

## 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	
<b>TOTAL</b>	<b>1,977</b>	<b>2,318</b>	<b>2,435</b>	<b>2,602</b>

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 be 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 increased 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 of 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.