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Dear Male

# HAEMOPHILIA AND HEPATITIS C

Your letter of 20 November asked for short briefing on this issue, together with a summary of the line the Prime Minister might take in a meeting with MPs. I hope the attached is helpful - with apologies for the delay in responding.

Your

**GRO-C** 

JOHN HOLDEN
Private Secretary



## HAEMOPHILIACS AND HEPATITIS C: Background

- 1. About 3000 non HIV positive people with haemophilia and are believed to have been infected with HCV as a result of NHS treatment. Additionally the "look-back" exercise, looking at previous recipients of blood from donors who have subsequently been shown to be HCV positive after September 1991, is likely to identify a further 3,000 HCV infected people who are alive. The Department has denied negligence and Ministers have refused calls for compensation.
- 2. Although patients receive the best treatment available based on existing knowledge it has to be recognised that not all medical interventions are risk free. Risks may be evident at the time of treatment or may be discovered later. If payments were to be offered for each such incident we would soon slip into a general no fault compensation scheme. The Government is opposed to a no-fault scheme, which would be unworkable and unfair.

#### Comparison with HIV

- 3. The Government accepted that the patients who, tragically, contracted HIV through NHS treatment were in a different position from others and we made provision for them because of their very special circumstances. Those affected were all expected to die within a very short time and were subjected to significant social problems, including ostracism. In the case of the infected haemophilia patients, the problems of HIV were superimposed on the health, social and financial disadvantages they already suffered because of their hereditary haemophilia.
- 4. Hepatitis C is different from HIV. Many people infected with Hepatitis C may enjoy a long period without any symptoms appearing. 50% of sufferers may progress to chronic hepatitis with varying degrees of good and ill health. Perhaps 20% of infected patients will develop cirrhosis, a progressive destruction of the liver, that may take 20 to 30 years. The majority of those years will be trouble free in terms of ill health and only a small percentage will actually die of liver disease.

### Haemophilia Society Campaign

5. The Haemophilia Society have stated in the press release launching their current campaign that over 40 haemophilia patients have died through infection with hepatitis C virus. It is important to retain a clear sense of proportions and timescales. The figures quoted by the Society relate to the 5 year period 1988 to 1993. In 1993 12 haemophilia patients died with the cause of death shown as liver disease. This was out of 126 haemophilia patients known to have died in that year. Of these 12, 8 were also HIV positive. Without seeking to minimise the tragedy these are small numbers when weighed in the balance of the good that treatment has brought to many of these and countless others.



#### Departmental action

6. Discussions are taking place between the Department and the Directors of the Haemophilia Centres about what needs to be done, including development of further good practise for the treatment of HCV positive haemophilia patients, and to ensure that they have ready access to treatment centres. The Department is supporting an initiative by the Haemophilia Society to undertake a study into the best way to support its members who are infected with the virus.

### Republic of Ireland

7. The Irish government has proposed the setting up of a tribunal to determine payments for individuals infected with Hepatitis C, from blood or blood products, as well as women following use of anti-D. The levels of compensation being offered are fairly low. DH officials have had discussions with Irish officials, but do not see any reason for DH to change its stance. Most countries have also decided not to make payments to those who have contracted Hepatitis C, even where they have made such payments where HIV has been contracted.