

Appendix A

COMPENSATION FOR HAEMOPHILIACS INFECTED WITH HEPATITIS C

Current position

* About 3,000 non HIV positive people with haemophilia , and possibly a further 3,000 people who are still alive who had blood transfusions prior to September 1991 (the figure for blood transfusions could be significantly higher), are believed to have been infected with hepatitis C as a result of NHS treatment. (These figures are best estimates only - the precise figures are not as yet known.)

* The effects of the hepatitis C virus have only become known recently and there is still a degree of uncertainty, but it is estimated that some 50% of those infected with hepatitis C may progress to chronic hepatitis with varying degrees of good and ill health. 20% may develop cirrhosis, a progressive destruction of the liver, that may take 20 to 30 years. The majority of those years will be trouble free. A small percentage will actually die of liver disease. (It has been suggested that 50 to 60 of the above group having died so far.)

* Those with haemophilia were infected before blood products, including those used to treat their condition, began to be heat treated to inactivate viruses in 1985. Those infected through blood transfusion were generally so infected before a reliable test for hepatitis C became available in 1991.

* Special payments schemes, including lump sum payments and a hardship fund, for all those infected with HIV through blood transfusion/blood products were introduced in the light of the unique circumstances affecting sufferers. (See Appendix B for details of schemes). The unique features of the HIV claim included the stigma attached, at the time the decision to compensate was made, to HIV and AIDS, the public revulsion surrounding all aspects of the virus at that time; the fact that the condition was easily transmissible to the spouses of those affected, and that in some cases their children also became innocent victims of these circumstances. Some £90m has been spent on these schemes so far.

* Some of those infected with hepatitis C have taken out writs for damages against SoS, the Department and/or HAs alleging negligence. Liability has not been admitted.

* The Department made £1m available last year for research into the natural history, transmission and prevalence of hepatitis C, and made a further £0.5m available this year.

Key developments and issues

* In spring 1995 the Haemophilia Society began a campaign for a scheme similar to that provided for HIV sufferers to be provided for haemophiliacs infected with hepatitis C. The campaign has been supported by a number of MPs of all parties. The Society's

request for financial help for this group was turned down by the previous administration in October 1996, mainly on the grounds that patients received the best treatment available at the time, treatment which was essential to their survival and, in the absence of negligence on the part of the NHS, there was no basis for making payments.

* In answer to a group of Parliamentary Questions on this subject in June this year, Ministers said "we have agreed to give this matter careful consideration".

* If help were given to haemophiliacs, it would be difficult to justify not extending the scheme to other patients infected with hepatitis C through blood/blood products, as was agreed in the case of those of those infected with HIV.

* All of the various schemes proposed would involve the expenditure of substantial sums. The estimated costs range from £6m a year for a hardship fund available to infected haemophiliacs only, to £360m a year for lump sum payments to all those infected with hepatitis C through blood or blood products. (See Appendix C for summary and estimated costs for some options.)

* If those infected with hepatitis C through NHS treatment were given financial help, without negligence having been accepted, this would inevitably lead to increased pressure from other patient groups inadvertently affected by NHS treatment which would be difficult to defend. The scheme could then quickly develop into a general no-fault compensation scheme, which would involve huge expenditure thereby reducing the sums available for direct patient care. (See Appendix D for fuller briefing.)