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From: M A Harris
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COMPENSATION FOR BLOOD TRANSFUSION AND ORGAN RECIPENTS INFECTED WITH HIV

1. I understand that Secretary of State has asked how financial help could be provided to recipients of HIV infected blood and organs in a similar way to the haemophilia scheme.

2. There are two main avenues open; either set-up a new trust to distribute funds or extend the remit of the Macfarlane Trust. The latter course is to be preferred. The framework of the Trust exists; the Trustees have gained experience; full-time officers have been appointed and a precedent has been established for excluding payments from the Macfarlane Trust when assessing benefit entitlement (although the Regulations would need some amendment).

3. However Solicitors advise that because of the specific remit of the Macfarlane Trust set out in its deed we would need to take Counsel's opinion on whether its role is extendable in law. Any extension would in any case need the approval of the Trustees and of the Charity Commissioners.

4. We can be optimistic that the Trustees would be amenable to taking on this task if only to keep Ministers' goodwill. However they would need to be considerably strengthened with specialists in transfusion and transplant medicine in order to assess claims. Their task will be much more complicated than with haemophiliacs, because the medical history of applicants will be much less clear cut.

5. New money would be required. The money (£10m) given to the existing Macfarlane Trust cannot in law be expended other than on its present objectives.

6. We have been careful to refer to the haemophilia scheme as financial help for special needs <u>not</u> compensation for some NHS failing. On that basis it would be difficult to argue that any new scheme should be restricted to those UK citizens given blood in the UK. It would therefore need to be open to all those infected with AIDS by blood transfusion or organ transplant (and their dependents) wherever they received the causative treatment. We will have to recognise that this is an open-ended group because given the infection level of blood supplies in other countries (eg in Africa) it is likely UK citizens will continue to get infected whilst abroad.

7. We will have to try and distinguish the needs of those with HIV infection from those of patients/dependents with other transfusion acquired diseases eg hepatitis, which can be equally disabling and/or deadly. This line is not an easy one to hold.

8. The Trustees would have a difficulty job in contacting those in need. The new beneficiaries are not, like haemophiliacs, a close knit group in contact with

a small number of specialists. They will mainly be under the care of GPs if not yet suffering from AIDS. Too much publicity could undermine faith in the BTS.

9. Proving causation will be difficult. There is no obvious way of proving that a blood donation given prior to HIV testing by a donor who has not subsequently been tested was responsible. Excluding those who might have acquired HIV infection by other routes, and attracted by publicity, would be a problem.

10. The cost of any extension is hard to predict. At present we know of around 100 cases of HIV infection from transfusions (UK and abroad) plus organ recipients (including deaths). If a fund was set up pro-rata to the Macfarlane Trust then about £800,000 would be required. This could well increase following publicity. The Trustees would incur considerably greater costs in distributing this money so perhaps £50,000 p.a. would be required for their services. However the class is not closed, as explained above, and further cases could arise. I suspect we will have to meet any costs ourselves. We only squeezed the £10m out of Treasury because of the political pressure brought to bear by the Haemophilia Society´s campaign. There is no parallel pressure for blood transfusion recipients we could pray in aid. We do not anticipate any major pressure since these victims are isolated and unorganised.

11. This could be the top of a slippery slope to a general demand to help those injured by their medical treatment (eg Opren victims). The "uniqueness" of haemophiliacs might be artificial but it is important. Following the meeting of H(A) which discussed the haemophilia case in November, we gave thought to their view that non-haemophiliacs should be included provided that the ring fencing arrangements, which they regarded as "clearly vital" were not weakened. It was our view at that time that the haemophilia ring-fence was not particularly robust and thus advised that it should not be weakened further by the inclusion of other groups. I think this remains valid.

Way Ahead

12. If Secretary of State wishes to proceed in spite of these problems, the next step could be to obtain Counsel´s opinion on the legality of extending the role of the Macfarlane Trust.

GRO-C

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