APPENDIX 13

MINUTES OF SPECIAL MEETING OF HAEMOPHILIA CENTRE DIRECTORS held at ST. THOMAS HOSPITAL on 13.5.83. at 11.00 a.m.

Present: Professor A.L. Bloom (Chairman)

Dr. John Craske

Dr. Peter Hamilton

Dr. Peter Kernoff

Dr. Christopher Ludlam

Dr. Geoffrey Savidge

Dr. Eric Preston

Dr. Irvine Delamore

Dr. C.R. Rizza

Dr. Diane Walford (D.H.S.S. observer)

Apologies for absence received from Dr. Elizabeth Mayne

Professor Bloom briefly outlined the background to the meeting and its purpose. The recent publicity in the press, radio and television about the problem of acquired immuno deficiency syndrome (AIDS) had caused considerable anxiety to haemophiliacs and their medical attendants as well as to the Department of Health. There was clearly a need for Haemophilia Centre Directors to discuss what should be done with regard to the surveillance and reporting of suspected cases and the management of patients. To date in the United Kingdom one haemophiliac is suspected of suffering from AIDS. In London there are reported to be 10 cases of confirmed AIDS in homosexual males. Concern was expressed about the definition of AIDS. It was felt that there might be many individuals with evidence of impaired cell-mediated immunity but only a very small number of these might progress to a full blown picture of the condition. It is important that such individuals are not classified as suffering from AIDS. It was accepted that because of our lack of knowledge of the nature of AIDS,

decisions about diagnosis and reporting of suspected cases would prove difficult. Nevertheless the criteria laid down by the Centres for Disease Control, Atlanta, Georgia, and in the form prepared by Dr. J. Craske for use at U.K. Haemophilia Centres, should be followed for diagnostic purposes. The importance of opportunistic infection as a diagnostic criterion was stressed. It was agreed that any patient who was suspected of suffering from AIDS should be reported immediately on the form provided and thereafter the clinical course of the patient would be followed and a definitive diagnosis attached if the patient developed intractable disease.

The steps to be taken should a patient develop the features of the full-blown condition were then discussed. It was agreed that there was insufficient information available from the U.S. experience to warrant changing the type of concentrate used in any particular patient. Moreover once the condition is fully developed it seems to be irreversible so that there would seem to be no clinical benefit to be gained by changing to another type of factor VIII.

With regard to general policy to be followed in the use of factor VIII concentrates, it was noted that many directors have up until now ~~restricted their use of~~ National Health Service concentrates to children and mildly affected haemophiliacs and it was considered that it would be circumspect to continue with that policy. It was also agreed that there was, as yet, insufficient evidence to warrant restriction of the use of imported concentrates in other patients in view of the immense benefits of therapy. The situation shall be kept under constant review.

It was noted that the Blood Transfusion Centre Directors were due to meet to discuss the problem of donor screening in relation to AIDS. The news of this meeting was welcomed by the Haemophilia Reference Centre Directors.

There being no further business the meeting closed at 2.15 p.m.

GRO-C: A Bloom