MACFARLANE TRUST

PROPOSAL TO SPEND THE RETAINED RESERVES

1. Background

1.1The Macfarlane Trust (MFT) was established on the 10 March 1988 at the initiative of the then Government, following the transfusion of contaminated blood and blood products to men with haemophilia. Initially, there were 1246 infected beneficiaries, all of them suffering from HIV as a result of their treatment of their condition by the National Health Service. In the first instance, the Government allocated a £10m fund, further funding has since been received and for the year ending 31 March 2012 since its inception, the total amount of such funding is £59,474,607. There are, approximately, 360 surviving primary beneficiaries and, in addition, during 2011/12, over 200 non-infected beneficiaries were supported, these included widows, partners and children (including orphans) and carers. The Department of Health (DH) now allocates approximately £2M per annum (including funds from the devolved administrations). The MFT is wholly funded by the Department of Health.

1.2 The MFT Trustees reserves policy, as required by the Charity Commission and pre the Archer Inquiry report in February 2009, was to maintain a level of retained reserves equal to 12 months charitable and operational expenditure. This reserves policy and the level of the retained reserves reflected the approach to funding of the MFT by the DH and were maintained with their full knowledge.

1.3 All financial support agreed by the Trust are waived as far as benefit calculations are concerned and are free of income tax. Financial support from the Trust, other than the series of non-discretionary payments from MFET Ltd and in certain circumstances the Skipton Fund, is the only means of financial support in particular for the non-infected community.

1.4 The notion of "charity" allied to the root cause of their HIV/Hep' C infection can be illustrated by:

Many of the beneficiaries are, understandably, still very angry with the effect on their lives and it is, therefore a highly political issue, with constant contact between some beneficiaries and their MPs

1.5 The MFT is currently developing a Business Case for submission to DH in September 2012 aimed at paring the Reserves down to an operating balance in the region of 200k to meet DH interpretations of retained funds. The process of paring down, in policy terms, is not prescribed to a single financial year and the possibility of utilising some of the retained reserves as an "off-set" against future discretionary expenditure allocations is understood.

1.6 To meet the Charity Commission requirements of "objective assessments of individual beneficiary circumstances to identify charitable need" the MFT has engaged with the community of care to prepare a business case, with the foreknowledge of DH, to establish embedded capital needs, in particular those that arose pre-Archer. Disbursements will be according to identified charitable need and not simply to provide unquantified financial support.

1.7 This has proved to be a controversial topic with some of the community, although there is strong support from all for the disbursement of the Reserves and an expectation this will happen later in 2012/13. Beneficiaries have raised their concerns with their MPs and, in total received approximately 10 letters raising grave concerns. It is clear that:

Any decision not to proceed with the commitment of Reserves will generate a very strong reaction from the beneficiary community, most probably with MP engagement.

1.8 By definition, there will have to be a shadow upper limit of financial support; this will be determined when the beneficiary engagement programme has been completed. The engagement programme comprises a survey of individual (infected and non-infected) beneficiaries to identify their circumstances NOT to make individual assessments of charitable need.

1.9 The advantages of such a survey, to enable the MFT to start to plan for the future will be recognised.

2.0 The Pre-Archer Deficit

2.1 Prior to the Archer Inquiry (that reported in February 2009) MFT was limited to two main channels of disbursement funding. These were calibrated regular payments to the infected community, according to household income, and a range of single grants. In addition, there were winter payments to meet the additional utility costs that arose through the cold weather, which were particularly damaging to those persons with haemophilia who had been infected with the HIV virus.

Funding allocations provided to MFT have never been capable of enabling the Trustees to provide a comprehensive range of disbursement relief across the whole beneficiary constituency.

2.2 MFT, through its various policies in respect of charitable disbursements, treated as primary the needs of the infected community and their families. The bereaved community, widows and parent/carers, had very limited assistance and were certainly not fully supported, because of limited funding.

With the ageing population, the needs of widows and carers are becoming critical. MFT intends addressing these through the disbursement of Reserves.

2.3 The MFT does not substitute and is not a proxy for other bodies or agencies which have responsibilities for providing certain items, for example the Benefits Agency or Social Services. The MFT will consider claims for items only if public funding has failed/is inadequate/not available.

