

HAEMOPHILIACS INFECTED WITH HEPATITIS C

NOTE OF A MEETING WITH JOHN MARSHALL MP AND SIR GEOFFREY JOHNSON-SMITH, 25 JUNE 1996

Present

PS(H)

John Marshall MP

Sir Geoffrey Johnson-Smith MP

Marguerite Weatherseed

1. Mr Marshall outlined the difficulties facing haemophiliacs infected with hepatitis C. While the condition was not as severe as HIV, it could nonetheless be very debilitating. This was a tragedy for haemophiliacs, who had already overcome significant difficulties in an attempt to lead a normal life.
2. Mr Marshall explained that the Haemophilia Society had two key demands:
 - i) To award an additional £20m to the Macfarlane Trust to make provision for haemophiliacs facing hardship;
 - ii) To award £10k to each haemophiliac infected with HepC (total cost £30m)

He suggested that the Government should, at the very least, agree to the first of these demands. If nothing were offered, the Haemophilia Society would continue and intensify its current campaign.

3. Mr Horam remarked that the demands put forward by the Haemophilia Society were very costly, especially since any award would have to cover infected non-haemophiliacs as well. On that basis, the total cost of the Haemophilia Society's demands would be £80m. Mr Marshall's own proposals for a scheme which restricted payments to those who had developed cirrhosis would cost £40m upfront, with another £40m over ten years. While this option would be cheaper in the short term, the cost would be similar over the longer term.

4. Mr Horam stressed that it would be very difficult to justify payments of this magnitude with so many competing demands on the health service; this was money which might otherwise be spent on patient care. Mr Marshall acknowledged this point and explained that he was keen to explore alternative sources of finance. For instance, he wondered whether the cost might be met through the Government's contingency reserves, as had been the case with HIV. Mr Horam pointed out that this was a matter for Treasury, but thought it was extremely unlikely to receive support. A second option might be a grant from the National

Lottery. Mr Horam was not sure whether this would be appropriate, but offered to investigate the criteria for eligibility. As a third option, Mr Marshall wondered whether the pharmaceutical industry could be persuaded to make an out-of-court settlement, as Bayer had done in the US. Mr Horam did not consider this likely, since the situation in the UK was somewhat different.

5. Mr Marshall and Sir Geoffrey summarised their position, which was to urge Ministers to accede to at least some of the Haemophilia Society's demands (although they stressed this was not an "Edgeware scenario"). In their view, the current campaign by the Society would intensify, making some form of payment inevitable in the end. It would be less damaging and probably cheaper to get the matter settled now.

6. Mr Horam warned Mr Marshall and Sir Geoffrey that they should not be over-optimistic. However, the Haemophilia Society's demands were under consideration, and he was particularly keen to examine their demands for progress in areas such as support, public education and research which, he felt, were more productive areas for expenditure.

MMW