



Business case for increased funding for the Macfarlane Trust from 2014/15

1. Background

The Macfarlane Trust (MFT), a registered charity number 298863, was set up in 1988 to support approximately 1,200 people with haemophilia who were infected with HIV as a result of contaminated NHS blood products, and their spouses, parents, children and dependants. At the beginning it was anticipated that the organisation would only be needed for a relatively short period of time. The number of primary beneficiaries is now significantly lower than previously (306 people), due to high mortality rates in the early years. With advancements in treatment for HIV, for the existing beneficiary community HIV is now a chronic condition. However, with the advances in treatment have come the long-term effects of treatment regimens combined with what, for many, are the debilitating effects of haemophilia in terms of decreasing mobility.

An organisation which was originally only intended to be short-lived therefore continues to have a responsibility to support people whose needs have changed, and arguably become more complex, as the years have passed. In addition there are dependants, notably spouses and partners (of whom 42 have been infected with HIV and are therefore considered to be primary beneficiaries themselves, in addition to the 306), widows and children. In the aftermath of the Archer report (2009), and the introduction of non-discretionary regular payments to MFT primary beneficiaries through MFET in 2011, financial allocations to MFT from the Department of Health (DH) have decreased. The current level of annual funding from the DH has now reached a level which is inadequate for the needs of MFT's beneficiary community.

2. Financial position in 2013/14 and financial challenges

In 2013/14, the allocation from DH is £2.2 million, compared with ongoing commitments for the year of £3.014 million, a gap of £814,000, which the board has agreed should be met from reserves this year.

By far the largest proportion of MFT's annual spend (approximately £2.4 million) goes on its long-standing scheme of discretionary top-up payments to its beneficiaries (primary beneficiaries and widows).

Because of the annual increase to MFET non-discretionary payments in line with the September CPI, there is an expectation amongst MFT's primary beneficiaries that their top-up payments will increase at the same level. This creates an inflationary pressure on MFT's annual budget.

When the Caxton Foundation was introduced, and MFT's trust deed was amended to reflect its provision of support to those co-infected with Hepatitis C, no additional funding was made available to MFT in support of this. MFT's policy to date when calculating household income for the purpose of discretionary top-up payments has been to include Skipton Stage 2 regular payments as part of household income. This is deeply unpopular with, and resented by, those who are co-infected, who feel that not only are they excluded from seeking support from the Caxton Foundation, they are then penalised by MFT in financial terms for their Hepatitis C having progressed to Stage 2. **MFT sympathises with this view and would like to be able to afford to change its policy.**

In addition, support is provided through the provision of an annual winter fuel payment to primary beneficiary households in recognition of the absolute requirement for those with haemophilia and HIV to keep warm during the coldest months of the year. This has become even more important with the increase in energy costs. The impact of illness, ageing (77% of primary beneficiaries are now aged



40 and over, 36% are aged 50 and over) and reduced mobility has significantly decreased the ability of many of our beneficiaries to work, and many that do are in relatively low-paid employment. Financial concerns and access to benefits are therefore a significant problem, and a key strand of our support is providing access to specialist money management/debt and benefits advice. MFT also makes a small number of grants to beneficiaries.

The budget for this aspect of MFT's support to beneficiaries is inadequate for the level of demand, and in 2012/13 and to date in 2013/14, the MFT grants committee has only be able to meet a relatively small proportion of requests. In 2012/13, in financial terms only 21% of grant applications were funded - £127,262 funded against requests totalling £614,158. In the current financial year to the end of September 2013, the percentage is even lower. In some cases, beneficiaries have been given the option of taking out a loan from the Trust, repayable from their discretionary top-up payments, in the absence of MFT being able to provide a grant. However, many people simply cannot afford to do this, and MFT's cash reserves to support this are also diminishing. The grants budget was increased in 2013/14 in an attempt to provide additional support in this way. However, it was done by taking the difficult decision not to run any weekend events for beneficiaries. The absence of an adequate grants budget is a significant cause of dissatisfaction amongst the beneficiary community.

