

Secretary of State

From: **PS(PH)**

Date: 3 December 2003

Hepatitis C Financial Assistance Scheme

Issue

1. Following your recent announcement I met with Michael Connarty MP (Chairman of the All Party Group) and the Haemophilia Society on 29 October at their request. One of the items on the Agenda was the Hepatitis C Scheme and Michael was able to bring me up to date with the views of the All Party Group.
2. It was clear that the All Party Group were very supportive of your announcement and in fact had fielded and dealt with criticism from some quarters. It became evident during the course of the meeting that both the All Party Group and the Haemophilia Society were unhappy about certain elements of the Scheme even though these have not yet been made public. The Haemophilia Society had been provided with some detail, in confidence, as part of discussions centred on obtaining the MacFarlane Trust's agreement to administer the Scheme. It is unfortunate that the Society without knowing the final details of the Scheme decided to resurrect their media and Parliamentary campaign.
3. On 3 October you were sent a submission seeking your agreement to the various elements of the Scheme (I attach a copy of the draft eligibility criteria at Annex A), three of which are of major concern to the All Party Group. In fact Michael has now written to you on behalf of the Group asking for a meeting. Leaving aside the size of the proposed payments which they claim are too low the main stumbling blocks are:
 - a) no payments to dependants of those who have died prior to the announcement of the scheme;
 - b) no payments to those co-infected with HIV
 - c) no payments to those who cleared the hepatitis C virus (HCV) following treatment.
4. It was clear from my meeting with Michael that if the scheme did not contain the above three elements he would no longer be able to

continue to support its existence. I did put to Michael the possibility of cutting the overall payment package into different pieces to accommodate some of the above but he was clear that these needed to be extra to what is currently being considered. I therefore asked the Blood Policy Team to do a rough estimate of the cost of including these extra elements within the package accepting that these costs will have to come from the existing health budget.

5. The original cost estimates for this scheme were made on the basis that up to 8,500 potential claimants would be eligible for payments under the initial draft eligibility criteria (attached as Annex A). This suggested that a budget of between £162.5m and £212.5m would be required depending on the number of eligible claimants making applications (£162.5 = 50% take-up, £212.5m = 100% take-up). DH Finance has a £150m provision scored in the 2002/3 accounts to fund the scheme.
6. Updated estimates and a more comprehensive analysis of these figures appears to show them to be an over-estimation due to double counting and inclusion of some non-eligible groups. Further analysis shows that the original calculations included those patients that have cleared the virus with treatment and those who are co-infected with HIV. However, the analysis also found that two patient groups were overlooked in the original submission. Despite this, the balance of the revised estimates indicates that there are significantly less potential claimants (6,707 as opposed to 8,500). The revised costs are therefore estimated to be approximately £179m at 100% take-up. Given that there is unlikely to be such a take-up, the revised costs fall within the scored funds currently available.
7. The estimated cost of extending the scheme to –
 - People with HIV co-infection - £12m if considered alone, but already included in original calculations
 - People who cleared HCV following treatment - unknown, but was part of the original calculations.
 - Dependents – estimated minimum of £144.7m
8. The £12m required to extend the initial payment to co-infectants does not represent any actual increase in cost as this group was mistakenly included in the original calculations. This group is already eligible for the second payment under the draft eligibility criteria.

9. The cost of extending the scheme to dependants (£144.7m) would at least probably double the cost of the scheme and remains unaffordable within the existing budgets of all the four Health Departments.
10. With the figures above in mind I believe we are in a strong position to negotiate with the Society and the All Party Group and would be able to accommodate the people who are co-infected and those who have cleared under treatment within the scheme. I have detailed the pros and cons of this approach at Annex B.

Conclusion

11. There remains little scope for satisfying the All Party Group's demands in full. Their request that the Department considers increasing the size of awards and that dependants be eligible for financial assistance are unsustainable on the grounds of affordability. However, extending the eligibility criteria to include co-infectants and successfully treated patients would not require additional funding.
12. By agreeing to extend the scheme, the All Party Group could be appeased by what they see as a partial victory. More importantly, if you agree to include co-infectants, the MacFarlane Trust will sign up to the scheme.
13. If you agree to extend the eligibility criteria as indicated above I suggest we open a dialogue with the other three Health Department's to obtain their agreement and that I write to Michael Connarty on your behalf declining a meeting but indicating we are considering the points that he made both in his letter and at my meeting with him.
14. I am aware that submissions are currently being drafted to you and the other Health Ministers about making a further announcement about the scheme. This submission will seek your agreement to finalise the eligibility criteria and payment structure to be shared by the four administrations and begin work to set up and constitute the new scheme. It will also include a handling strategy and suggested date for the announcement and provide an update on outstanding issues, the resolution of which will not delay the announcement. Officials expect to submit this shortly.

MELANIE JOHNSON