

*Caring for people with bleeding disorders*



H1M16/2?

H1M8?

THE  
HAEMOPHILIA  
SOCIETY

UNITED KINGDOM

Richard Gutowski  
Head of Blood Policy Division  
Department of Health  
Skipton House  
80 London Road  
LONDON  
SE1 6LH

17 October 2003

Chesterfield House  
385 Euston Road  
London NW1 3AU  
Helpline: 0800 018 6068  
Admin: 020 7380 0600  
Fax: 020 7387 8220  
Email: [info@haemophilia.org.uk](mailto:info@haemophilia.org.uk)  
WebSite: [www.haemophilia.org.uk](http://www.haemophilia.org.uk)

Dear Richard

**Hepatitis ex gratia scheme**

Thank you for inviting the Society to meet you and colleagues at the Department this week to discuss the proposed scheme. Based on the information you provided at that meeting, I have now had an opportunity to consult the Society's trustee board, and am writing to let you know our formal response to the proposed design of the scheme as we understand it.

The Society clearly welcomes the government's acceptance of the principle that people who were infected with hepatitis through their NHS treatment should receive payments. We very strongly support the government's intention to disregard these payments for tax and benefits purposes, and are very pleased that awards made under the scheme will be not decided by means testing. The commitment to continue the scheme into the future for as long as the claimant group are alive is extremely positive, as this will help allay some concerns about those whose health may deteriorate seriously due to the virus.

However, we have some very significant concerns. Overall, we are very disappointed by the actual sums of money to be offered (£20,000 for those with hepatitis and £25,000 for those with cirrhosis), which fall very far short of those proposed by our own expert working group and by Lord Ross's independent expert group in Scotland.

*Furthermore, as currently formulated the scheme would provide nothing for some of those most in need who have suffered particularly as a result of hepatitis specifically*

- a) it would include no provision for those who have died of hepatitis, who arguably have suffered the worst outcome from their infection HCV.
- b) it would provide nothing for those who have cleared the virus through treatment, ignoring the distress and suffering they have undergone both prior to and during this very onerous and painful treatment.
- c) by opting for cirrhosis as the trigger for the higher payment of £25,000, the scheme excludes many who may be suffering serious, advanced liver disease and liver damage: our estimates show there are some 1500 people in this advanced disease category compared to 480 in the cirrhosis and decompensated liver categories.
- d) the scheme does not properly include the HIV/HCV co infected group whom we understand would be eligible only for the higher £25,000 payment in case of cirrhosis - despite the evidence that co infection presents a greater risk to health and liver disease has become the leading cause of death within this group.

In view of these concerns, the Society would not find it possible at the moment to support the government's proposed package. We therefore hope to have urgent discussions with ministers and officials about these points, recognising that to a degree some of the improvements we seek may be political decisions. Meanwhile, we shall continue to raise our concerns through the All Party Group on Haemophilia and such other channels as are available.

Yours sincerely

**GRO-C**

Karin Pappenheim  
Chief Executive