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HAEMOPHILIA SOCIETY- REPORT ON FINANCIAL ASSISTANCE FOR HAEMOPHILIACS WITH HEPATITIS C

Issue

1. Michael Connarty MP, Chair of the All Party Parliamentary Group on Haemophilia, has written to Ministers requesting a response to the Haemophilia Society's proposal for financial assistance for haemophiliacs infected with hepatitis C through NHS blood products. In view of the lapse of time you have agreed that a response should now been made to the Haemophilia Society and Michael Connarty that there is no prospect of a special payments scheme being set up for haemophilia patients in England.

Background

2. On 12 June 2002 you met with representatives of the Haemophilia Society and Michael Connarty MP when they presented you with the report from the Haemophilia Society's Hepatitis C Working Group. It was agreed that we would consider the report and respond in due course.

The Report

3. The Report details a package based on the Canadian Hepatitis C compensation scheme. The scheme is based on an estimate of 3641 people with haemophilia and hepatitis C as at 1 January 1993. The model provides for payments to be made according to the stage the liver disease (resulting from hepatitis C) has reached with a formulae being used to calculate the amount of the award. There is also an allowance to be made for dependants and family, for loss of earnings, inconvenience of drug therapy, expenses and costs towards care. The report details an extremely generous package.

4. The estimated cost of the scheme over a 10-year period is £52.26 million per year. The total could vary depending on inclusion or exclusion of certain elements e.g if only deaths from liver disease, rather than all deaths, were compensated savings could be around £100m in total.

5. We asked the Department's Economic and Operational Research Branch to look at the Report in detail. The proposal is for full compensation for loss of earnings in addition to a series of one off payments linked to progression of the disease: However, there is no justification offered for the level of payments.

Proposed Scheme costs over 10 years

- The proposal is for full compensation for loss of earnings (in Canada it is 70%).
- The proposal includes compensation (£11.7m over 10 years) for those haemophiliacs with HIV through infected blood products. Compensation payments are already made to haemophiliacs with HIV through the Macfarlane Trust
- The questionnaire used to survey haemophiliacs with hepatitis C for the Report, implicitly attributes all disability to hepatitis C. To assess expenditure and compensation properly there would need to be a control group of haemophiliacs who were not infected with hepatitis C.
- The payments linked to death (£56.1m over 10 years) and for dependants and family of the deceased (£25.0m) and for loss of guidance, care and companionship (£25.0m) also assume that hepatitis C is the cause of death.

Item	Cost £ million over 10 years
Cash payments	59.7
Loss of Earnings (=60.4 + 143.8)	204.2
Drug therapy	6.8
Costs of medication	Nil
Costs of care	24.2
Out-of-pocket expenses	1.8
For HIV as well	11.7
For deceased prior to 1/1/02	56.1
For dependants & family of the deceased	45.1
For loss of guidance, care and companionship	25.0
Future costs over the next 10 years for those whose conditions deteriorate & those who die, including payments to family /dependants of deceased	88.0
Total	522.6

Other Schemes

6. We are aware of four countries with compensation schemes for haemophiliacs infected with hepatitis C through blood:

- Canada
- Republic of Ireland
- Hungary
- Sweden

Canada and Ireland set up schemes because patients in both countries were being infected with hepatitis C after it became possible to remove the virus from blood products. We understand that the Canadian scheme is limited to those people infected with hepatitis C between 1 January 1986 and 1 July 1990 (in England, action was taken to virally inactivate blood products in 1985).

Hungary has a no fault compensation scheme for all people whose health has been damaged as a result of medical treatment. In Sweden, compensation is available from pharmaceutical companies but is limited to the social and psychological suffering the virus has caused, not for the physical damage. None of the situations in these countries offer parallels for the UK.

Scottish Executive proposals for compensation

7. As you know the proposals announced in January from the Scottish Executive (SE) for a financial assistance scheme are:

- Paying a lump sum of £20k to all people living who have hepatitis C through blood and blood products;
- Paying a further £25k to those who have developed cirrhosis

If we were to adopt the same policy in England we have assessed estimated cost to be around £150m.

