

MEETING WITH MACFARLANE TRUST: TUESDAY 18 APRIL

Attending:

Peter Stevens (Chairman of the Trustees)
Dr Mark Winter (Trustee – Haemophilia Centre Director)
Ann Hithersay (Chief Executive)
Nicholas Lawson (Treasurer)

Purpose of Meeting

The Trust wish to discuss:

- the changing needs of Trust registrants, resulting from their longer term survival and the impact on their lives of co-infection with HIV/HCV, and the position of surviving partners and their children. They argue that, as a result, the poverty, and therefore the financial needs, of registrants and dependants are increasing.
- the Trust's resulting financial requirements – they are proposing to increase payments to registrants and dependants from around £2m pa in 1999/2000 to £2.5m in 2000/2001 (against a planned spend in 2000/2001 of £2.3m), rising to nearly £3m in 2005/2006. This increase in payments would need to be funded by the Department.

A note summarising the Trust's main points on the changing needs of registrants and dependants is at *Annex A*.

Remit of the Trust

The remit of the Trust, as stated in the Deed, is:

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.

To do that, the Trust is empowered to provide financial help, holidays, food, clothing, other articles or help, shelter, hospice, housing or other accommodation and promote education /scholarships/apprenticeships for children and young people in need.

Profile of Trust Registrants and Dependants

The Trust started life with 1239 registrants (ie haemophiliacs with HIV). 802 have since died. The current position is:

Registrants: 437 (roughly half aged between 25-40)

Infected Intimates: 39 (partners or widows infected with HIV)

Dependants: 369 widows (140 with children)
347 children (half no longer have a father, 19 are orphans)

Strategic Review of the Trust

The Trust undertook a strategic review in 1998. This highlighted the changing needs of registrants and included a recommendation that:

“Ministers/Department of Health should recognise the changing patterns and increasing financial demands and expectations of registrants. They should provide policy guidance and priorities and furnish the required level of resources”

Following Lady Hayman's meeting with the Trust in June 1999, she wrote to say that:

“We will of course continue the commitment to provide the finances which you need for the Trust Fund. We will also continue to fund the efficient administration of the Trust...”

A copy of this letter is at *Annex B*.

Payments made by the Trust

Current

Currently, the Trust makes three sorts of payments totalling just under £2m in 1999/2000, increasing to £2.3m in 2000/2001 (includes a one off payment of £140K):

- **regular monthly payments** of between £140 & £300, depending on whether the registrant is in receipt of income support and the number of dependant children. These are paid to registrants, infected intimates, widows with children and disabled widows, and totalled £1.3m in 1999/2000. Payments have increased by 11% from April 2000 (the first increase in 4 years) and will total £1.53m in 2000/2001 – this increase also takes account of the growing number of dependants.
- **single grants** for specific one-off costs, totalling £400K in 1999/2000. Examples include house moves/setting up home (conveyancing fees, removal costs, furniture); travel costs (hospital travel costs, driving lessons, car purchase); education (course fees, school trips etc); convalescence costs; special equipment (wheelchairs, special beds) and adaptations/repairs (house adaptations, redecoration, window replacement).
- **winter payments** heating, food etc, totalling £264K in 1999/2000.

These payments are made from the Trust fund. At 31 March 2000, the fund stood at £7.9m. Of this, the Trust maintains at least £4m as investment capital, yielding income at approximately 4.25% pa. . When the fund dips close to £4m, it is topped up by the Department. We provided £2m in 1999/2000 and were expecting to have to make a further payment in 2002/2003 of around £3m (this need was identified in the Trust's strategic review).

The administrative costs of the Trust (currently approx £190K pa) are met through a S64 grant. We also provided an additional one-off core grant to the Trust of £52K in 1999/2000 to pay for new IT equipment and software.

Proposed

From September 2000, the Trust propose to:

- increase monthly payments for registrants and infected intimates by £100 a month, an increase of roughly £600Kpa (full year cost for 2001/2002),
- provide an additional £50K pa to meet the increased financial needs of dependants.
- limit single grant payments to cases where there is a real medical need, resulting in a saving of £200K a year.

This would increase annual payments to £2.4m in 2000/2001 (against £2.3m planned), rising to £2.6m in 2001/2002 and £2.7m in 2002/2003.

| | 1999/2000 (actual) £000s | 2000/2001 (plan) £000s | 2000/2001 (proposed) £000s | 2001/2002 (proposed) £000s |
|------------------------------|--------------------------------|------------------------------|----------------------------------|----------------------------------|
| Regular Payments | 1,313 | 1,527 | 1,814 | 2,101 |
| Increase for dependants | | | 30 | 50 |
| Grants | 400 | 400 | 200 | 200 |
| Winter Payments | 264 | 251 | 251 | 251 |
| Backdated payments (one-off) | | 140 | 140 | |
| TOTAL | 1,977 | 2,318 | 2,435 | 2,602 |

As a result, the Trust are asking for a top up payment of £4m in 2001/2002, a year earlier than planned and of a greater sum than anticipated. At present, there is no provision to make any payment to the Trust in 2001/2002 and there is no contingency funding that year.

