MEETING WEDNESDAY 22 JANUARY 2003 - MACFARLANE AND EILEEN TRUSTS

Contents

Macfarlane Trust - Overview

1. The Trust was set up by the Government in 1988 to administer a fund for haemophiliacs infected with HIV through contaminated blood products.

2. In 1988 none of the 1,240 registrants infected with HIV were expected to survive for long. Today, 408 are still alive, 238 with families. Three-quarters are in the 25-50 year age range. All are co-infected with hepatitis C. The Trust also supports 38 widows or partners infected with HIV through intimate contact, 288 other widows and 438 children, 220 of whose fathers have died.

3. Despite continued uncertainties about health, many registrants are becoming more optimistic about life expectancy and the ability to live a more normal life. They want to get back to work, marry, start families etc. Many of those who were young boys when the Trust was set up now have partners and young children. This means that, for the future, the Trust 'community' is likely to grow.

4. This long-term survival and change in expectations places demands on the Trust's resources, and there is a resulting tension between the expectation of registrants, the Trustees assessment of what it is reasonable to support and the Department's wish to keep Trust spending within agreed budget limits. We are managing this tension at present because of the close and amicable working relationship between the Trust and officials (we have a particularly good relationship with Peter Stevens who appreciates the Department's wish not to let costs spiral) but this may get harder as the expectations of registrants increase. To take one example, the Trust has been pressed by some registrants to support the cost of assisted conception techniques to avoid transmission of HIV. The Trustees have decided not to help with the cost of treatment but to assist with expenses such as travel and hotel accommodation close to the hospital providing the service.

5. The Trust started life with a £10m fund which, until a couple of years ago, was topped up by the Department on an ad hoc basis. We now have an annual budget for the Trust of £2m. This is inadequate as the Trust currently spends close to £3m pa (although, for this year, the Trust Fund balance is large enough for this

not to matter). You will be able to tell Peter Stevens that further funding for the Trust has been obtained through SR2002 giving them £3m in 2003/04; £3m in 2004/05 and £3.05m in 2005/06. This will allow the Trust to meet current costs but does not give them any room to increase provision beyond that. In addition, we meet the Trust's administrative costs through Section 64 payments. These will reach £287K pa by 2004/05.

6. The Trust has always put as much of the fund as possible into investments, usually a minimum of £4m. At the end of 2001/02, this had enabled the Trust to spend close on £30m and to have a balance of cash and investments of nearly £7m from DH funding totalling £27.25m. There has been a significant loss of value in the Trust's investments over the past couple of years but the Trustees believe that portfolio values will recover as stock market conditions improve.

7. Roughly £2.5m is spent by the Trust annually on regular payments to registrants. The remaining £0.5m is spent on single grants. Most of the grants are of relatively small amounts of money. However, long-term survival is bringing growing numbers of requests for help with more costly items such as

- maintaining, repairing and adapting housing;
- re-training and other aspects of education, both for registrants and for dependants (particularly widows)
- car purchase, insurance and maintenance, since the Motability scheme is frequently failing to provide registrants with a satisfactory service (by the standards of the Trust);
- the incidental costs (eg travel and accommodation) associated with assisted conception.

DH Support for the Trust

8. Over the past couple of years, we have focussed on:

- providing annual top-ups to the Trust fund that match the Trust's spend as far as possible whilst allowing the Trust to maintain a reasonable balance in investments;

- supporting the Trust in developing its financial management systems. This was accomplished through an initial DH review to identify scope for improvement, seconding a NHS finance trainee to the Trust for 6 months to set up new financial and operating systems, and funding a new financial assistant to maintain those systems.

- ensuring that they have a full complement of well qualified Trustees;

- meeting Peter Stevens and Ann Hithersay quarterly to review progress and discuss issues.

9. Looking forward:

- we have sought advice from DH solicitors on the extent of the Department's financial obligations to the Trust under the terms of the Trust Deed. We wanted to be sure that we were on safe legal grounds in capping the Trust's expenditure. SOL has advised that we have no legal obligation whatsoever to provide further funding. The deed simply sets out what the trustees must do as regards the money that comes into their possession.

