

BRIEFING FOR MEETING WITH THE MACFARLANE TRUST - 7 SEPTEMBER '89

Background

1. The Department has strictly observed the independent status of the Macfarlane Trust since it was established on 10 March 1988. However MS(H) has requested two-monthly reports on the Trust's activities. The third of these, covering the period to 31 May 89 is attached (Appendix A). A copy of their balance sheet to 31 March 1989 is at Appendix B.

2. The Trust seek this meeting to determine whether present activities are in line with Government expectations; to seek approval for expansive variations to the Trust Deed; to seek approval for a major escalation of financial help in areas they have so far treated with caution (eg loans for housing). At a preliminary meeting on 31 August the main items of interest expressed were as below.

Allocation Policy/Financial Investment

3. The Trust will be looking for a general assurance that their grant allocation policy, and investment policy are broadly on the right lines. They feel vulnerable having received no communication from the Department; an exchange of letters when the Annual Report is submitted might be a suitable mechanism.

4. Their "cautious" allocation policy has been influenced by uncertainty over how long the £10m fund was expected to last; by the uncertain prognosis of the disease; by uncertainty about the numbers of dependents likely to draw upon their funds. Recent developments in management of HIV infection suggest that the prognosis for sufferers is less bleak than had generally been anticipated; the problem of dependents is detailed below.

Dependents

5. The Trust are finding that some haemophiliacs marriages/relationships are breaking up as a consequence of HIV infection. Claims are therefore being received from partners/children who may no longer be strictly dependents but who nevertheless are living with the complication of HIV infection. The Trust will wish to discuss how far the term "dependent" can be stretched for the purposes of the Deed and may seek an amendment to the Deed.

Juveniles

6. For juvenile dependents of haemophiliacs who have died, or juveniles with HIV, the timescale of dependency could be a lifetime. They seek advice on how long the Trust should undertake responsibility for juveniles.

Duration

7. If present allocation policies prevail the Trust anticipates a £2m expenditure in the current financial year, of which about half would have to be drawn from the capital sum. At that level the £10m fund would run for approximately 5 years.

Housing loans/Life Assurance

8. The Trust wish to help people who are unable to meet existing mortgage payments or to obtain a mortgage because of their HIV status. Haemophiliacs cannot obtain life assurance and are discriminated against by employers thus suffering loss of earnings. The housing loans envisaged (of 80% of property value) would be recoverable. However in view of the high cost of housing help they will be interested to *know* if the fund is likely to be topped-up or if they can expect help in other ways eg. a loan from the Department recoverable from the increase in equity. So far the Trust *have* not thought through in detail what kind of scheme they wish to operate. They will probably seek help in obtaining expert assistance to examine ^{their} options. They could be asked to elaborate on what work would have to be done and ^{we could} offer to consider what help the Department could give.

Block grants for support groups.

9. We will need fuller particulars of this agenda item, but in

essence they wish to give financial support to "self-help" groups of HIV infected individuals. Being nonprofessional "talking-shops", it is debateable whether any useful counselling would ensue, and whether in equity such support would be a proper use of the Trust Fund which is designed to help individuals. We understand that the Trust has managed to help in some cases by accepting individual claims from all members of a group for the same items eg. cost of a short break. This might be the best course for them to follow. When the Trust Deed was first drawn up the Department resisted attempts to empower the Trust to make payments to other bodies; we did not want to see the Macfarlane Trust become just another AIDS charity but wanted to concentrate its efforts in helping individuals in need. Apart from that consideration, it might be difficult to devise a form of words to restrict help to the self-help groups.

Section 64 grants for administrative expenses

10. The Government are committed to meeting reasonable administrative costs from S64 funds to give the Trust full benefit of capital and interest. Because the Macfarlane Trust is low-profile it cannot fund-raise, and the Trust are likely to seek central funding at a higher level than the £100,000 p.a. which has so far prevailed. They have been offered that sum for this year and application forms for next year's grant have gone out to them. It would be better if they could make their case for additional help in the context of next year's round rather than try to reopen this year's now that all the monies have been allocated.

Summary

11. In addition to the above the Trust are likely to wish to discuss the interface between their activities and the Haemophilia Society's demand for an out-of-Court settlement of the current HIV litigation (see Appendix C). This litigation will no doubt heighten public awareness of the Trust's activities, and any amendment of the Trust Deed will need to be justifiably an extension of the Governments original intention for the £10m ex-gratia sum.