From: R. M. Gutowski PH6

Date: 6 January 2004

Cc: As Attached

Hepatitis C financial assistance scheme – Announcement of details

lssue

The four health departments are now all in a position to announce the basic eligibility criteria and payment structure of the hepatitis C financial assistance scheme. We ask that you re-confirm the details of the scheme, note the outstanding issues, agree the proposed name for the scheme and agree the handling strategy to announce these details.

Details of scheme

The already agreed details of the scheme are summarised in annex A.

Outstanding issues

A number of issues regarding the administration of the scheme remain outstanding. Work is in hand to resolve each as quickly as possible, but none directly affects the announcement. These outstanding issues are –

Social security/tax disregard – In letters to you from Andrew Smith, Paul Boateng and Dawn Primorolo, DWP and HMT have agreed in principle to disregard the scheme's lump sum payments when assessing means tested social security benefits and tax charges/credits. In the case of social security disregard, the proposed new regulations must be approved by the Social Security Advisory Committee, which will meet to consider them on 4 February.

The regulations are also subject to a six-week Local Authority Association consultation period. This process cannot begin until the announcement of the details of the scheme is made, but work is in hand to ensure that this process starts immediately after the announcement. Once approved and finalised, it is expected that the regulations will come into force in April.

Medical trigger – the group of experts advising DH on the trigger point for payment of the second lump sum has agreed that it should be paid once a claimant has developed cirrhosis. However, agreement has not been reached on the test or tests that will be used to confirm this diagnosis. The group will meet again this month to finalise its recommendations. We are therefore in a position to announce the trigger point (cirrhosis) but not the non-invasive diagnostic tests.

Administration of the scheme – the Macfarlane Trust has now agreed in principle to administer the new scheme but will require support to handle inevitable enquiries from potential claimants. We are discussing handling with

them. Work on the development of the application process, level of evidence required to support claims and the structure of the trust (trustee involvement etc) is continuing. Stakeholders will be meeting to take forward this work later this month.

Funding – formal discussions of how the new scheme will be jointly funded by the four administrations have not yet begun. Each administration has already identified funds however.

Proposed name for scheme

For the joint purposes of the announcement and the drawing up of social security legislation, we now need to agree a name for the new scheme. Officials from the four health departments propose that the new scheme be called the 'Skipton Trust'. This follows the precedent of the Eileen Trust, which was named after Eileen House, the DH building where the Trust was developed. This choice will reflect the neutral bias of the scheme and ensure no obvious links with HIV.

Handling strategy

A copy of the proposed handling strategy for the announcement is attached as annex B.

Conclusion

You are asked to agree the name for the new administering Trust and that we proceed with the Devolved administrations in making a joint announcement.

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Copy list:

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Annex A

'HEPATITIS C FROM BLOOD' EX GRATIA SCHEME – DETAILS OF PROPOSED PARAMETERS AND ADMINISTRATION

SUMMARY

Eligibility and awards

- £20,000 to people who were infected with Hepatitis C as a result of being provided by the NHS with blood or blood products before September 1991 (date of introduction of donor screening).
- £20,000 to people who have been infected as a result of the virus being transmitted from a person who themselves were infected as above.
- Additional £25,000 to people who are eligible for the £20,000 award when their condition progresses to cirrhosis, liver cancer or if they have received a liver transplant.
- No payments to those who have cleared the virus spontaneously.
- People co-infected with HIV will be dealt with in the same way as those infected only with Hepatitis C.
- People who have had a liver transplant will receive both the £20,000 and £25,000 awards.
- People who have cleared the virus under treatment will be dealt with in the same way as those who still have the virus.

Payments to the 'deceased'

- No payments to dependants of people who died before 29 August 2003.
- Where people eligible on 29 August die before the scheme is in a position to make payments, awards will be made to their dependants.
- Once the scheme is in a position to make payments, awards will only be made to dependants where a claim has been received on behalf of the infected person prior to their death.

Variations and conditions

- People who have received compensation as the result of a successful legal action against the NHS (or an out of court settlement in relation to a legal action) would have that deducted from the total award.
- People who have received compensation as the result of a successful legal action against a product supplier would have that deducted from the total award.
- People who receive payments under the scheme would undertake not to institute future legal proceedings against the NHS or Ministers in relation to the situation that formed the basis of those payments.

Evidence

- Generally evidence will be judged on the balance of probabilities.
- It would be presumed that claimants with Hepatitis C who have received pooled products were infected by the product. (Virtually all haemophiliacs will fall into this category).
- No requirement for invasive tests to establish cirrhosis.

Administration

• Single UK scheme operating to common parameters in Scotland, England, Wales and Northern Ireland.

Administered by a single independent charitable Trust.

Handling Strategy

Subject to agreement of this submission, we propose the following handling strategy -

- Agree date of announcement with special advisers, press office, planning and policy teams. Officials propose that an announcement be made at the earliest opportunity (ideally week beginning 12 January) to prevent further speculation about the announcement. Press office to advise on vehicle for announcement – possibly a press statement as with the original announcement.
- In the meantime, continue liaison with devolved administrations to ensure consistent and simultaneous announcement (sharing of press statement/Q&A etc)
- Inform Macfarlane Trust (new scheme administrators) in advance of announcement to ensure they have system in place to cope with inevitable enquiries from potential claimants
- Following announcement, policy team to write to all those who have registered an interest in scheme with details of announcement (including Michael Connarty MP, chair of All Party Parliamentary Group on Haemophilia and Haemophilia Society). Reassurance given that further updates will be forthcoming (eg. on application process)
- Work continues to establish new trust with operational target of April 04 (subject to necessary social security legislation)