

Secretary of State

From: R M Gutowski
Date: 3 October 2003
Copy: As attached

HEPATITIS C EX-GRATIA PAYMENT SCHEME

Purpose

1. To update you with progress on setting up the Scheme and to seek your agreement on the various component parts.

Timing

2. Urgent – you have expressed a wish that the announcement of the parameters of the Scheme is made quickly.

Background

3. On August 29 you and the Devolved Administrations made announcements about the Hepatitis C ex-gratia payment scheme. Since the announcements we have been working to put together the parameters of the Scheme and significant progress has been made.

Parameters of The Scheme

4. We met with colleagues in the Devolved Administrations and agreed that the Scheme should be identical to that proposed by Scotland ie initial payment of £20k plus an additional £25k on reaching a medically defined trigger point. Payments only to those alive when the scheme was announced on 29 August and who have not cleared the virus spontaneously. Within the basic criteria there are a number of exceptions and variations and these are listed at Annex A. These refer in the main to those patients who have received payment elsewhere or who have undergone some sort of medical treatment as a result of the infection.

Medically Defined Trigger

5. A key element of the discussions has been the medically defined trigger for the additional payment. The detection of hepatitis C related disease relies upon invasive tests such as liver biopsy, a procedure with a high risk of bleeding. We would obviously wish to avoid relying on such tests, particularly for haemophiliac patients, where they have not been carried out as part of clinical management for individual patients. We are therefore in the process of setting up a small meeting with liver specialists to explore whether there are a series of non-invasive tests that could be used reliably to predict the particular stage of liver disease (possibly cirrhosis) chosen to trigger the second payment.

MacFarlane Trust

6. We have also met with the Chairman and Chief Executive of the MacFarlane Trust and a representative of the Haemophilia Society to discuss whether they would be prepared to take on the responsibility of administering the Scheme for the whole of the UK. They have agreed in principle subject to the condition that the scheme was in the interests of their registrants and knowing the exact details. I therefore intend to meet with the Trust next week to go over the scheme with them so, if they agree, work can commence on drawing up the Deeds and putting the necessary structure in place.

Other Outstanding Issues

7. We now have confirmation from Wales that they agree that the Scheme is a devolved matter for them. In addition officials in DWP have advised their Secretary of State that payments be disregarded in full. To introduce such a disregard will require negative regulation and DWP's likeliest start date for amending regulations is April 2004. DWP have requested that it would be helpful if the announcement of the detail of the scheme included reference to the social security elements. They have also asked whether you could write to Andrew Smith seeking his formal agreement to the disregard and to Dawn Primorolo to ignore the payments in tax credits. If you agree we can quickly draft the letters for your signature early next week.

Patients Associations and Other Interested organisations

8. Any announcement will clearly generate a degree of reaction from patients particularly at the level of the payments we envisage and the fact that there will be no payment to dependants. The Haemophilia Society have already stated that they could not accept a scheme which contained the above elements and that they would want discussions on the detail of the Scheme before any final decisions were made. Given the warm welcome to the announcement we received in Parliament we thought it would be a good idea to invite the Society to the meeting we intend having with the Trust. I realise that you have expressed reservations about involving pressure groups in such discussions but in this case it could prevent some criticism when the announcement is finally made. Are you happy for us to have such a meeting?

Timing Of Announcement

9. Provided we get agreement from the MacFarlane Trust to run the Scheme on our behalf and the meeting on 14 October agrees upon a medically defined trigger an announcement could be made on schedule late October. Once final details of the Scheme are agreed between Officials it would be helpful if you could write to the other Health Ministers and Chief Secretary to the Treasury setting out the proposed scheme, seeking their formal agreement and proposing a simultaneous announcement

Conclusion

10. I would be grateful for your agreement on the criteria of the scheme plus the exceptions and variations. Also that we meet with the MacFarlane Trust and the Haemophilia Society and that once discussions have concluded you write to the other Health Ministers and the Treasury and we move to announce the Scheme late October. In addition that you agree to write to Andrew Smith and Dawn Primorolo on the Social Security and Tax issues.

R M GUTOWSKI
PH6.6
633B SKH
Ext **GRO-C**

Cc
Lee McGill – PS/CMO
Robert Finch – Ps/PS(PH)
David Harper – PH
Graham Bickler – PH6
Vicki King – PH6
Richard Douglas – FD
Martin Campbell – FD
Mary Trefgarne – SOL
David Daley – COMMS
Robert Holmes – DWP
Gerald McHugh – SO
Simon Stevens – No 10
Richard Olszewski – Pr Off
Steve Bates – Pr Off
Paul Corrigan – Pr Off
Jill Taylor – PH6
David Reay – PH6
Bob Stock – SE
Cathy White – WA
Gerry Dorrian - NI

Annex A

Exceptions and Variations to the Hepatitis C Scheme

1. People who have cleared the virus spontaneously would not be eligible for any payment.
2. People who have received payments linked to HIV infection from the MacFarlane trust or the associated Government scheme of payments shall not be eligible for the basic payment. They will receive the additional payment if they reach the medically defined trigger point.
3. People who clear the virus under treatment shall only receive the basic payment.
4. People who receive a liver transplant shall receive both the basic and the additional payment.
5. People who have received compensation as a result of a successful legal action against the NHS (or an out of court settlement in relation to a legal action) shall have that compensation/settlement deducted from the total award made under this scheme.
6. People who have received compensation as a result of a successful legal action against a product supplier shall have that compensation deducted from the total award made under this scheme.
7. People who receive payments under this scheme shall undertake not to institute further legal proceedings against the NHS or Ministers.
8. No payments shall be made to the relatives, dependants or estates of eligible claimants who were deceased at the time the scheme became operative.