

DRAFT

Minutes of the Fifteenth Meeting of the AIDS GROUP of Haemophilia
Centre Directors, held at the ROYAL FREE HOSPITAL on Monday 1st
February, 1988 at 2.15 p.m.

Present: Dr. C.R. Rizza (Chairman)
Dr. A. Aronstam
Prof. A.L. Bloom
Dr. J. Craske
Dr. M. Greaves
Dr. P.B.A. Kernoff
Dr. C. Lee
Dr. G.D.O. Lowe
Dr. C. Ludlam
Dr. P. Jones
Dr. E.E. Mayne
Dr. P. Mortimer
Dr. M. O'Doherty
Prof. F.E. Preston
Dr. G. Savidge
Miss R.J.D. Spooner
Prof. I. Temperley
Dr. R.T. Wensley

1. Apologies for absence:

Dr. Alison Smithies.

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

3. Matters arising from the Minutes:

a) Counselling Courses for Haemophilia Centre Staff

Dr. Wensley reported that nurses and social workers who
attended the meeting held in Manchester last month had said they
found the meeting very useful. Dr. Jones said that a
notification had been sent to all Haemophilia Centre Directors
regarding the meeting on Paediatric AIDS which was being
organised by the Institute of Child Health in London for
Wednesday 10th February, 1988. Dr. Rizza reported that he had
received a letter from the Royal College of Physicians asking for
the Haemophilia Centre Directors to be informed about meetings
which the Royal College was organising. He had sent a list of

all the U.K. Haemophilia Centres to the Royal College of Physicians so they could send notifications of meetings directly to the Directors. It was agreed that the Reference Centre Directors' AIDS Group should continue to organise meetings on AIDS on an annual basis and that the next meeting would be held in the Autumn in Newcastle. Dr. Jones would make the arrangements and advise the Chairman of dates as soon as possible.

ACTION PJ

4. a) Seroprevalence Study

i) Publication of the 1986 Survey

Dr. Rizza said that the 1986 Survey had been accepted for publication in "Clinical and Laboratory Haematology".

ii) Report on the 1987 Survey (Appendix A)

The report was presented by Dr. Rizza. During the discussion which followed Professor Temperley said that 40% of all the haemophiliacs in Eire who had been tested were positive. Dr. Rizza said that 65% of all haemophiliacs registered in the United Kingdom had now been HIV tested and 78% of all the severely affected patients had been tested. Dr. Kernoff asked if any information was available on exposure to NHS products. In particular he thought it would be interesting to have information regarding patients who were seronegative when they were first treated with the 8Y product and if any of these patients had sero-converted. After further discussion it was agreed that the AIDS Group would go ahead with a survey for 1988 along similar lines to the 1987 Survey. Several members reported on the birth of children to women of antibody positive haemophiliacs and questions were asked about the current birth rate in families where the father was antibody positive. Although some Directors

ACTION CR, RS

ACTION CR, RS

were concerned that a survey might cause anxiety to patients others felt that it would be reasonable to ask Directors for the number of children born to haemophiliacs and for the HIV status of each child. It was thought that this information was vital when counselling haemophilic patients. After further discussion it was agreed that Haemophilia Centre Directors should be asked to give information about the numbers of children born to the wives of all anti-HIV positive haemophiliacs, their date of birth and their state of health. Dr. Mortimer and Dr. Craske both thought that testing of children for anti-HIV should be postponed until the child was 2 years of age. It was suggested that blood samples should be collected at yearly intervals from these children and the samples for testing at a later date if necessary.

With regard to data collection Dr. Rizza said that he had received a letter, dated 25th January from Ken Milne of the Haemophilia Society stating that the Society felt that collection of the HIV data was extremely important and should continue.

Dr. Rizza distributed information which he had received from Dr. Tony Ellam of CDSC, Colindale regarding paediatric AIDS. Dr. Ellam wished to draw the Directors attention to the paediatric AIDS surveillance programme and to the questionnaire which was being used for this purpose. Dr. Rizza said that the question of reporting of HIV related illness in children, had been discussed with Dr. Tillet of CDSC, who was going to take up the matter again with Dr. Ellam to make sure that he was aware that she was liaising with Oxford regarding information on the haemophilic patients.

