

## **THE ARCHER INQUIRY**

### **Evidence submitted on behalf of the Board of Trustees of the Eileen Trust ("ET") by the Chairman of the Board of Trustees, Peter Stevens.**

#### **Personal background**

*My name is Peter Stevens. I am Chairman of the Eileen Trust, which was established in 1993 by the Government to provide assistance to people who had been infected with HIV through NHS treatment with contaminated blood or blood products of conditions other than bleeding disorders. I have been a Trustee since 1999.*

*I was appointed by the Haemophilia Society to be a Trustee of the Macfarlane Trust from its inception in 1988 until 1992. I was re-appointed in 1999 and succeeded the Revd. Prebendary Alan Tanner as Chairman in 2000. I retired from that Trust in January this year.*

*I was a Trustee of the two non-charitable Trusts established in 1990 and 1991 to administer, to HIV-infected haemophiliacs, respectively the ex gratia payment and the settlement payments. I am still a Trustee of both, although they are in practice dormant.*

*I was closely involved in the discussions with the Department of Health ("DoH") and the Devolved Administrations in the establishment of Skipton Fund Limited, following the 29 August 2003 announcement by John Reid of the Hepatitis C ex gratia payments scheme, and have been Chairman of the Board of that company from its inception.*

*I was the father of two sons with severe haemophilia A. My elder son died in August 1989 from HIV-induced lymphoma, aged 22. My younger son, now 37, was infected with Hepatitis C, but is currently well, with a wife and daughter and in employment. Both boys were patients of Professor Savidge at St Thomas's Hospital (after an initial period at Great Ormond Street); my elder son also received treatment at the Nuffield Infirmary in Oxford between 1985 and 1988 when he was at university there.*

*My sons' mother died in early 1989. Most of the memory of their treatment, information and other aspects of their condition effectively died with her, so I am not intending to give evidence relating to their infection or disease.*

#### **The Eileen Trust ("ET")**

*This Trust was established in 1993 following a campaign led, at least in part, by one of the Trust's surviving registrants, who lives in Scotland and has been invited to give evidence to the Inquiry. ET was directly modelled on the Macfarlane Trust ("MFT") and, from the outset, was administered by MFT staff, having no staff of its own. Of its five Trustees, all appointed by the Secretary of State, three are required by its Trust Deed to be MFT Trustees (one of these, curiously in the context of ET's registrants, to be a Haemophilia Centre Director).*

*There have been fewer than 100 registrants of the Trust so far, of whom about a quarter are still alive; about half of the registrations were made posthumously. The circumstances of their infection vary, but generally were all the result of single*

transfusions of blood in the course of surgery or other medical treatment. As with MFT registrants, ET registrants were infected in the mid-1980s. None of the current ET registrants was infected with Hepatitis C, as far as the Trustees know.

While some of the survivors continue to live with some aspect of the condition for which they received the treatment, others are well other than their HIV infection. Some people in this situation might well have received no medical attention since they were infected. In consequence of this, ET has had 7 new registrants in the last 6 years, who had been HIV+ since the 1980s but with either no symptoms or no correct diagnosis of their condition until recent years. This has resulted in some cases in progression of the infection to a level of acute severity before they could obtain any help from ET.

The DoH has made occasional efforts to alert medical practitioners to the existence of ET and, therefore, to the possibility of finding patients who were infected through NHS treatment during the 1980s. It is questionable whether this work has been sufficient given the risks of onwards transmission of the infection from those affected. The Trustees are currently aware of a new application for registration, and believe that there is a strong probability that the number of registrants will continue to grow.

Because of the relative sizes of MFT and ET, ET has until recent years seemed somewhat of a Cinderella in terms of the time given to its registrants. However, the smaller numbers have enabled the ET Trustees to develop a much closer knowledge of each individual registrant's circumstances than is possible within MFT. It is probably fair to say that ET now gives a more personal service to its beneficiaries than MFT has ever managed, with the help of a dedicated case-worker.

#### Rate of funding

ET was set up with a fund of £500,000. It also received a separate annual grant, under a scheme known as Section 64, to cover administration costs. In practice, with virtually all its operations run by MFT staff, MFT makes a charge to ET that absorbs the S.64 grant apart from what is needed to fund costs incurred directly.

This initial £1/2 million lasted until 2001, when a second £500,000 tranche was provided. This was disbursed more rapidly, and in 2006 and 2007 ET received further annual funding of £140,000, together with a S.64 grant of £38,000; the DoH has indicated that the total figure of £178,000 will probably be matched next year, without a discrete element for administration costs.

The principal reason for the acceleration of the rate of disbursement is the increase in the number of registrants. This is contrary to MFT, for which virtually all registrants were known at the time of inception, all but handful of new cases since then having arisen from indirect infection (i.e. through sexual transmission). In the case of ET, as outlined above, while the period of direct infection closed at the same time as that for MFT registrants, there was less knowledge of those that had been infected and new cases, both direct and indirect, have been discovered throughout ET's existence.

