

Lady Hayman

From Gwen Skinner

HSD1

Date: 12 April 1999-04-12

Copies: Dr McGovern

Mr Lister

## MACFARLANE TRUST

1. I am sorry there has been a delay in responding to this invitation. You sent an interim reply in March. We have needed to consider the recommendations of the Macfarlane Trust's Strategic Review, which was funded from S.64 monies. The Trust wished to establish the right direction for itself, as circumstances have changed in the management of haemophilia and the treatment of people with HIV.

### The issue

2. The Macfarlane Trust operates the special payment scheme for people with haemophilia infected with HIV through NHS treatment with blood products. The Trust has reviewed its work after 10 years in operation. It makes a number of recommendations for Ministers/the Department, and for itself and the Haemophilia Society who have participated in the review and whose campaign in the 1980s prompted the establishment of the Trust. It asks for a meeting with Ministers to discuss the review's findings and we recommend acceptance.
3. Essentially, the Trust recommends that it continues expenditure at about £2 million a year. This would require top ups to the Trust every two to three years of several million pounds to maintain its annual disbursement. Although there are fewer registrants with the Trust, their needs have changed and the items of expenditure are different. The main difficulty is that their financial support for HIV infected people with haemophilia might be considered over generous, eg help with house purchase and furnishings. There would also be a widening gap between this and the self help ethos which we are encouraging for those with hepatitis C.

### Background

4. The Trust was established by Government in 1988 with an initial sum of £10 million. Its objectives are broadly stated, in terms of relieving the suffering of haemophiliacs infected with HIV through NHS treatment with blood or blood products (and the families of those affected). It receives a S.64 grant for its administrative costs and blocks of funding every few years, for its payments to registrants. It invests a certain amount, to yield income, and has so far received £20.5 million, disbursed £20.1 million and has assets of approximately £7.5 million. (Additionally, as a settlement to avoid litigation, registrants received further ex gratia sums of £24 million and £42 million in 1990 and 1991).
5. There is a sister Trust, the Eileen Trust, administered by the Macfarlane Trust, which makes the payments to non-haemophiliacs infected with HIV through blood transfusion or tissue transplantation. The numbers involved are much smaller – about 40 in total. The Eileen Trust is not covered in this review.
6. There have been approximately 1,200 registrants with the Macfarlane Trust since 1988. This has reduced to 474 living registrants and 175 families of the deceased. 190 of the current registrants are below age 30. £2 million a year continues to be disbursed, and the payments are expected by the Trust to continue at this level – lesser numbers, but higher payments.
7. There are several types of payment:

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regular monthly payments (to assist with the additional costs of living with HIV) £12.5 million total

single grants (specific one-off costs) £4.3 million total

winter payments (additional winter costs relating to HIV) - £3.2 million total

8. There has been a change in the nature of the single grants given – due to improvements in medical treatment, young people infected with HIV are living long enough to want their own homes and families. Apart from financial assistance with bereavement costs and hospital travel, there is now a substantial amount given towards house moves and setting up home (mortgage arrangement fees, furnishings, removal costs, bed and linen, legal costs, conveyancing fees.) The Trust suggest that although the remaining registrants have a longer life span than expected, and are able to carry out more activities, the side effects of their medical treatment make them a special case.

#### **The request**

9. The Trust make the case that complex patterns of health needs mean that higher levels of support will be required for longer periods for survivors, and it asks Ministers to consider the changing financial demands and increasing expectancies, and to provide guidance on policy and priorities, plus resources. The review report lists recommended priorities for the Trust itself, and recommendations to Ministers (eg issues to take on board in benefit reviews).

#### **Potential difficulty**

10. A potential difficulty is the focus which the report (perhaps unintentionally) brings to the balance between the relatively generous help for those who contracted HIV through blood products, and the absence of any special payment scheme for those infected with hepatitis C in the same way. This is especially noticeable in the case of young people, where those with HIV have help in setting up home, and those with hepatitis C have the Youth Information and Support project.
11. The Haemophilia Society have been encouraged to promote the forward looking, positive thinking, self help route for those with hepatitis C. The exceptional circumstances leading to the past introduction of the HIV scheme have recently been requoted in a significant number of PQs - the widespread public fear of the disease at the time, when the infection was rapidly fatal and associated with sexual transmission. The HIV scheme has been justified on the basis of past circumstances, but in effect the difference today in the circumstances of a haemophiliac severely affected with hepatitis C and one infected with HIV is not so great.

#### **Advice**

12. We recommend that the Macfarlane Trust's suggestion of a meeting to discuss the review is accepted. Officials would provide briefing on all the issues beforehand, plus a pre meeting if you wish. It might be possible, for example, to explore with the Trust whether they see any scope for project work to encourage a move towards self help, and to put to the Trust the potential imbalance between the "recompense" for those with hepatitis C and to seek their advice on how this might be addressed within existing resources.
13. A suggested reply to the Reverend Prebendary Alan Tanner is attached.

Gwen Skinner

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