A table showing the Trust's projections of their capital needs over the next 5 years is at Annex C.

Assessment of Position

The Trust first discussed these proposals with officials on 6 April. No commitment has been given to provide the increased level of funding requested by the Trust, other than the general commitment in Lady Hayman's letter at Annex B.

We have no reason to doubt that the financial position of the Trust's registrants is worsening. It is also true that the outlook for people co-infected with HIV and HCV is not good:

- HIV and HCV turn each other on, making the conditions hard to manage;
- the 40% response rate from HCV combination therapy is much reduced in people who are co-infected;
- anti-HIV treatment is liver toxic
- more Trust registrants are now dying from HCV induced liver disease than from AIDS-related illness (11 out of 13 deaths among Trust registrants in the past year were from liver disease).

We think that the Trust's proposal to increase regular payments and cut back on the less equitable grants is the right response. However, we also have some concerns:

- that the additional needs identified by the Trust – complementary therapies, adaptations to housing, fuel costs etc – should more properly be provided (if at all) by other agencies, eg HAs, LAs and the social security system. This point was picked up at the meeting last year with Lady Hayman and reflected in her follow up letter (Annex B). It is likely that the Trust is picking up the cost of services that other agencies have decided are not a priority for spending.
- the growing number of dependants, and the uncertain life expectancy of registrants, means that the life of the Trust could be extremely prolonged, with considerable long-term costs (£12-13m over the next five years and probably similar sums beyond that).
- the more special treatment given to haemophiliacs with HIV the more the gap widens between their circumstances and haemophiliacs with HCV only, making it harder to sustain the argument for treating the two groups separately.

It is hard to resist the Trust's request for additional funding to meet the needs of registrants when the Trust is acting within the terms of its remit as laid down in the Trust Deed. However, before additional funds are committed (assuming the money can be found in 2001/2002), we recommend that the Department commissions an independent review of the Trust's activities. This could:

- address the needs of the Trust's registrants;
- make recommendations on how the Trust might best use its resources to meet those needs;
- consider whether there is scope for the Trust to increase its investment income;
- consider what the Trust and the Haemophilia Society might do to ensure that registrants receive the support they are entitled to from other agencies;
- examine the case for the Department providing increased resources.

This would need to be done quickly and could be presented in a positive way - as a means of working constructively with the Trust to ensure that the needs of registrants are fully addressed. Although the Trust has undertaken its own strategic review which went over some of this ground, it would hard to justify additional spending without an independent assessment of the position.

Points to Make

- stress the continuing commitment of Ministers to the work of the Trust. We were pleased to be able to provide a further £2m in 1999/2000 to top-up the Trust Fund and will continue to maintain the Fund at a mutually agreed level;
- we will also continue to fund the efficient administration of the Trust, but agree that Section 64 is not the ideal mechanism for this. We will see if it is possible to fund the administration of the Trust some other way;
- understand and sympathise with the worsening position of the Trust's registrants, particularly the problems faced by those who are co-infected with HIV/HCV;
- we have not set aside top-up funding for the Trust in 2001/2002, expecting that the need would fall the following year. This may present us with difficulties as there is no contingency budget for that year.
- we will look carefully and quickly at the Trust's proposal for increases resources to meet the needs of registrants. Given the severe constraints on resources at present, we propose – before making a decision – to commission an independent assessment of the situation by someone with a knowledge of haemophilia, who can work with the Trust and report quickly to the Department. This would build on an update the Trust's own strategic review.

Other Issues the Trust may Raise

Section 64 – application for a project grant on bereavement

We have turned down the Trust's request for S64 funding for a bereavement project (£25K over 3 years) to establish mutual support networks and counselling for bereaved families of haemophiliacs with HIV who remain distressed, damaged and unable to come to terms with their grief. The reason was lack of funds rather than any doubts about the value of the project.

Appointment of Trustees

There are two vacancies which need to be filled by DoH nominees – a haemophilia centre social worker and a retired civil servant. We will be putting a submission to you shortly with recommendations for these appointments.

Letters to Retiring Trustees

When Peter Stevens wrote to you recently accepting his appointment as Chair of the Trustees of the Eileen Trust, he asked if you would write valedictory letters to his predecessor – the Rev Alan Tanner – and to the recently retired Deputy Chair, Clifford Grinstead. You have already written to thank Alan Tanner for his years of service. We will be sending you a similar letter shortly to send to Clifford Grinstead.

