Note of MS(PH) meeting with representatives of the Macfarlane and Eileen Trusts on 12 July 2006

Attendees

DH**:** MS(PH); J Buchan; B Irons-Roberts; J Stopes-Roe; B Bradley;

Macfarlane Trust: P Stevens (chair); A Evans; GRO-A ; GRO-A ; M Harvey (Chief Executive of MFT and ET)

Eileen Trust; S Phipps

Discussion

PS noted that these Trusts were created in 1988 and 1993 to provide *ex gratia* payments to haemophiliacs (Macfarlane) and other (Eileen) who were infected with HIV following treatment with blood or blood products. Both Trusts had originally been expected to be short-lived, but nearly 20 years on they were still very much needed

The Dept presently give the Macfarlane Trust £3m pa and the Eileen Trust £100k pa to provide these payments. This funding has been flat funded since the last review 3 years ago, when this settlement was agreed for the years 2003/4 to 2005/6. a considerably larger settlement was now sought, which PS represented as being a realistic assessment of the real and practical needs of their registrants.

The nub of the claim from the Trusts is that

- The Govt has a moral obligation to provide these special payments to their registrants, over and above what may be payable from other benefits, as they were harmed by NHS treatment
- It cannot be right for their funding to be subordinate to the requirements and problems associated with NHS budgets
- Previous DH ministers have promised on several occasions to review this provision regularly
- The basis of the original settlement was that registrants were not expected to survive for long and the payments should have eased their remaining few years
- However, modern treatments have substantially changed this prognosis and the remaining registrants expect to live for many years
- Because of this unexpected longevity, the underlying role of the Trusts has changed – they are assisting people to live in relative physical comfort and managing 'unplanned for' costs such as housing maintenance, washing machines, schooling of children etc
- While some of the registrants earn their own living, most cannot and so have no pension and no financial security
- Many registrants fear exposure of their HIV status and for some this is seen as a barrier to claiming their benefits from other sources (although the Eileen Trust has a very conscientious case-worker who assists registrants in seeking all the available benefits and in other areas such as minimising debt)

- The current claim is the first comprehensive review of what the Trust is doing (and it has been prepared at least partly with the Department's encouragement)
- For the Eileen Trust, although there are presently very few registrants, there is significant potential for new registrants to be identified in coming years and the Trust expects still to be running in 20 years time

The Trust's representatives presented an emotive case, describing the impact of their infection on their lives and the need for adequate funding to maintain their dignity and independence.

MS(PH) said that she had listened carefully to the presentations provided by the Trusts and thanked them for their efforts on behalf of all the registrants. She noted that the Trusts had been created originally to supplement the range of welfare benefits available from other sources and not to provide an alternative source of funding for the same needs. It had been, and remained, the Department's intention in setting up the Trusts to recognise that harm had been caused which was not anyone's fault, but which nevertheless justified some *ex gratia* to those affected. She noted that the payments provided by the Macfarlane Trust had been able to increase substantially within the available funding due, sadly, to the smaller number of registrants still surviving. She said that she would write to Mr Stevens in the next week or two with a decision about future funding.