With the current economic situation, and reductions in areas of public spending beneficiaries are finding it increasingly difficult to have their needs met from within the public sector and are having to turn to MFT, requesting funding.

2.4 It is a sad fact that, in almost all cases, the charitable relief offered by MFT was revenue driven to meet immediate needs. MFT has never had sufficient funds to address properly the capital requirement of the community. These are:

- **Necessary repairs to property**

- The MFT Board is aware of the deteriorating condition of some beneficiaries' living accommodation. Improvements are necessary not only to reach a generally acceptable standard (such as modernisation of bathrooms/kitchens) but also for health reasons. For instance, installation of double glazing and central heating systems to aid those whose clinical conditions are adversely affected by the cold weather.

- **Alterations and adaptations to property necessary for beneficiaries to cope with their deteriorating physical conditions**

  It will assist if this section is amplified. There will be, inevitably, increasing burdens on infected and non-infected beneficiaries as they age. The average age of the infected beneficiary is in the region of 50 years, mobility difficulties exacerbated by haemophilia and accentuated by HIV will lead to a declining health condition for the community of care. I anticipated that the survey will identify the range of needs and (current) indicative costs of the range of needs identified. The MFT accepts that it is unlikely that all such future needs will be met. Anonymous case papers of an adaption that may well have met the requirements of any capital disbursement from the Reserves are attached (Annex A).

- **Inherent debt issues**

  Some beneficiaries, in particular non-infected beneficiaries, are increasingly, through no fault of their own running into serious financial difficulties that include running up substantial debts. This is often the case where an infectee dies and the "debt" remains with the widow or bereaved partner. MFT, in line with the Caxton Foundation, wishes to support beneficiaries who find themselves in need caused by non-frivolous debt and cite this as an illustration of how the retained reserves might be used. The MFT and the Caxton Foundation have an agreed arrangement to share the costs of a debt counsellor and advisor (on an independent contractor basis) to bring effect to the management of debt.
  Only non-frivolous debt would be considered for relief and where there was little or no chance of the beneficiary clearing the outstanding debt from their resources. Uninsured mortgage debt,

where no mortgage protection or life insurance risk cover existed would be deemed non-frivolous debt.

Education and Training:
To make-good educational opportunities that were lost by both the infected and non-infected communities because of prevailing health conditions coupled with the provision of carer services provided by family members. Equally, careers were interrupted or lost for the same reason and the trustees feel that it would be an appropriate use of the reserves. It is a known fact that widows and partners, after the grieving process, will view their lives as incomplete and seek a form of redress through educational or training empowerment or, in the case of dependent children, look to the Trust to assist with tertiary or vocational education to meet lost opportunities.

This, in the round, is "the Pre-Archer Deficit".

3.0 Future Employment

3.1 Many of the Trust's primary beneficiary community are unable to find suitable employment that can reasonably accommodate the mobility effects of haemophilia and the erosion to the immune system caused by the HIV virus. This is not the situation in all cases and many of the Trust's primary beneficiary community are gainfully employed or manage their own SME but there is considerable room to expand the opportunities available. The same can be applied to the non-infected community.

3.0 Addressing the Pre-Archer Deficit

3.1 The Trustees recognised that, to ascertain the extent of the capital requirement necessary to deal with the Pre-Archer deficit, it would be necessary to conduct a detailed review of individual capital needs.

3.2 To assist them in this work the Trustees have engaged a specialist firm to contact (sometimes visit) every living infected beneficiary and bereaved family, to ascertain the appropriate level of capital relief required. The Trustees recognise that a full and comprehensive survey of the living environment will have to be prepared before a detailed estimate of the cost of the exercise can be ascertained. Initial enquiries suggest that a detailed

review along the lines proposed will not cost more than £100,000 which will be fully funded by the Trust.

3.4 It is estimated that the surplus level of reserves will be fully utilised by the end of 2013/14.

4.0 CONCLUSION

THE NEEDS OUTLINED IN SECTION 2 ABOVE CAN ONLY BE MET BY THE UTILISATION OF A SUBSTANTIAL AMOUNT OF THE RESERVES

Roger Evans
Chairman

Martin Harvey
Chief Executive

26th July 2012

Annex A
Illustrative case where public funds were not available for adaptions to a primary beneficiaries accommodation.

Annexe B
2 sample responses from the survey questionnaire.