- we need to work with the Trust to establish how best to meet the needs of registrants within funding constraints. We have agreed to support the cost of 3 yearly assessments of registrants' needs and the strategy to meet them. Peter Steven's will probably suggest a further meeting with you when the first of these reviews is completed.

- we need to move away from using Section 64 grants to support the Trust's administrative costs. Section 64 is not designed to support bodies such as the Macfarlane Trust, where the Department has a long-term commitment to fund to whole of the organisation's admin costs. Furthermore, the level of support now needed by the Trust restricts our ability to support the kind of voluntary groups the Section 64 scheme is intended to help.

- both we and Trustees recognise that some of the support provided by the Trust would be more appropriately provided by statutory bodies (eg local authorities rather than the Trust should be supporting the cost of housing adapations). The Trust argue that the service provided by local authorities is slow, insufficiently comprehensive and lacking in confidentiality (the stigma of HIV remains an issue among Trust registrants). The Trust have asked the Department to see if local authorities - and others (eg the Motability scheme) - will reimburse costs where the Trust has provided a service that these agencies would/might otherwise have provided. We have not even begun to pursue this but we suspect that the chances of success are very slim.

The Eileen Trust

10. The issues here are much simpler. The Eileen Trust was established by the Government in 1993 to assist non-haemophiliacs who contracted HIV through contaminated blood products. The Eileen Trust provides similar services to the Macfarlane Trust but on a much smaller scale. It currently gives support to about 30 people. It has five trustees (who also serve on the Macfarlane Trust).

11. So far the Trust has made payments of £730,000. A year ago we provided the first top up to the original Trust fund. The Trust's current funds total £550,000, sufficient to keep it running at least until 2006/07. The costs are low and we have no difficulty given an unequivocal commitment to supporting the work of the Trust.

Lines to Take

- Welcome the opportunity to discuss the work of both the Macfarlane Trust and the Eileen Trust. Pleased to hear that the advance of new treatments for HIV has meant that the life expectancy for many of the registrants is now much longer. Recognise the demands on the Trust caused by co-infection with hepatitis C and the changing expectations of registrants.

- Give an assurance that we are fully supportive of the Trusts work, and the help given to registrants and their families in the face of the uncertainties about their health. Have confidence in the way the Trust has conducted its financial affairs. Pleased that the Department has been able to help the Macfarlane Trust improve its financial management systems.

- Pleased that we have been able to put top-up funding for the Macfarlane Trust fund onto an annual basis to give the Trust more financial certainty. We will be increasing the Trust's central funding to £3m in each of the next three years starting 2003/04. We look to the Trust to keep their spending within this limit plus their investment income.

- Express hope that the Trust and officials will continue to work together to discuss ways of managing the demands being placed on the Trust.

- Give an assurance that the Government will provide ongoing support for the work of the Macfarlane and Eileen Trusts, including financial support. However, this must continue to be within strict budget limits. Within this context, happy to consider the outcome of the forthcoming review of needs.

- Convey message of thanks to the other Trustees for all their hard work.

ANNEX A

Macfarlane & Eileen Trusts

Key points for disucession

1 Macfarlane Trust

1.1 400 surviving registrants, creating need for Trust beyond original expectations.

1.2 Co-infection with hepatitis C is main threat to survival.

1.3 Registrants' health ranges from those who are severely ill to those who are able to work and some who are now able to contemplate returning to work.

1.4 Extended life has generated

- many more dependents than originally expected – MFT "community" includes 750 dependents, of whom about 40% receive Trust help exhaustion of financial and physical assets and of family relationships
- increasing dependence on Trust for help not available from social services
- need for help with re-training, mobility and assisted conception.

1.5 Stigma over HIV remains, causing most families, even after registrant's death, to live without ability to share problems with relatives and friends.

1.6 MFT has disbursed over £32 million from Government funding of £27 ½ million plus investment returns, with current funds of some £4 million.

1.7 Trustees seek

- re-affirmation that Trust's registrants and their families remain a special case
- assurance of ongoing Government support for work of Trust
- possibility of review of funding rate following review of needs being undertaken this year.

