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MAH/21/7.

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From: Dr R J Moore HS1A

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**SCHEME OF FINANCIAL HELP FOR BLOOD TRANSFUSION AND ORGAN/TISSUE  
RECIPIENTS WITH AIDS**

The attached submission outlines a scheme to provide special financial help in accordance with Secretary of State's request. Consultation has been as wide as possible in the time available but the legal problems of extending the Macfarlane Trust need further enquiry. The scheme as outlined is thought to be workable for the groups which would benefit but undermines the logical ringfence surrounding the original haemophilia scheme. Other patient groups may press for similar help.

Medical colleagues and colleagues in the AIDS unit remain unhappy with the basic concept of helping this group in this special way and may be minuting their views separately.

**GRO-C**

R J MOORE

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Ext **GRO-C**

Alan o/a

recent paper attached. We are  
waiting to see what the new SoS  
will do on this issue. Hopefully  
HS1 will now be putting up  
a balanced briefing on this subject.

**GRO-C**

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## SCHEME OF FINANCIAL HELP FOR BLOOD TRANSFUSION AND ORGAN/TISSUE RECIPIENTS WITH AIDS

### Summary

The submission outlines a scheme for providing financial help to categories of AIDS sufferers who contracted the disease from blood transfusion and organ/tissue transplant. It is suggested that subject to solving certain legal problems that the Macfarlane Trust be extended to provide this help. Although the numbers likely to qualify for help are uncertain, it is estimated that a fund of £1m might be required.

### Purpose of Proposed Scheme

1. To provide financial help in cases of need to those in the categories mentioned below and their dependents.

1. UK nationals who are suffering from AIDS as a result of receiving an infected blood transfusion in the UK.
2. UK nationals who are suffering from AIDS as a result of receiving infected organs and tissues in the UK.

Financial need would be determined by the administrators/trustees of the fund and help for dependents would continue if needed after the death of the infected person. Dependents of people already dead would be eligible to claim.

### Extension to UK recipients of transfusions overseas

2. Limited extension of the above categories whether by occupation eg civil servants or to people on business would pose considerable problems. It would be unfair to single out one occupation and very difficult to justify distinguishing between people on business and holiday. The extension could only practically apply to all UK recipients overseas.

3. Given that many overseas blood supplies are not as safe as our own, extension to this group would be an open-ended commitment. Additionally problems of verifying medical treatment overseas would impose a heavy burden on the administrators/trustees. It could be argued that the public are now well acquainted with the risks involved with travel to places where AIDS is widely prevalent and medical services less advanced. Furthermore such travellers will be mainly from wealthier and insured sections of the population. Overall it appears justifiable to exclude people who acquired their infection overseas.

#### Extension to those with HIV infection (as opposed to full AIDS)

4. The scheme as proposed would be limited to sufferers of AIDS itself and not extended to HIV positive patients. This is different to the Haemophiliacs scheme which does include HIV positives. The difference in approach is justified by the fact that whilst there are only 7,000 haemophiliacs, there are probably at least 3 million blood transfusion recipients. A formal testing programme to seek out those who are HIV positive would be prohibitive and even the cost of testing just the 'worried well' who asked to be tested would be unacceptable and place an undue burden on counselling facilities. The scheme will instead react when people get AIDS. Although this avoids giving the 3 million any incentive to be tested it must be recognised that the medium survival time for AIDS sufferers is only a year. Dependents in need are likely to be the major beneficiaries. Experience from the Haemophilia scheme suggest that sufferers are more concerned about their dependents than themselves.

#### Rationale for Financial Help

5. The financial help would be in the form of an ex-gratia payment in recognition of special financial need, ie not compensation. People who accept the help will not be impeded from proceeding with litigation if they wish.

#### Method of Payment - Extension of the Macfarlane Trust

6. The most effective way of making payments appears at this stage to be by extending the remit of the Macfarlane Trust set up to administer the Trust fund for haemophiliacs. Provided that the considerable legal obstacles can be overcome and with the agreement of the Charity Commissioners, an extended Macfarlane Trust would enable the experienced Trustees to assess need and make payments. These would be exempt from income tax and disregarded for social security purposes. The Trustees have in confidence given their general acceptance to such a proposal but it is by no means clear that the legal obstacles will be resolved. If they cannot, then a new charitable trust will need to be established. This and other possible options are outlined in Appendix A.

