HAEMOPHILIA AND HIV INFECTION

1. Haemophilia and its Treatment

Haemophilia is an inherited disorder characterised by absence or reduced amount of a blood clotting factor, normally Factor VIII.

Severe haemophilia may cause spontaneous bleeding into joints, or even the brain. Those less severely affected may have bleeding problems only following accidental trauma or operations.

The earliest forms of treatment used either fresh whole blood or fresh plasma. Cryoprecipitate, an early concentrate developed in the late 1960s, was gradually superseded by FVIII, which could be readily used at home by patients. All of these are human blood products. The amount of FVIII used in the UK has increased from 6.9 million units in 1969 to 100 million units in 1988.

2. HIV and AIDS

The state of knowledge of the cause of AIDS, the methods of transmission and the implications for haemophiliacs only developed over a period of time.

The first cases of what is now known as AIDS were reported in homosexuals In June 1981 in US. In July 1982 3 Haemophiliacs in US were reported with AIDS, although even in December 1983 only 3 in 1000 haemophiliacs in the US and Europe were infected. The first case of AIDS in a UK haemophiliac was reported in the Lancet of 19 November 1983. In May 1984 the virus causing AIDS (HIV) was isolated and accepted by most scientific authorities although the same virus had been reported 1 year previously when doubt was cast as to its relevance. In the latter part of 1984 and in 1985 tests were being developed to diagnose the presence of HIV.

Retospective testing of stored blood samples has shown that the first positive HIV test in a UK haemophiliac dates back to 4 December 1979. It is possible that other haemophiliacs had positive tests at that time or even before. Both imported FVIII as well as UK product have been implicated in the transmission of HIV.

3. Actions to prevent transmission of HIV

- warnings to donors in at risk groups
- testing of blood for HIV antibody
- heat treatment of clotting factors, to destroy HIV or other viruses

4. Current Litigation

Of 1216 haemophiliacs infected with HIV in the UK through use of

FVIII, 212 have been diagnosed as having AIDS, 143 have died. 775 haemophiliacs and 164 partners or close relatives are suing the Department of Health, Welsh Office, Medicines Licensing Authority and Committee on Safety of Medicines for damages. The main court hearing is set for March 1991.

The Plaintiffs allege negligence in that the Government did not act quickly enough to prevent transmission of HIV in blood products, and in some cases that medical treatment was inappropriate. The defendants deny negligence and claim that the measures were taken in the light of then available knowledge.

Over 1200 haemophiliacs became infected with the AIDS virus (HIV) as a result of NHS treatment with coagulation products, Factor VIII in particular, made from human plasma. Up to the end of September, 1216 haemophiliacs had been reported with HIV in the UK, 212 had been reported with AIDS and of those reported with AIDS, 143 have died.

5. "No Fault" Compensation

It has been argued that there should be some form of "no fault" compensation. Demands for similar treatment from other groups disabled as a result of a medical accident, who would not have to prove negligence, could be hard to resist. "No fault" schemes, which the Pearson Commission came down against in 1978, would introduce unfairness between those disabled as a result of a medical accident, and those who are equally disabled through natural causes. A "No Fault" system would almost certainly pay less than the Government has already made available to infected haemophiliacs.

The payments to the MacFarlane Trust in recognition of the special plight of haemophiliacs are different, and could provide a route by which something could be done, if it is decided that the action could be settled out of court. In 1987 £10 million was made available to meet special needs and a further 24 million in 1989 to fully fund payments of £20,000 to each infected haemophiliac. The Secretary of State has said that the these sums will be kept under review to ensure that they are adequate.