2 Eileen Trust

2.1 As with MFT, about one-third of original registrants still alive.

2.2 Trust currently gives support to about 30 people. More significant decline in short/medium term foreseeable than for MFT, but greater possibility than MFT of new registrants.

2.3 Most difficulties for ET concern care for dependent children and orphans.

2.4 Trust disbursements total £730,000 from Government funding of £1 million plus investment income; current funds £550,000

2.5 Trustees seek

- re-affirmation that Trust's registrants and their families remain a special case
- assurance of ongoing Government support for work of Trust

ANNEX B

Key Facts

The Macfarlane Trust

1. Set up by the Government in 1988 following a campaign by the Haemophilia Society on behalf of those people with haemophilia who had contracted HIV infection through contaminated blood products in the late 1970s and early 1980s.

2. Remit:

" to relieve people suffering from haemophilia who as a result of receiving infected blood products in the UK are suffering from AIDS or are infected with HIV and who are in need of assistance or their needy spouses, and other dependants after the death of the person".

3. Spend to date:

- £24m initial settlement in 1990 (£20k to each individual)
- £44m in a further settlement in 1991 (payments varied – see below for details)
    - single adult: £ 43,500
    - married adult without dependent children: £52,000
    - adult with dependent children: £80,500
    - children under 18: £41,000
- The Trust has disbursed over £32 million to date. £27½ million plus investment returns, with current funds of some £4 million.

Monthly payments range between £255 to £650 depending on whether partners are also affected and number of dependent children. Payments do not affect entitlements to benefits.

4. Individuals who have received payment

The trust started with 1,240 registrants, of whom 408 are still alive, 238 with families. The Trust also makes payments to 38 widows or partners infected with HIV through intimate contact, 288 other widows and 438 children, 220 whose fathers have died.

5. Trustees

The Macfarlane Trust has 10 Trustees. Six are appointed by The Haemophilia Society and four are appointed by Secretary of State (the DH appointees are Elizabeth Boyd, Dr Mark Winter, Patrick Spellman, and Roger Tyrrell).

6. Financing the Trust

Trust Fund – Annual payments from DH funds currently £2m pa. Should rise to £3m pa during the SR2002 period.

Admin Costs - Both the Macfarlane and Eileen Trusts receive core Section 64 funding to cover their administration costs. The existing commitments are:

	2002/03	2003/04	2004/05
Macfarlane Trust	£252,235	£279,000	£287,000
Eileen Trust	£30,200	£32,500	£33,600

The Macfarlane Trust has submitted a bid for Section 64 funding for £38k in the first year (2003/04) for their Long-Term Review. The aim of the project is to attempt to determine the continuing long term needs of the Trust registrants and to also determine the long term needs of bereaved families and dependant children. This will help inform the DH about the long term financial commitment to this group of patients. Pending final decisions on Section 64 funding we have agreed to make £38k available to the Trust from programme funding.

BIOGRAPHICAL NOTES

Peter Stevens - Chair of the Board of Trustees. He was first appointed as a trustee in 1989, and served till 1992. His elder son who had haemophilia died as a result of HIV contamination in 1989. Peter Stevens retired from a major international insurance broking firm. In July 1999 he returned as a Trustee nominated by the Haemophilia Society.

Ann Hithersay - Chief Executive and Secretary to the Trustees. Ann is responsible to the Trustees for policy, financial and legal affairs and for day to day liaison with the DH, the Haemophilia Society and other bodies.

Dr Mark Winter- is a Consultant Haemotologist and Director of the Comprehensive Care Haemophilia Centre in Canterbury. He is one of the few haemophilia doctors who maintains an active clinical and research interest in HIV related issues and serves on the HIV Working Party of the UK Haemophilia Centre Doctors Organisation. Dr Winter is also the Chair of the Haemophilia Alliance, the Alliance consists of the UK Haemophilia Centre Doctors Organisation, the Haemophilia Society and the RCN Haemophilia Nurses Organisation. Dr Winter has been a Trustee of the Macfarlane Trust for a number of years. He was reappointed by DH, for a further two year`s in May last year.

In his role as Chair of the Heamophilia Alliance, Mark has been actively lobbying the Government to fund recombinant clotting factors for all haemophilia patients. He has recently written to the Times and the CMO on this subject.