

## GENERAL BACKGROUND

1. A Haemophilia Society campaign, launched in March 1995, called for a number of actions to address the problems of haemophilia patients who have contracted hepatitis C from contaminated blood products, including financial assistance similar to Government help for HIV infected haemophilia patients.

2. DH Section 64 funding for the Society's Hepatitis "ABC project" enabled the society to employ a research worker to look at the needs of haemophiliacs infected with Hepatitis, although DH was not directly consulted about the detail of the approach taken. An interim report published on 4 December 1995 described the experiences of a number of members with HepC. Ministers written response at the time said that they wanted to give the report the attention it merited and they were reading it carefully, although their first impression was that although it appeared to relate to a relatively small sample of commentators it graphically described the range of problems experienced by people co-infected with haemophilia and Hepatitis C "in a way that cannot help but arouse great sympathy." The letter went on to reaffirm the government's opposition to paying compensation, in the absence of fault, and view that resources could best be used to improve treatment, research etc. It suggested a meeting in the New Year.

3. The Society sent the final report to Ministers on 20 February (see appended sheet for summary). The associated press release says that the report examines in detail the services which people with haemophilia need from both haemophilia centres and the Haemophilia Society. Treatment, counselling, information and self-help groups are mentioned. The press release recognises what the Government has done in dealing with problems about treatment with alpha interferon and in funding research. It calls for further Government action in terms of :

- Financial help for those infected with Hepatitis C through NHS treatment, especially those who are already ill and dependants of those who have already died
- Funding for, and clear guidance on, treatment, counselling and management of Hepatitis C
- Further research, particularly on combination therapies
- a public education programme about Hepatitis C
- funding for the Haemophilia Society in delivering information, advice and support
- funding to ensure that plasma-based products are replaced by recombinant products.

It also calls for a meeting with DH Ministers. The Society' letter to SoS covering the report took a similar line.

4. The majority of haemophilia patients treated prior to 1985, when measures were introduced to destroy viruses in Factor VIII products, will have been infected with hepatitis C through NHS treatment. The precise number of patients infected in this way is unknown. Best estimates suggest about 3000 haemophiliacs not covered by the HIV payment scheme have been infected. In addition it is expected that some 3000 live patients will be identified as a result of the lookback exercise of patients who had blood transfusions.

5. 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.

6. In the 1980s, the Government accepted that the patients who, tragically, contracted HIV through NHS treatment were a very special case and unusually made provision for them. Those affected were all expected to die very shortly and were subjected to significant social problems, including ostracism.

7. Ministers have said in debates in Parliament that they have great sympathy with those who have contracted Hepatitis Cs through blood or blood products, but that as no fault nor negligence on the part of the NHS has been proved, they have no plans to make special payments. They have also said that they are willing to consider suggestions for a limited scheme to help those affected, but have given no undertaking to accept any such proposals.

8. Steps already taken by the Department to improve understanding and treatment of the disease include :

- (i) Support for an initiative by the Haemophilia Society to undertake a study into the best way to support its members who are infected with the virus, with a grant of over £90,000 this financial year and £117,000 in 1996-97 (on top of core funding of £35,000 this year and £38,000 in 1996-97).
- (ii) With other Health Departments - a UK wide look back exercise to trace, counsel, and where necessary treat those who may be at risk of hepatitis C through blood transfusion. The start of the exercise was announced on 4 April 1995.
- (iii) Support for the British Liver Trust with assistance through the Sec 64 grant scheme. This includes a grant specifically to deal with the additional workload of advising patients infected with the virus.
- (iv) The Standing Group on Health Technology have identified the evaluation of the use of alpha interferon in the treatment of hepatitis C as a top priority for the NHS. This is being actively taken forward by the Medical Research Council.
- (v) Work is being taken forward on establishing a national registry of transfusion acquired Hepatitis C infection of a known date of acquisition.
- (vi) Research proposals are being sought on establishing the prevalence, transmission routes and natural history of Hepatitis C infection.
- (viii) A ministerial commitment to investigate allegations of problems of access to alpha interferon. A few cases were identified by the Society, all of which have been resolved.

**NOT TO BE DISCLOSED**

9. At the request of PS(H), officials put forward a submission on 9 February which discussed and gave estimated costs for various options for financial help to those affected, including schemes limited to those becoming seriously ill.