

KEEP ON FILE

Ms Harper

From: Dr R J Moore

Date: 13 October 1988

Dr Moore

cc: Mr Heppell
Mr Cashman
Mr Barton
Mr Harris
Dr Pickles

Thank you. A very

clear note

GRO-C

19-X

THE MACFARLANE TRUST

1. MS(H) has asked for a note on the Macfarlane Trust and the delay in paying potential beneficiaries alleged in the Sunday Times on 9 October.
2. Tony Newton then MS(H) announced on 16 November 1987 an ex gratia payment of £10m to enable the Haemophilia Society to establish a special trust to provide financial help to haemophiliacs infected with the AIDS virus and their families. He gave an undertaking that payments from the Trust would be disregarded when deciding entitlement to Social Security benefit.
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. Our files for the 4 months from 17 November 1987 to 17 March 1988 attest to the priority given to establishing the Trust. In that period 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. The scheme is unique for DHSS and innovative solutions needed to be sought and agreed.
5. The Macfarlane Trustees have met monthly since March with working groups meeting more regularly. They have appointed a full-time staff of three people: Administrator (from 8.8.88), Social Worker (from 24.10.88) and Secretary (from 1.9.88) and have obtained offices.
6. Their 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 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. Non-members were contacted through their doctors at Haemophilia Centres. So far

only about 800 people have registered which is some 400 less than had been anticipated. Those who have not registered have probably decided they are not in financial need.

7. It was never intended that the £10m should be compensation. The Trust is a charity and the Trust Deed restricts it to providing relief for those who are in need of assistance. Payments have been made from December 1987 by the Haemophilia Society on behalf of the Macfarlane Trust. The Allocations Committee of the Macfarlane Trust has dealt with applications since June 1988.

8. 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. Some applicants clearly thought they were entitled to 'compensation' and unless they could demonstrate need have not been given a grant.

9. The allocation policy 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.

10. The Sunday Times article refers to an Alan Arthurson (presumably a pseudonym since he is unknown to the Trust) who typifies those who think the £10m is a compensation fund to which they have a right.

Suggested Line to Take

11. The Macfarlane Trust was established as quickly as was practicable and our understanding is that all applications for help have been dealt with in a timely fashion. The average award of £440 reflects a cautious approach before the level of demand could be identified. It will be reviewed regularly and revised as necessary.

12. MPs can be advised to encourage those of their constituents who may be eligible to apply to the Trust for help.

GRO-C

R J MOORE
A403A
AFH
Ext GRO-C