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1. Mr M A Harris  
2. Flora Goldhill  
Private Office

From: M H Arthur HSLA  
Date: 27 October 1988

c.c. Dr Pickles  
Dr Moore

#### THE MACFARLANE TRUST

1. You asked for a note on the Macfarlane Trust and in particular how it relates to the dependents of haemophiliacs with HIV.
2. It was announced on 17 November 1987 by Tony Newton, then MS(H), that a £10 million ex-gratia payment would be made to enable the Haemophilia Society to establish a special trust, to provide financial help both to haemophiliacs infected with the AIDS virus, and to their families.
3. The Macfarlane Trust was established on 10 March 1988 and the £10m was presented to the Rev Alan Tanner, Chairman of Trustees on 17 March 1988.
4. In the period 17 November 1987 to 17 March 1988 DHSS solicitors and Haemophilia Society solicitors were in regular consultation on the form of the Trust deed. The Charity Commissioners and the Inland Revenue were also involved. The Haemophilia Society appointed six trustees and the Secretary of State appointed four. Regulations were laid to disregard any payments from the Trust for housing benefit, income support and family credit.
5. The Trust's initial priority was to contact all potential beneficiaries to establish a likely level of demand whilst formulating an allocation policy. From November 1987 onwards, those haemophiliacs with HIV and their dependents who were in need were invited by the Haemophilia Society to apply for help. In May 1988 they were invited to formally register with the Trust. So far, only about 800 people have registered <sup>which</sup> is some 400 less than had been anticipated. Those who have not registered have probably decided they are not in financial need.
6. The Trust's allocation policy (see Appendix 1) has developed in response to applications received. It is the intention primarily to make regular payments to those on low income as well as single payments for specific items. The Trust has adopted a cautious maximum regular payment of £20 per week subject to a means test. This amount will be reviewed when the Trust have more idea of the number of dependents who might need help over a long period. They are also investigating how best to help with mortgages and life insurance.
7. So far 350 applications have been received and 297 payments have been made totalling £132,000. The largest single grant was just over £3,000.
8. It was never intended that the £10 million should be compensa-

tion. Some applicants clearly thought they were entitled to compensation, and those refused help have been refused on that basis, or rarely, because their claim was unreasonable. Although the Trust cannot readily identify the total number of dependents helped to date, they categorically deny that anyone has ever been refused on the basis of being a dependent. They would be most willing to investigate individual complaints if a name and address could be supplied.

Suggested line to take;

The Macfarlane Trust was established to consider applications for help both from haemophiliacs with HIV and from their dependents. It is the duty of the Trustees to ensure that payments are made in the most effective way and take into account the differing circumstances of those affected.

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M H Arthur

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