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HAEMOPHILIA SOCIETY REPORT ON THE IMPACT OF HEPATITIS C

Line to Take

The Haemophilia Society does valuable work for people with haemophilia. Their latest report will be studied carefully, and Mr Horam will be meeting representatives of the Society on 6 March. On the 6 points referred to in the Society's press release:-

- The Government has great sympathy for those infected with hepatitis C as a result of NHS treatment. But these patients received the best treatment available in the light of medical knowledge at the time. No fault or negligence on the part of the NHS has been proved, and we have no plans to make special payments.

- It is Government policy to allocate NHS funds to purchasers of health care and to leave it to them to decide what services they wish to purchase to meet local needs within the framework of national policies and priorities. They, in consultation with local providers are in a far better position to know about local needs than Ministers or central government officials.

- 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. Work is also being taken forward on establishing a national registry of transfusion acquired Hepatitis C infection of a known date of acquisition. Research proposals will soon be sought on establishing the prevalence, transmission routes and natural history of Hepatitis C infection.

- The case for a targeted public information campaign on hepatitis C will be considered in the light of competing priorities.

- The Haemophilia Society is receiving grants totalling £126,900 from the Department in the current financial year. These will rise to £155,000 in 1996-97 - an increase of over 22%.

- The safety of blood products depends on a number of factors which taken together reduce as far as possible the risk of viral transmission. These include screening of donors, plasma pool testing and the ability of the manufacturing process to remove and inactivate viruses. Recombinant Factor VIII is significantly more expensive than Factor VIII derived from human plasma, and clinicians need to be convinced that the extra costs involved have demonstrable benefits.

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 . An interim Haemophilia Society report published on 4 December 1995 described the experiences of a number of their members with HepC.

3. The Society sent the final report to Ministers on 20 February. Their press release, coinciding with this, 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.

3. 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.

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 Department accepted that the patients who, tragically, contracted HIV through NHS treatment were a very special case and the Government made provision for them because of their very special circumstances. 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.

9. Mr Horam has agreed to meet officials of the Haemophilia Society on 6 March to discuss the report.

NOT TO BE DISCLOSED

10. 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. This did not recommend that any such scheme be adopted.

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