ANNEX A

Macfarlane Trust: Changing Needs of Registrants and Dependants

Longer Term Survival

The position, outlook and expectations of registrants has changed significantly since the early 1990s:

Early 1990s

most adults employed

partners also employed

many boys and young bachelors

no expectation of long-term survival

in receipt of recent lump sum settlement payments (1990/91)

2000 and beyond

mostly unemployed

partners generally full-time carers

growing dependant families – few still live with parents

uncertain life expectancy

Additional Needs Identified by the Trust

| | |
|----------------------------------|--|
| Housing | - cost of setting up home and of moving |
| | - cost of maintenance and adaptation |
| | - unreliability of Disabled Facilities Grants |
| Complementary Therapies | - inconsistency of availability in the NHS |
| Extra costs of living with HIV | - diet, fuel, clothing, bedding etc (est £400 a month) |
| Issues Arising from Co-Infection | - inconsistency of NHS treatment |
| | - greater dependency on complementary therapies |
| | - increased uncertainty of life expectancy |
| | - added stress on families |
| Dependants | - no insurance or pensions provision |
| | - partners generally unemployed (full-time carers) |
| | - education of children (many suffering from trauma) |
| | - post-bereavement trauma & poverty |
| Constructive use of Time | - mobility, communications, computers |
| Holidays | - respite for carers and other dependants |

ANNEX B

The Reverend Prebendary Alan Tanner OBE
Chairman
The Macfarlane Trust
Alliance House
12 Caxton Street
London SW1H 0QS

I was very glad to have the opportunity to meet with you on 17 June to hear about the Macfarlane Trust's work first hand. As I said then, your presentations left a much more lasting impression than correspondence ever could. I should be grateful if you would thank Ann Hithersay, Clifford Grinstead, Tim Hunt and Mark Winter on my behalf, and also the other Trustees and those who work with the Trust.

I can give you my assurance that we are fully supportive of the Trust's work and have great admiration for the thought and energy which you give to it. We will of course continue the commitment to provide the finances which you need for the Trust Fund. We will also continue to fund the efficient administration of the Trust and we will meet the costs of appropriate information technology to meet today's needs.

I have great confidence in the way the Trust has conducted its affairs, and your financial record speaks for itself. I was very appreciative of the way you expressed the Trust's clear commitment to the careful stewardship of the monies which it receives.

I was particularly interested to hear about the way in which you have assessed the changing patterns in the lives of people with haemophilia who have been infected with HIV, fully enabling the Trust's registrants to participate in the review and setting out the recommendations clearly. I do recognise that those who have had a changing life expectancy have needed to take a view of their lives, and the options open to them, according to what seemed possible at each moment. It must have been very difficult for the Trust's registrants to adjust to the moving goalposts, as you described it. It is clearly the right thing to do, as you recommend, to work with other organisations in addressing the issues as we can now see them.

I was pleased to hear from you that the Trust would obtain support for its registrants from the range of appropriate sources, for example benefits and local authority assistance with adaptations. For my part, I advised that we would consider the benefits issues which you have raised in the course of the Government's Welfare Benefits Review.

I would be very happy to meet with you annually to "stocktake" any outstanding issues and to offer help where I can. This does not mean, of course, that we cannot meet before that year is up, but it seems reasonable to start with the aim of meeting once a year. There are some residual issues, including full notification of the S.64 grant and the appointment of Trustees, which officials will be completing and discussing with you, consulting Ministers as appropriate.

Once again, thank you for the time you have given to presenting your work to me and I hope I have been able to reassure you on any concerns.

LADY HAYMAN

ANNEX C

Macfarlane Trust: Projected Movement on Capital 2000-2006

(assumes proposed increases are made to regular payments from September 2000)

| Year | Payments Made £000s* | Investment Income £000s** | Top Up Payment £000s | Capital Balance £000s |
|--------------------------------------|----------------------------|---------------------------------|----------------------------|-----------------------------|
| Starting Position – 31.03.2000 | | | | 7,908 |
| 2000/2001 | 2,500 | 336 | | 5,744 |
| 2001/2002 | 2,600 | 244 | 4,000 | 7,388 |
| 2002/2003 | 2,678 | 314 | | 5024 |
| 2003/2004 | 2,758 | 213 | 4,000 | 6479 |
| 2005/2006 | 2,841 | 275 | | 3,913 |
| 2005/2006 | 2,926 | 166 | 5,000 | 6,153 |
| TOTALS | <i>16,276</i> | <i>1,548</i> | <i>13,000</i> | |

* payments increase by 3% annually

** investment income estimated at 4.25% of previous capital balance.