Summary of 2013/14 budget

Discretionary top-up payments and supplements (to primary beneficiaries, widows, dependants and carers)	£2,427,301
Winter fuel payments	£115,000
Grants (including those processed under Office Guidelines)	£190,000
Specialist advice: money management and benefits	£27,000
Partnership Group (beneficiary forum)	£10,600
Service Delivery Payments and management costs	£244,044
Total	£3,013,944

3. MFT's reserves

At the beginning of the financial year, MFT had £4.2 million in reserves, which had been built up before 2009 in order to cushion the uncertainty of annual allocations from DH. Most of these funds were accrued before 2006 when MFT's funding structure was very different from now. In the autumn of 2012, MFT presented a case to the DH for committing the reserves in the context of the ongoing needs of its beneficiary community. MFT is extremely grateful for the DH's support in not reducing its allocation in 2013/14, which would have resulted in an even bigger funding gap needing to be met from reserves.

At its meeting in April 2013, the MFT board carefully considered its commitments and liabilities in the light of the DH allocation for the year, and as a result made the following provisions:

1. Provision for deficit in 2013/14	£800,000
2. Provision for deficit in 2014/15	£800,000
3. Provision in relation to widows (paid out by August 2013)	£395,000
4. Additional provision for widows (time-limited to 1 October 2013 and no longer required)	£474,000
5. General Reserve	£750,000
6. In-year Grants Programme: health and mobility related repairs and improvements to property	£981,000
Total	£4,200,000



The beneficiary needs analysis that was carried out by MFT in 2012/13 had identified that health and mobility related repairs and improvements to property were the top priority amongst the beneficiary community. A grants programme was therefore launched in August 2013, inviting all beneficiaries to make applications against well-defined criteria. This has been very successful and applications were received from approximately 25% of the beneficiary community. It is anticipated that the £981,000 set aside for this purpose will be disbursed in respect of eligible applications by the end of the financial year.

By the end of 2013/14, MFT's reserves will therefore have been reduced by over 50%, to £2,024,000, in covering the 2013/14 deficit (1), the provision for widows (2), and the disbursement of £981,000 through the grants programme (6).

4. Proposal for funding 2014/15 and beyond

In summary, the key financial challenges which MFT now faces are as follows:

- A recurring deficit of approximately £800,000 before inflation;
- Pressure from campaigners and beneficiaries to exclude Skipton Stage 2 regular payments from household income considerations when calculating MFT discretionary top-up payments, at a cost in the first year of doing so of approximately £200,000;
- A grants budget which is inadequate to meet the needs of beneficiaries.

We believe now is the time to stabilise MFT's financial situation in the context of annual funding rounds.

MFT is therefore requesting that the DH increase its annual allocation by £1 million from the current £2.2 million in 2013/14, to £3.2 million in 2014/15 and beyond. This would cover the ongoing deficit and enable MFT to continue to support its beneficiaries at existing levels. It would also enable Skipton Stage 2 regular payments to be excluded from household income calculations for the discretionary top-up payment scheme.

Alongside this, MFT would propose to release £400,000 from reserves each year for the next 3 financial years to run a grants programme which would be adequate to meet the ongoing needs of its beneficiary community. At the end of this period MFT would therefore only be left with a small general reserve.

Without additional funding, the only way the organisation would be able to address its deficit would be by significantly reducing – or even removing completely – regular monthly payments under its discretionary top-up scheme. This would leave people who are already in a precarious financial situation even more vulnerable. MFT would also be left in a position where it was unable to address the ongoing need for grants. All of this would cause a significant degree of anger and protest from campaigners and the beneficiary community, which would not only be targeted at MFT, but also at Ministers, MPs and DH in the run up to a general election.

MFT is aware that the Caxton Foundation will be submitting a business case to the DH for the introduction of a regular payments scheme to complement Caxton's existing grants programme. Providing MFT with financial support to maintain its own regular payments scheme, and enabling it to run a comparable grants programme, will place MFT and Caxton on a more parallel footing in terms of provision of support to the beneficiaries of both charities. This will address the ongoing demands of campaigners and beneficiaries alike for read-across between the two organisations.