8. We are still waiting to hear from the Law Officers as to whether the compensation scheme is within the devolved competence of Scottish Ministers and, if the SE were to introduce a scheme which the Law Officers thought was outside competence, they would consider it appropriate to either raise proceedings in the Court of Sessions or to refer the issue to the Judicial Committee of the Privy Council. Decisions on this will now not be taken until after the Scottish elections

Conclusion

9. The sum proposed in the Society's report is £522.26m over 10 years, however even if we were to accept a reduced payment scheme based on the lines of the SE proposal (if accepted), the position remains that there is no further funding available over the next three years. There is also a major concern that any compensation payment made to haemophiliacs with hepatitis C could open the floodgates for other groups who are currently seeking compensation

10. SofS has consistently held that compensation is not payable to haemophiliacs infected with hepatitis C and that an exception cannot be made to the general rule that compensation or financial help is only given when the NHS or individuals working in it have been at fault.

Action

11. Draft letters are attached at Annex A for Karin Pappenheim, Chief Executive of the Haemophilia Society and Michael Connarty MP advising that we have now considered the Society's proposal, but that our position remains that compensation is not payable.

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Annex A

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Michael Connarty MP

Thank you for your letter of 5 November 2002 about the Haemophilia Society's proposals for a financial assistance scheme to support people with haemophilia who were infected with hepatitis C through NHS blood products and also your further letter of 26 November about proposals announced by the Scottish Executive for financial support for people with haemophilia and hepatitis C. I am very sorry for the delay in replying to these letters.

Following the meeting in June last year, which you attended with representatives of the Haemophilia Society, the Department's officials have spent some time looking at the proposals contained in the Society's document and have also looked at other schemes currently in operation such as the Vaccine Damage Payment Scheme. However, the conclusion remains that the Government cannot support the Society's claim for financial assistance. I have enclosed a copy of my letter to Karin Pappenheim, Chief Executive of the Haemophilia Society, explaining the reasons in more detail.

You have also raised the issue of equity between England and Scotland following the publication on 6 November of the report from the Scottish Expert Group on Financial and other Support, for people with infected with hepatitis through blood and blood products.

I am sure you are aware that Malcolm Chisholm announced in January more details of the proposed scheme. I have been advised that officials from the UK government departments concerned and the Scottish Executive are looking at the Scottish Expert group's findings and their implications for the interface between the social security system and devolved responsibilities but that currently no conclusions have been reached. The Expert Group's report relates only to those people who contracted hepatitis C from blood and blood products provided by NHS Scotland. The outcome of these discussions will not have any effect on our position on payments for haemophilia patients in England.

HAZEL BLEARS

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Chief Executive

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**REPORT OF THE HEPATITIS C WORKING PARTY
TO THE HAEMOPHILIA SOCIETY**

I am writing to you about the Haemophilia Society's report on proposals for a financial assistance scheme for people with haemophilia infected with Hepatitis C through contaminated blood products.

I am sorry it has taken so long to respond to you but as you know I agreed at our meeting in June last year that we would thoroughly consider the proposals contained in your report. I appreciate the time and effort that went into the production of your comprehensive report and it was extremely helpful to see a fully costed scheme.

I appreciate that people with haemophilia and hepatitis C face many difficulties in their daily lives not only with continuing health problems but also financial struggles and that your report contains a proposal, which would certainly ease those difficulties. My officials have looked at the proposal in detail, as well as looking at other payment schemes, including the Vaccine Damages Payment Scheme, the Criminal Injuries Compensation Scheme and schemes in other countries for haemophilia patients with hepatitis C. However, all of these are very different and were set up in very specific circumstances. I realise that your proposal could also provide the basis for a modified scheme and I have taken all of these factors into account when reaching my decision. However, I have concluded that there is nothing here which changes the Government's longstanding decision on this issue. Although I realise that this will be disappointing news for the Society I cannot support your proposal for a payment scheme.

I was pleased that we were able to find extra funding to provide recombinant clotting factors for all haemophilia patients and I appreciate the input the Society is providing to the Department's Recombinant Clotting Factors Working Group.

I am copying this letter to Michael Connarty MP, Lord Morris of Manchester and Chris Hodgson.

HAZEL BLEARS