THE MACFARLANE TRUST

Alliance House 12 Caxton Street London SW1H 0QS
Tel: 0171-233 0057 Fax: 0171-233 0839

The Baroness Hayman of Dartmouth Park
Minister of State for Health
The Department of Health
Richmond House
79 Whitehall
SW1A 2NA

30th July 1998

Dear Baroness Hayman

THE MACFARLANE TRUST - A STRATEGIC REVIEW OF THE TRUST TEN YEARS AFTER ESTABLISHMENT IN 1988. INTERIM REPORT.

On 10th March 1988, The Macfarlane Trust Deed was signed, thus establishing a Trust to administer an ex-gratia grant to those people with haemophilia who became infected with the HIV virus as a result of treatment with infected blood products, as announced by Mr Tony Newton, Minister of State for Health at the time, to the House of Commons on 16th November 1987 following an all party initiative in response to the tragedy.

I wrote to your predecessor, Baroness Jay, last March advising her that Trustees had proposed, in the light of recent advances in treatment of people with HIV\AIDS, to carry out a detailed Strategic Review of the Macfarlane Trust. Such a Review would seek to consider the effects of a changing but still uncertain life expectancy for our Registrants and would identify their present needs so that Trustees could report to the Department on the probable future duration of the Trust and estimate the financial support that may be required to enable the Trust to continue to support its beneficiaries.

Until mid 1996 mortality trends of Trust Registrants had been steady, and at that time it was thought possible that within five years Registrant numbers would have reduced to a point that the Trust could be maintained by a diminishing staff team, and that funding requirements would also reduce in a similar steady pattern. As you will see from the enclosed Interim Report, 33 Registrants died in 1997 compared to 90 dying in 1995. At today's date only 8 people have died in 1998.

These significant changes have been cautiously welcomed, for it is recognised that past apparent successes in treating HIV/AIDS have not withstood the test of time; it is also recognised that for some people with haemophilia the added complication of being doubly infected with HIV and Hepatitis C has made it difficult for some Registrants to sustain treatment with new triple combination therapy.

Whilst our Review has only now reached the point when we are able to send the Department the enclosed Interim Report, it is already clear that there is a most urgent need to research the psychosocial issues related to living with the multiple effects of haemophilia, HIV\AIDS, hepatitis C and a rigorous drug regime with some very unpleasant side effects.

You will see from the enclosed Interim Report that our Review is well underway, and that we are on target to present a Final Report to you in November. However, I am conscious that although your officials have agreed that we may use the £3,500 'underspend' from 1996/97, and despite the large amount of work that is being done 'in-house' by Trustees and staff, there will be considerable costs involved that cannot be met from our current Section 64 Grant.

If we are to gain a true picture of the emerging needs of our Registrants, the work of conducting Focus Groups and One-to-One Interviews, as well as analysing the results of our detailed Questionnaire, must be carried out by professionals who are independent of the Trust and the Haemophilia Society. It would therefore be most helpful to know at this stage whether it would be possible for your Department to identify further funds to allow us to complete this important Review. The additional sum required is likely to be in the region of £15,000.

I and my colleagues would welcome an early meeting with you if you would like to learn more about the Macfarlane Trust at this stage; however you may feel that it would be more appropriate for us to meet when we present our Final Report in the Autumn.

With all good wishes,

Yours sincerely,

GRO-C

The Reverend Prebendary Alan Tanner OBE, Chairman

ENC: MACFARLANE TRUST STRATEGIC REVIEW - INTERIM REPORT
JULY 1998