

## RESTRICTED – POLICY

PS/MS(PH)

From: Brian Bradley HP S&L

Date: 14 June 2006

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### Macfarlane and Eileen Trusts - funding

#### Issue

1. This submission invites MS(PH) to consider the options for continued funding of the Macfarlane and Eileen Trusts.

#### Timing

2. Urgent: This financial year is well under way and central finance are on the point of confirming the available budget levels for this year.

#### Background

3. The Macfarlane Trust (MFT) is a DH-funded registered charity which was created in 1988 to provide financial aid for haemophiliacs who were infected by HIV as a result of contaminated blood products. The Eileen Trust (ET) was created in 1993 to provide similar aid for non-haemophiliacs.
4. The DH funding for the Macfarlane Trust has been running at £3m per year since 2003. This supplements the return from the residue of a £10m settlement in 1988, which continues to generate interest. (MFT's accounts for 2004/5 showed a closing balance of some £4.6m.) The MFT's running costs of approximately £294k per year are added to this general fund. The Eileen Trust is a much smaller body, which is presently given £137k per year. A further £100k is available from provisions for new claimants.
5. Up to now, Ministers' position on funding the Trusts has been that the Department has provided a settlement and a steady flow of income which was sufficient for the identified needs of claimants at the time. We have kept an open view on changing future needs. You may recall your response to recent PQs, which gave details of how many haemophiliacs had received payments from the Macfarlane Trust (Annex C)
6. The chair of the Macfarlane Trust, Peter Stevens, wrote to MS(PH) in November 2005 making a case for increasing the funding of the MFT to £7m per year for the next 5 years and for doubling the funding of the

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ET. This case is based on the position that the surviving registrants are living longer than was expected in the original settlement and they have a significant life expectation. Their living costs and needs are therefore substantially different (and greater). Many of them, however, have very little prospect of earning a realistic income and they (and their families) are dependent on a combination of welfare benefits and this income. A paper copy of the case has been forwarded separately, of which the two-page executive summary is attached at Annex A.

7. Mr Stevens asked in the same letter for a meeting with MS(PH). The reply was sent on 26 January offering a meeting in "April or May", once clarity had been reached on the central budgets. That meeting was pencilled in your diary for 12 July, but is being moved forward at MS(PH)'s request, possibly to 28 June.

### Financial position

8. As you know, DH has faced acute pressure on NHS funds and (as a consequence) on the raft of central budgets from which MFT and ET are funded. Major ALBs are being required to make challenging cuts in expenditure, to the point of 'thinking the unthinkable' about service reductions. The upshot of the prolonged review is, quite simply, that an extra £4m for MFT and £137k for the ET is not available. The most that could be found, within the budgets now available to us, might allow for growth of around 10%, or £400k across both Trusts. Officials have so far informally advised the Trust to plan on the basis of 'flat cash' funding for 2006/7.

### Argument

9. The option of **outright refusal** of this case, and flat cash funding, may be justified on the grounds that payments to the relatively small number of surviving registrants have increased substantially in the last 5 years, as the level of funding has not declined in parallel with the decline in registrant numbers. Using MFT's own figures, the average annual level of benefits payment per registrant since 2001 is 70% greater in real terms than the equivalent figure for the previous 12-year period. The historical data (see Annex B) indicates that the average annual payment to each registrant was relatively constant at around £3,500 from 1989 to 2001, when there was a step increase to an average of around £6,000. This supports the view that the Trusts have already secured much, if not all, of the increase in the rate of annual benefit needed by registrants. Blood policy colleagues have commented that they do not consider any increase in overall funding is justified.
10. It could also be argued that the Department of Health should not be bearing the full financial responsibility for these registrants and their families, as there are several other public services whose functions include supporting these unfortunate people. The business case makes a number of claims that could be questioned in detail, e.g. the payments for general housing maintenance and repair and for maintenance and adaptations of gardens, which could reasonably be

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rejected or redirected to other agencies. One could also query the justification for the elements of the claim describing the need for expenditure by registrants on holidays, on hobbies and pastimes, and possibly on childcare and assisted conception. These activities are no doubt relevant to registrants' quality of life but they have strayed somewhat from the original intention in setting up the Trusts and from the Department's original commitment to support these people.

11. The Trusts' representatives have referred to earlier Ministerial commitments to review and to provide adequate funding for these registrants. We have not located a record of such commitments, although the 2003 settlement, following the meeting with Hazel Blears may be the basis for their position. The Department has, however, accepted some responsibility for their plight (i.e. not for the haemophilia but for the HIV and possibly for any subsequent hepatitis C infection). Refusal may be difficult to justify in this context. It would also be very likely to spark an active campaign by pressure groups such as the Haemophilia Society, who we have been advised are very effective lobbyists. It is difficult to predict the exact form such a campaign might take, but there have already been several recent PQs and some media activity on this topic.
12. **Full acceptance** of this claim seems neither affordable nor justifiable. It would more than double the average level of benefit per registrant (all else being equal), which could be considered excessive. It would be difficult to defend complete acceptance of a case for increased expenditure in some of the questionable areas noted above without rigorous questioning and assessment against other spending priorities. The case clearly represents the maximum statement, which may be regarded as a negotiating position rather than meriting settlement in full.
13. A **partial acceptance** of this claim might, however, be justifiable as it would indicate that the Department is indeed able and willing to renew its commitment to supporting those infected by contaminated blood products, while living within our reasonable resource limits. While the historical data show that average annual payments increased significantly in 2001, the MFT's case still makes some valid points in support of a further increase – albeit not on the scale requested. A recurrent increase of up to £400k across both of the Trusts would be affordable. This would represent a further step increase of slightly more than 10% in the overall funding, including administration costs.

### Conclusion

14. On balance, we feel that the justification for an increase is not strong. There is, however, a lot of pressure from the Trust and registrants, and MS(PH) could consider increasing the funding for the Macfarlane and Eileen Trusts by £400k (£350k for the MFT and £50k for the ET). The split could be adjusted on the advice of the Chairman.

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### Handling the meeting with the Chairman

15. Further briefing on individuals, points to make and defensive briefing will be provided in good time for the meeting.
16. We understand that the chair of the MFT and ET will be accompanied by several Trustees at the meeting on 28 June (one of whom has recently written to Secretary of State with a question about his legal position) and it may not be possible to conduct an objective dispassionate discussion under these circumstances. MS(PH) may therefore wish:
  - to listen to their presentation of the case without comment and announce her decision later;
  - to divide the meetings into two parts, the latter part being 1:1 with the chairman; or
  - to conduct the whole meeting with all the attendees and announce her decision at the time (noting that any of the affordable options are not likely to be well received).
17. It would be helpful to have a decision on handling the meeting once MS(PH) has considered the substance set out in this submission.