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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.

Annex A

Executive Summary of “Funding long term survival”

Introduction

Registrants of the Macfarlane Trust (“MFT”) have always been a special case.¹

The infection with HIV of 1,250 people with haemophilia in the 1980s was one of the worst NHS disasters in modern times. In response, the Government (“HMG”) set up a charity, MFT, to provide financial aid to those infected and their families. Capital and recurrent funding was predicated on the medical assumption of early deaths. Advances in drugs and better treatment have led to the survival of 380 people, a cause for celebration. For too many, however, deteriorating health and burgeoning financial hardship makes such survival a very mixed blessing for them and their dependents, while MFT has little funds spare for the widows and families of the deceased.

This business case highlights the evidence for re-evaluating earlier assumptions about the funding needs of long-term survivors now coping with prolonged ill health, unremitting personal and social stress, strained family relationships, erosion of capital and savings, falling standard of living, susceptibility to the poverty/benefit/credit traps, burgeoning debt and other financial disadvantage.

Government commitment

In 1988 HMG committed £10 million to MFT for the relief of those infected with contaminated blood. In 1990 the Department of Health (“DoH”) made an *ex gratia* payment of £20,000 to each surviving infected person or their bereaved families, following this in 1991 by payments in settlement of potential litigation. Annual deaths rose from dozens in the late 1980s to nearly 100 in both 1994 and 1995. Life expectancy at that time was still measured as one or two more years at most. Survivors recall being advised by their medical consultants to spend their financial settlement “while you still can” without setting aside provision for future years.

Throughout the 1990s, DoH funding, supplemented by stock market returns from MFT’s investment, permitted an annual disbursement by MFT of £2 million. The 3-year settlement for April 2003 to March 2006 is £3 million a year, with an increment of £50,000 for 2005-06.

Longevity

DoH commissioned MFT to undertake a Long-Term Review which reported in December 2003 (entitled ‘*A Life, not just an Existence*’). Longevity is the main issue facing MFT’s registrants, because:

- survival beyond two decades has led to acute poverty and the erosion of capital values for the majority of registrants who are unable to work, renew savings or protect their futures and their families’ security through private insurance;
- the classification of HIV as a ‘chronic manageable condition’ for those who are otherwise well does not apply to MFT’s registrants;
- return to full-time, reasonably paid work is not an option for most surviving registrants, nor for their long-term carers or the recently bereaved who have been out of the employment field for many years.

Without a realistic uplift to HMG’s present financial commitment, surviving registrants face a bleak future of growing impoverishment.

¹ “*The plight of the plaintiffs –or many of them–is a special one*” - Mr Justice Ognall

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Need

New needs have arisen over the past two decades, such as major repairs, adaptation and maintenance of registrants' housing stock. Strategy reviews in 1998 and 2003 highlight above-normal costs to registrants of special diets, heating and domestic consumables. Complementary therapies, holidays and respite breaks carry a higher premium for those unable to lead a normal life of employment or education. Limited assistance with the costs of assisted conception, an immediate cost-of-living upgrade, mobility needs, re-scheduling accumulated debt and more support for widows and bereaved dependents all now need to be addressed, as detailed in Appendices C-H.

Projected requirements

Analysis of revised annual need is set out as follows:	<u>£m annually</u>	
Housing costs, including repairs and maintenance	3.0	(para 4.1)
Diet, heating, domestic materials, clothing & communications	1.5	(para 4.2)
Dealing with stress, including costs of respite breaks or holidays	1.1	(para 4.3)
Childcare costs and help with associated conception	0.25	(para 4.4)
Cost-of-living up-grade	0.25	(para 4.5)
Mobility, trends in types of grant, and debt relief	0.15	(para 4.5-4.6)
The needs of bereaved dependents	1.0	(para 4.7)

Revised estimated need: £7.25 million annually

Deficiencies in the statutory sectors

MFT registrants are frequently inhibited in their access to Disabled Facilities Grants and the Social Fund while the encouragement of the welfare benefits' system towards re-entry into the employment market is unrealistic for them. Many suffer from "post-coding" of NHS services such as dentistry, social work and counselling support, free prescriptions and transport to and from home. (See Appendix I).

Renewal of commitment to those infected

The National Blood Agency has recently agreed a settlement of £750,000 in the case of one individual's blood-borne infection with the HTLV-1 virus.

