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GRO-C

Miss Murie DS/SoS

From : Ann Towner CA OPU2
Date : 19 April 1996
Copy : See appended list

COMPENSATION FOR HEPATITIS C - MEETING WITH JOHN MARSHALL MP 29 APRIL

1. Ms Jarvis's E mail of 27 March notified us that the meeting had been deferred from 27 March to 29 April. I attach a revised briefing pack which has been updated where relevant in respect of developments since material was submitted on 25 March.

2. The briefing is under the following heads :

- * Compensation
- * General background
- * Summary of recent representations from John Marshall MP
- * Annex A - Haemophilia Society proposed compensation
Annex B - Submission to Ministers on Mr Marshall's proposal

3. The official attending the meeting will be Mr Pudlo.

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Copy recipients (minute only, except for Mr Pudlo)

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Mr Guinness CA-OPU
Mr Pudlo CA OPU2
Dr Harding EOR3
Dr Nicholas HP3B
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Mr Sharpe HP4
Mr Waterhouse HCD SCS
Mrs James SOLB4
Mr Young HCD SCSB1
Mr Snedden SO
Mr Williams WO
Mr Baker DHSS NI

COMPENSATION

Line to take

1.1 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. The Government remains opposed to no-fault schemes.

1.2 Our view remains that the best way the government can help is to encourage research, and best treatment for those infected, as well as supporting voluntary groups working with those infected. I really do think it is better to spend NHS money on treating patients than on paying compensation to people who had the best possible treatment available at the time. [See DH action para 2.8]

If pressed for a scheme based on paying people with cirrhosis

1.3 Our objections to a no-fault scheme are not simply financial. Furthermore, there are problems about any scheme based on making payments to people who have developed cirrhosis. Because it is already over 10 years since any haemophiliacs were infected, there would be quite a substantial amount payable now, though the subsequent costs would be spread over a number of years. We also do not think we could confine compensation to haemophiliacs - it would have to be extended to people infected through blood transfusion, as we did with HIV infection. Again there would be quite a substantial amount payable now, with subsequent costs spread. There are also problems about diagnosing cirrhosis. Finally, it is clear that the Haemophilia Society would not be satisfied with such a scheme.

Background

1.4 John Marshall is a strong advocate of compensation for those haemophiliacs who were inadvertently infected with hepatitis C through blood products. He has argued that this group is in no different a position to those who have been compensated for HIV infection in identical circumstances.

1.5 A campaign seeking a range of benefits for infected haemophiliacs has been waged by the Haemophilia Society since 1995. Most recently they set out their aims in a letter dated 19 February to SofS, which accompanied a copy of their research report on the effects of haemophilia and hepatitis C (details at paragraph 2.3).

1.6 The Society are well aware of the Government's position. They accept that no negligence was involved in infecting their members but argue that natural justice demands equal treatment with the HIV infected group. Ministers' line has been that the HIV group were in a special position because of the nature of the disease and the ostracism that it attracted. [In evidence to the Health Committee last year SofS, reaffirming the Government's opposition to no-fault negligence, acknowledged that payment to the HIV group was illogical.]

1.7 The cost to public funds of a settlement has not been a significant factor in the public debate. However the Society were encouraged by what they saw as a Ministerial expression of interest in a proposal by John Marshall during the adjournment debate on 13/12/96. This was to restrict payment to those who had developed cirrhosis. In making this suggestion it is likely that John Marshall believed that progress could be made if an affordable solution could be identified.

1.8 PS(H) met representatives of the Society on 26 March when the Society presented their proposals for further Government action (Annex A). We know that John Marshall has been given a copy of this for his meeting with SofS but it is not known to what extent he will represent the Society's position. Although allied to their main aims he has tended to act independently. It is clear that Mr Marshall's proposal would not be acceptable to the Society as it would split their membership (SofS will recall meeting the Manor House Group with Roy Hattersley). They want a scheme along the lines of the HIV scheme, but at higher levels, and including an element of further compensation for people infected with both HIV and hepatitis C. The Society are expecting a response to their proposals for compensation and will be looking to feedback from the meeting with John Marshall for a signal.