#### Medical criteria for Financial Help

7. The applicant or his dependents would have to produce medical evidence to show

- a) that he had a blood transfusion or organ/tissue transplant in the UK
- and b) that he has AIDS (or died from it)

Unless the doctors concerned (Regional Transfusion Directors in the case of blood) could show that the donation had definitely not been infected, the applicant would need to be given the benefit of any doubt that his AIDS was caused by the medical treatment.



8. If a large proportion of fraudulent or suspect claims were received then more extensive validation and verification would be necessary. This could prove very difficult in some areas of tissue transplant especially bone and skin grafts where records on source material are generally less complete than those kept for blood. The Trustees might have to consider shifting the burden of proof slightly in the light of experience.

#### Numbers likely to be involved

9. At present we know of 12 people who have contracted AIDS from blood transfusions in the UK and less than 10 from organ/tissue transplants. The majority have died but their dependents could apply. We do not know how many are in financial need and would apply for help. We know of around 40 people who are HIV positive following a UK blood transfusion. A very crude estimate suggests an outside limit of 200 on the number of patients who became HIV positive from a blood transfusion in the past and who are still alive. (Many will have died from non AIDS related causes). We have no means of estimating the number of organ/tissue recipients who may be HIV positive but it is likely to be small. For practical purposes we estimate that perhaps 100 people may develop AIDS and need financial help either for themselves or dependents.

#### Funding

10. The £10 million given to the Macfarlane Trust cannot now, by law, be used other than for the present objects of the Trust. This fund worked out at £8,000 per person and at least a similar sum would need to be made available under the proposed scheme for a new separate fund. Our estimate of 100 people in need would therefore require funds of at least £1m. Given the uncertainty in the estimate it would be prudent to make payments to the Trustees in instalments, with perhaps £250k in the first year. There is no existing provision for any level of funding in the current year. The assurances given to HM Treasury about the haemophiliacs' unique treatment make their response to a request for additional funds predictable.

11. There would also be some increase in the administration costs of the Macfarlane Trust which would necessitate a larger Section 64 grant. This will depend on take up. The burden of validating applicants would fall on the NHS and the Blood Transfusion Service in particular.

#### Launch of the Scheme

12. Ideally the scheme should be given a low-key launch. This is to avoid engendering public concern about the level of safety of the blood supply and organ/tissue transplants; losing blood donors; and encouraging other patient groups to press for similar help. This is probably not possible given public interest in blood and AIDS and the legal requirement to advertise changes proposed to the Trust Deed of the Macfarlane Trust. To minimise problems the timing of any announcement should avoid the traditional troughs in the blood supply which occur during the summer and Christmas holiday periods. Regrettably any link between blood and AIDS has a marked effect on blood donors.

#### Way Forward

13. If Ministers are content with this outline scheme, we would propose that further work is undertaken to firm up the legal aspects of extending the Macfarlane Trust so that a paper outlining proposals can be prepared for H(A) committees in the Autumn.

## Appendix A

### Options for Payment

#### 1. Direct ex-gratia payments from DHSS

Advantages: low key, simplicity.

Disadvantages: would involve considerable extra staff time in assessing claims; payments would be taken into account against other social security benefits; payments would be taxable; direct DHSS involvement might imply liability/compensation; Treasury agreement needed.

#### 2. A new purpose-built charitable Trust

Advantages: would be tailor-made; payments would be tax free.

Disadvantages: would need time to set up involving Charity Commissioners; body of Trustees would need appointing (but Macfarlane Trustees could serve in dual capacity); payments would be taken into account against social security benefits unless SS regs were amended to exempt payments from the new charity; might involve higher profile announcement.

NB. Although we were able to exempt payment from the Macfarlane Trust for SS purposes, without other charities crying 'me too' it would be difficult if we were to add another 'unique' case.

#### 3. Extend the Macfarlane Trust

Advantages: ready made board of Trustees with experience; overhead costs would be shared with Macfarlane Trust; payments would be tax free; payments would not be taken into account against social security benefits; could be established with low-key announcement; Trustees have agreed in principle.

Disadvantages: may not be legally possible; additional specialist trustees will be needed; legal formalities may take some time (6 months); may need some amendment to notes accompanying SS regs.