RESTRICTED – POLICY

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	Date:	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. From 2001/2 to 2005/6 [DN Ted can you please check the accuracy of this statement for 2001/2/3 (we are OK for the later years), the DH funding for the Macfarlane Trust has been running at £3m per year, 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 the general fund. The Eileen Trust is a much smaller body, which is presently given £137k per year, with a further £100k 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. [DN Ted please can you identify a relevant PQ statement e.g. PQ 09558)

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

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 execitive 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 has now been pencilled in your diary for 12 July.

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.

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 needed.

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 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 **[DN Ted** I think we have already looked in vain for this, but would appreciate a further look please before we so advise Minister – unless you are absolutely sure about it) but the Department has 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.

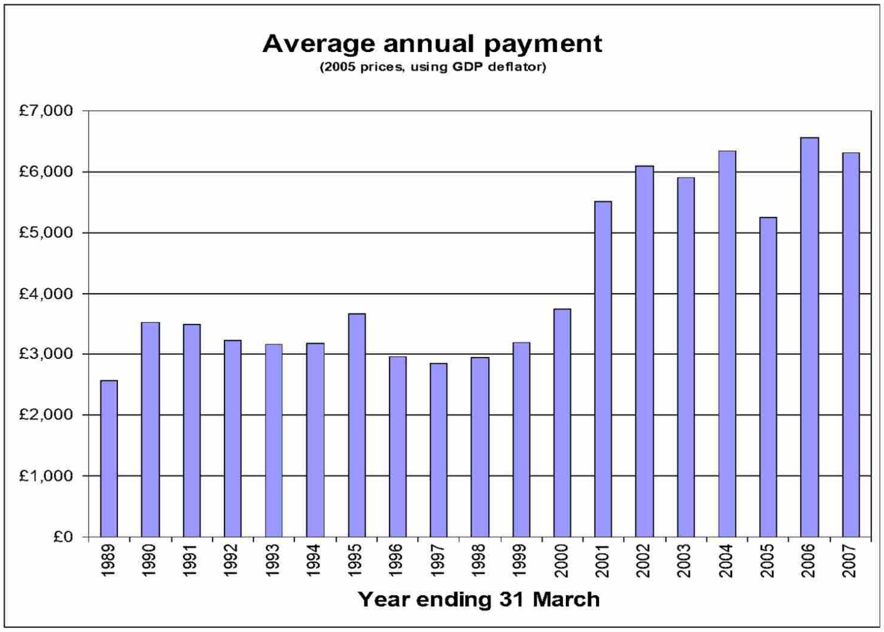
Conclusion

14. On balance, we recommend that the funding for the Macfarlane and Eileen Trusts should be increased in response to their business case by £400k - £350k for the MFT and £50k for the ET. This split could be adjusted on the advice of the Chairman.

15. As PS(PH) has agreed to a meeting with the chair of the MFT this would be a good opportunity to hear his argument before coming to a final decision about the level of that funding

Annex B

The graph below shows the trend in the value of the average annual payment to a registrant of the Macfarlane Trust, over the period since its foundation. Payment data have been provided by the Macfarlane Trust. The data for the year ending 31 March 2006 is their estimate of the outturn for the year just closed. The Trust have also provided an estimate, on current trends, of the likely average payment in the next financial year, on the assumption that their funding is, again, £3m. We have applied the standard index of inflation approved by HM Treasury (the GDP deflator) to bring each year's value to a common 2005 price-base.



It is reasonable to infer from the Trust's own figures that, for the first twelve years (to 2000) the average annual payment to a registrant hovered closely around £3,200 (at 2005 prices). By contrast, over the last six years (omitting the forecast for 2007) the average annual payment to a registrant has been around £5,900 (at 2005 prices). The Trust may argue that the costs faced by registrants increase at a faster rate than inflation in the economy as a whole. Whether or not that is so, it does seem to be the case that the Trust has been able to nearly double the real-terms benefit provided to a registrant, on average, in recent years – albeit owing, sadly, to the mortality of the cohort of registrants. If this average level of benefit can be achieved with DH funding of £3m, it is open to question whether the Trust's proposal - that the level of funding should be more than doubled to £7m - is adequately justified.