

## **BACKGROUND NOTE**

### **Cause and extent of infection**

About 3,000 non HIV positive people with haemophilia - and possibly a further 3,000 people who are still alive and who had blood transfusions prior to September 1991 (although the figures for blood transfusion people could be very much higher) - are believed to have been infected with HCV as a result of NHS treatment. Those with haemophilia were infected before blood products, including those used to treat their condition, began to be heat treated to destroy viruses in 1985. (Those infected through blood transfusion were generally so infected before blood donations began to be tested for hepatitis C in 1991 - as soon as reliable tests became available.)

### **Haemophilia Society Campaign**

In spring 1995 the Haemophilia Society launched a campaign to obtain financial help (they insist that they are not seeking "compensation") for haemophilia patients infected with hepatitis C. In February the Society produced a "Haemophilia and Hepatitis Research Project Report" relating the experiences of people with haemophilia who have also contracted hepatitis C. In March Ministers met representatives from the Society who put forward proposals for Government action, including financial assistance.

Most recently, the Society wrote to John Horam, on 18 June asking, among other things, for the Government to set up a £20 million Trust Fund to make payments to those infected who were in financial need, and their dependents, and also to make payments of £10,000 per person to those who had been infected. It also called for increased resources for treatment, research, and education, and for the Society's own work.

John Horam's reply of 1 October, whilst emphasising the Government's sympathy for those infected in this way, refused the request for compensation, on the basis that the NHS had not been negligent, the patients concerned had received the best treatment available at the time, and that the significant sums involved could be better spent elsewhere in the NHS. However, he reiterated his willingness to listen to further arguments. He also highlighted the funding the Department was providing for research into hepatitis C and ongoing support being provided to the Haemophilia Society through the Section 64 grant scheme.

The Society's response of 3 October expressed their disappointment and argued that, while they agreed that negligence was not a factor, there was nevertheless a strong moral case for a payment scheme comparable to that introduced for those infected with HIV in similar ways.

### **Support for the campaign**

John Marshall MP had a meeting with Health Ministers on this subject in April, and with John Horam in June. At the latter Mr Marshall put forward proposals for more limited financial assistance schemes, for example, restricted to those developing cirrhoses. Very significant costs still proved to be involved.

There have been 3 EDMs since the summer of 1995 in support of the Society's campaign, each attracting quite a large number of signatures from all parties. There have also been a number of parliamentary questions, including 3 tabled by Alfred Morris in March and April. He also instigated an adjournment debate on the subject in May.

### **Comparisons with HIV**

The Government accepted that the patients who, tragically, contracted HIV through NHS treatment were in a different position from others and made provision for them because of their very special circumstances. Those affected were (at the time) all expected to die very shortly and were subjected to significant social problems, including ostracism. It was also argued that this was a very special case and would not set a precedent for future claim of a similar nature.

Hepatitis C is different to HIV. Many people infected with hepatitis C may enjoy a long period without any symptoms appearing. 50 per cent of sufferers may progress to chronic hepatitis with varying degrees of good and ill health. Perhaps 20 per cent 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.