MFT's Trustees now urge HMG to renew its original commitment to those infected by the NHS by way of a further direct capital payment that assures survivors the independence they did not achieve after the 1990/91 capital settlements.

The Case for additional funding of MFT

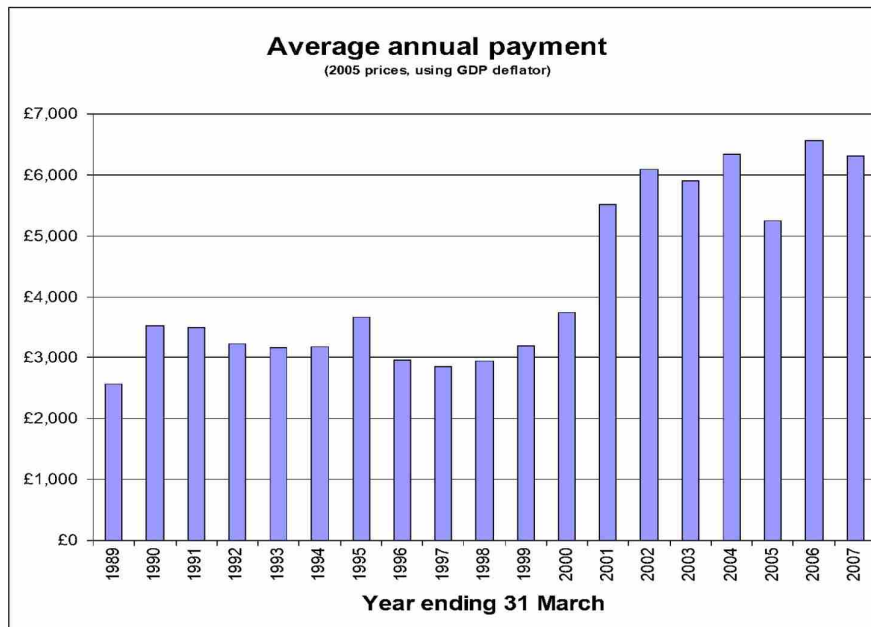
To fulfil their quasi-agency role in a way that, while doing credit to DoH, properly meets the needs of registrants and their families, MFT's Trustees recommend that the rate of Departmental funding should rise to £7 million annually for 5 years from April 2006, index-linked to HMG's preferred annual cost of living indicator.²

² "The Government have repeatedly said they will keep under constant review the payments made to the Macfarlane Trust and the fund attached to it to ensure they match the case" - Stephen Dorrell (the then Parliamentary Under Secretary of State for Health)

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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.

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Annex C

Monday 27 March 2006	PQ09558 PQ09559 PQ09560 PQ09561	2005/2006
Written Answer	Han Ref:	Vol
Wednesday 12 April 2006		Col

MACFARLANE TRUST

Sir Nicholas Winterton (C. Macclesfield):

290 To ask the Secretary of State for Health, how much has been paid out by the Macfarlane Trust since 1988; and what proportion of the Trust's total assets such payments comprise. [61876]

291 To ask the Secretary of State for Health, how many haemophiliacs infected with HIV as a result of NHS blood transfusions have received payments from the Macfarlane Trust in each year since its inception in 1988; and what assessment she has made of the efficacy of the Macfarlane Trust in providing financial support in such cases. [61877]

292 To ask the Secretary of State for Health, how many haemophiliacs infected with HIV are currently receiving payments from the Macfarlane Trust; and if she will make a statement. [61878]

293 To ask the Secretary of State for Health, if she will make a statement on the future of the Macfarlane Trust. [61879]

Answer

From its creation in March 1988 until 31 March 2005, the Macfarlane Trust paid out £38,740,399 to haemophiliacs with HIV, infected intimates and infected widows, non-infected widows, dependents, etc. Comparisons with the trust's total assets would not be meaningful, since the Department provides additional funding to the trust, as needed.

368 haemophiliacs infected with HIV are currently receiving payments from the Macfarlane Trust.

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Background

The Macfarlane Trust was created in March 1988. The number of haemophiliacs infected with HIV as a result of National Health Service blood transfusions who have received payments from the Macfarlane Trust in each year since the trust's inception is shown in the table.

Year to 31 March	Number of registrants
1989	700
1990	674
1991	970 ¹
1992	947
1993	905
1994	850
1995	767
1996	731
1997	660
1998	651
1999	642
2000	579
2001	422
2002	411
2003	401
2004	396
2005	380

Notes:

¹ Reflects increased registrations