Costs

1.9 Prior to the meeting, at PS(H)'s request, officials had submitted a range of costed options, including schemes limited to those becoming seriously ill. This is not public knowledge and would risk giving the impression that the Government is considering compensation if it became known. The submission emphasises that, although the Society's interest is limited to its own group, in practice it would be difficult to confine any settlement to haemophiliacs.

1.10 Officials have also looked specifically at the option, believed to be favoured by Mr Marshall, of compensating only people who develop cirrhosis. A copy of the submission is attached (Annex B). On the basis of a number of sometimes quite heroic assumptions the costs of such a scheme are estimated as follows:-

	Haemophiliacs £ million	Blood Transfusion Recipients £ million	Total £ million
Payable now	21	20	41
Payable each year until 2005	2	2	4
Payable each year from 2006 to 2011	0	2	2
Payable each year from 2012 onwards	0	*	*

* = less than £1 million.

The submission also draws attention to the difficulty in diagnosing cirrhosis in the absence of a liver biopsy. The table above is based on payments of £60,000 (the average paid under the scheme for compensating haemophiliacs infected with HIV).

1.11 Since the meeting the Society have presented, informally, more detailed information to officials about the level of settlement they are seeking. Again on the basis of a number of assumptions the cost for haemophiliacs alone has been estimated at £147 million now, £16 million a year for 10 years, and £4m million a year for a further 10 years.

1.13 The Republic of Ireland has introduced a compensation scheme administered by a tribunal. It made its first awards on 11 March 1996. The amounts awarded have been reported as ranging from £35,000 to a woman infected in 1971 (but hepatitis free), to £251,900 to a woman in her 40s who "is likely to develop cirrhosis". The latter award included £140,000 for pain and suffering; the remainder being for loss of earnings and home help expenses. These sums, particularly at the top end of the range, are very much higher than any that have been included in our calculations, or those of the Society.

GENERAL BACKGROUND

Haemophilia Society Campaign

2.1 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.

2.2 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.

2.3 The Society sent the final report to Ministers on 20 February. This looked at the services which people with haemophilia need from both haemophilia centres and the Haemophilia Society. Treatment, counselling, information and self-help groups were mentioned. The press release recognised what the Government has done in dealing with problems about treatment with alpha interferon and in funding research. It called 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.

Numbers infected with Hepatitis C and severity of disease

2.4 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.

2.5 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.

Government line

2.6 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.

2.7 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.

Departmental action

2.8 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.
- (vii) 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.

RECENT REPRESENTATIONS FROM JOHN MARSHALL MP

Adjournment Debate 13/12/96

John Marshall drew comparisons with payments made to those infected with HIV. Recognising that not all infected with Hepatitis C suffered any ill effects, he suggested a compensation scheme limited to those who went on to develop cirrhosis of the liver.

PS(H)'s response included "I would be interested to hear details of the of the relatively modest and restricted proposals which my hon. Friend made during the debate".

EDMs

One of 5 sponsors of EDM 3 of 15/11/95 -calling on government to acknowledge that 3,000 haemophiliacs have been infected with hepatitis C through NHS treatment, and to consider compensation (as for those who contracted HIV)

Also sponsor of EDM 1219 of 8/6/95, to similar effect (mentioning 50 deaths from hepatitis C).

PQs (since Jan 95)

PQ 175 - answered 5/12/95 - asking what representations received..

PQ 3867 of 8/6/95 - " " " "

Correspondence

POH 3/43091/370 : constituent John Cheetham - allegations of insufficient funds to offer alpha interferon treatment. Reply sent March 1996 confirmed that treatment will in fact be provided . No other POs since July 1995.