Because of the close co-operation between Oxford and CDSC it

had been agreed with CDSC that the form AIDS/3 should be used by the Haemophilia Centre Directors to report cases of AIDS/ARC and that it was not necessary for them in addition to fill in the Colindale reporting forms.

b) AIDS/ARC cases

Dr. Craske in a tabled report gave an analysis of the information he had regarding AIDS/ARC cases. Dr. Rizza reported that he was collaborating with Professor Doll in analysing the AIDS/ARC data and hoped to be able to provide some information on life expectation and rate of progress of the disease for the next meeting of the AIDS Group.

5. Heterosexual transmission of HIV in female sexual contacts of haemophiliacs

Dr. Rizza presented the questionnaire, Forms S1 and S2 (Appendix B) which had been drawn up with Professor Richard Doll's advice and collaboration and asked if the Reference Centre Directors would be willing to use it at their Centres. It was envisaged that health visitors/social workers from Haemophilia Centres would ask the questions of the wives of the haemophilic patients. Dr. Savidge said that he was not very happy about it and had sent his comments in writing to Dr. Rizza. Dr. Lee and others queried whether the information on the frequency of intercourse five years prior to the interview was likely to be reliable. Dr. Mortimer suggested that a trial run should be carried out with the questionnaire before proceeding to use it more widely and Dr. Kernoff suggested that it should be made clear on the form that the questionnaire was strictly confidential. It was suggested that information regarding anal intercourse should be added to the form although this had caused

the Directors some anxiety in previous questionnaires considered by them. The purpose of the Survey was to find out what factors encouraged the transmission of the virus. Dr. Mortimer suggested that it might be more suitable to study the 18 positive female contacts of haemophiliacs rather than to question the wives of all the positive haemophiliacs. He suggested that a case control study be set up to study the above 18 women. After further discussion Dr. Rizza agreed to discuss further with Professor Doll the proposals for a case control study of the 18 infected sexual partners and to look again at the prospective questionnaire under discussion.

ACTION CR

6. Safety of dry-heated Factor VIII concentrates

Professor Bloom reported on a recent meeting in Atlanta, Georgia which had been called to consider 6 seroconversions in Canada in 1987 following use of heat treated factor VIII concentrates. These seroconversions raised again the question of safety of the currently available products. After much

DECISION

discussion it was agreed that the Reference Centre Directors should prepare a document for circulation to Haemophilia Centres as soon as possible giving advice on which of the available products were considered safest. Dr. Kernoff suggested that the document which Professor Bloom had presented to the members should be used as a basis for a first draft which he agreed to prepare once he had seen the document on the subject being prepared by the National Hemophilia Foundation in the United

ACTION PK

States. It was agreed that Dr. Kernoff would send the draft document to Dr. Rizza for circulation to the Reference Centre Directors for their comment and that when all the comments from the Reference Centre Directors had been received a final version

of the document would be prepared and circulated to all U.K. Haemophilia Centre Directors from the AIDS Group.

DECISION

Following discussion of safety of the heated products Dr. Jones proposed, as at the morning session of the Reference Centre Directors, that Dr. Kernoff should chair a Working Party or some such group on the Safety of Blood Products and draw up a draft document for circulation to all Haemophilia Centre Directors.

Dr. Kernoff agreed to become Chairman of such a Group.

7. A.O.B.

1. Dr. Savidge regarding trials of AZT. Dr. Savidge referred to the meeting with Wellcome held on 26th January, 1988 to discuss a proposed study of AZT in haemophiliacs. There was general dissatisfaction with the way in which Wellcome were behaving with regard to the organizing and funding of the trial and some Directors felt that Wellcome probably were not particularly interested in pursuing the trial. After further discussion it was agreed that Dr. Rizza should write to the Wellcome Foundation about the trial to try and get matters clarified and to voice the Directors concerns.

ACTION CR

8. Date and place of next meeting of the AIDS Group

It was agreed that the next meeting of the AIDS Group would take place at St. Thomas' Hospital on Monday 5th September, 1988 at 2.15 p.m.

The meeting closed at 4.30 p.m.