Minutes of the Fourteenth Meeting of the AIDS GROUP of Haemophilia Centre Directors, held at St. Thomas' Hospital on Friday 11th September, 1987 at 2.15 p.m.

Present:

Prof. C.D. Forbes (Chairman) : Dr. C.R. Rizza (Secretary)

Prof. A.L. Bloom Dr. I.W. Delamore Dr. P.B.A. Kernoff Dr. C. Ludlam Prof. F.E. Preston Dr. G. Savidge

Dr. R. Tedder Dr. J. Craske Dr. P. Jones

1. Apologies for absence:

Dr. A. Aronstam, Dr. G.D.O. Lowe, Dr. E.E. Mayne, Dr. Alison Smithies, Miss R.D.J. Spooner and Prof. I. Temperley.

2. Minutes of the Thirteenth Meeting:

The Minutes were approved and signed.

- 3. Matters arising from the Minutes:
 - a) Heterosexual transmission of HIV in female sexual contacts of haemophiliacs

Dr. Craske reported that 16 female sexual contacts of haemophiliacs have been found to be anti-HIV positive. He described reports which suggest that the risk of transmission increases with time from first infection in male and also with the degree of antigenaemia. Unborn children were more likely to be affected if mother clinically ill. He drew attention to a report that 15% of spouses of seropositive haemophiliacs are seropositive in the U.S.A. Some were wives of seropositive but well males. The problem of AIDS in babics was discussed in particular the risks of acquiring infection in utero and the need for close follow up of HIV antibody and HIV antigen in these children at risk. Dr. Jones reported briefly on the experience of HIV infection in childhood in Berlin, Padua and Edinburgh.

b) Dr. Craske reported on HIV related disease in the U.K. and drew attention to a seemingly marked increase in the number of AIDS cases. Some of this increase he thought was due to retrospective reporting. From an analysis of cases it seemed that increasing age increased the risks of becoming ill. Dr. Craske felt that it was important now to reassess the kind of information the Group should collect and should be looking to develop the appropriate forms and questionnaires.

There was some discussion about how long it took for antibodies to appear following exposure to HIV. Dr. Ludlam reported that from his experience with his cohort in Edinburgh the longest interval between infection and seroconversion was approximately one year.

c) There was no discussion on this item.

5. Information exchange

It was agreed that Dr. Jones would try to organize a satellite Symposium on HIV infection in childhood as part of the British Paediatric Association meeting in York in April 1988. The Chairman felt however that the directors should continue to organize counselling courses for haemophilia centres and associated staff. It was suggested that the next counselling meeting should be held in Manchester. Dr. Delamore agreed to look into the possibility of organizing such a course.

4. Progress Report on AIDS GROUP Projects:-

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a) Seroprevalence study

Dr. Rizza reported that questionnaires had been sent out for the third study of anti-HIV prevalence in haemophiliacs. On this occasion the questionnaire also sought information on sexual partners of haemophiliacs. The closing date for the return of the questionnaire was 31.7.87. At the time of reporting only 60 replies had been received. Because of this it was not possible to give a detailed report and analysis. Initial analysis shows that 2,292 haemophilia A patients have been tested for anti-HIV, 890 (39%) are positive; 409 haemophilia B patients have been tested 22 (5.3%) are positive; 411 von Willebrands disease patients have been tested 17 (4%) are positive. With regard to heterosexual transmission, 306 female sexual partners of seropositive men have been tested, 17 (5.5%) are positive. Four patients have apparently seroconverted since September 1986. The intervals between the last seronegative result and the first seropositive in these patients were 6, 14, 16 and 22 months. Dr. Rizza said that the report of the 2nd survey of anti-HIV prevalence had been turned down by New England Journal of Medicine. It was suggested that the article be submitted to British Journal of Haematology.

6. A.O.B.

A.Z.T. Dr. Kernoff discussed his local problems with regard to funding for A.Z.T. and asked the other members of the group about their experiences. The A.Z.T. trial organized by Wellcome was proceeding but there was some concern that a number of haemophiliacs were being treated outside the trial and on whom important data might be lost. Dr. Savidge commented that he had written to several centres inviting participation but had in many instances received no reply. It was agreed that the question of co-ordinated A.Z.T. studies should be raised at the A.G.M. on 25.9.87 and that Dr. Savidge should talk on the subject.