree to information regarding deaths of HIV infected patients being passed on to CDSC for inclusion in their AIDS Surveillance data. After brief discussion it was agreed that information from Directors on HIV+ patients who die could be passed on to CDSC by the Secretariat in Oxford.

7a. Haemophilia Society's letter concerning publication of "Safer Sex: The Choice is Here".

After disucssion it was agreed that no seminars should be held to discuss how to use the above document.

The Chairman thanked Dr. Kernoff for his hospitality and the meeting closed at 4.05 pm.