The rate of disbursement has risen also because of increasing need. In November 2005, following a thoroughly researched and fact-based survey, a report was presented to the DoH titled "*Funding Long Term Survival*" which made the case for a substantial rise in annual disbursements by MFT from about £3.5 million to about £7.5 million, with



matching funding; the basic justification for the increase was that the current registrants who had been infected with HIV in the 1980s have now survived much longer than the few years originally expected, and in consequence had present and accumulated needs that MFT could not meet on its present funding; in addition, it was recommended that further capital payments be made to registrants. An Appendix to this report made similar recommendations in respect of ET. The recommendations have not been accepted by the DoH, which has so far not even shown a willingness to provide for cost of living increases.

Furthermore, the DoH have shown no understanding of, or willingness to increase ET's funding for, increases in the number of ET registrants.

#### Means of support

As a result of the afore-mentioned close connection with MFT, identical means of giving financial support to registrants have been adopted:

- a monthly income supplement to cover the extra costs of living with HIV
- an annual income supplement to cover the further additional costs incurred in winter
- single grants, in response to specific applications to help with anything that registrants needed (not all applications are successful).

Generally about two-thirds of the Trust's total annual disbursements have comprised the monthly income supplements. These vary in amount depending on each individual registrant's circumstances, for which the welfare benefits are used as a proxy for a more rigorous means test.

Only recently has there been divergence in the rates of monthly income supplements between the Trusts.

Because the underlying health problems of ET registrants, other than HIV, differ from those of MFT registrants and vary between individual registrants, there is less consistency of single grant requests and applications. On the other hand, the small number of ET registrants has enabled the Trustees to have a much better knowledge of each registrant's circumstances and needs and to vary grant-giving policies accordingly.

#### Capital payments

ET registrants, once identified and accepted as such, receive capital payments on the same tariff as the 1991 settlement payments to MFT litigants, through ET but funded, individually and *ad hoc*, by the DoH. A recent outrageous suggestion that ET should meet such payments without special funding, in the event of further new registrants – an eventuality which the Trustees regard as highly likely – has been withdrawn after strong objections from the Trustees.

These capital payments were, by modern standards and by comparison with those made in other countries, very small. The tariff for the ET settlement payments also discriminates against those who were still minors, or were unmarried, or had no children. In the context of the expected deaths of all concerned within a very short period of time, this discrimination might have been justified in the early days of the Trust. In the

context of survival to today and beyond, and of new registrants, both the size of the payments and the way they discriminate are totally unjustifiable.

Recipients of the capital payments are required to sign a waiver of their litigation rights against the DoH, the NHS and individuals employed therein.

*"Funding Long Term Survival"* recommended that ET registrants should receive a substantial new capital payment for the same reasons as MFT registrants.

#### The benefits system

It has always been the belief of ET Trustees and registrants that the Trust was the first line of support for its registrants. This was clearly constrained by the level of resources available, so that registrants also needed to have recourse to the benefits system (at least there is no reduction in their entitlements thereto because of receipts from ET).

This belief was not only in line with all indications received from the Government, but also recognised the stigma that has always, even to the present-day, tended to be attached to those infected with HIV, making approaches to sources of welfare benefits fraught with difficulty and, all too often, resulting in dangerous breaches of confidentiality.

Recent meetings at the DoH revealed that this belief is no longer shared by Ministers or officials, but that the DoH now feels that ET registrants should look primarily to the benefits system for their welfare, with ET providing only "top up" support.

Given the nature of the problems associated with HIV infection, especially for those who had been unaware of their infection for many years, as well as other problems linked to the underlying conditions that necessitated the faulty treatment, this attitude is wholly inappropriate.

#### Responsibility

The NHS was clearly responsible for the infection of ET registrants.

This is not a statement of blame, liability or accountability, but simply one of fact. Furthermore, since blood transfusions have been a standard feature of much medical treatment for a very long time, there is no reason why the physicians treating ET registrants might have been aware of any concerns about the safety of blood that they required for their patients. So the real responsibility is within the DoH, an arm of the Government, which did not ensure the safety of the blood.

In contrast to liability or accountability, responsibility cannot be discharged or transferred. Just as parents will always be responsible for their children, so the Government's responsibility for the health and well-being of ET's registrants is permanent. The current attitude of the DoH towards the Trust is an abnegation of responsibility.

In a letter of July 2006 addressed to both MFT and ET, giving the Government's response to the report *"Funding Long Term Survival"*, the Minister of State for Public Health said that "she was satisfied that an increase of approximately 11% to the Trusts' funding will maintain an appropriate level of support to their remaining registrants". The

Minister has no right to express satisfaction when the Trustees, who had carefully researched and know their registrants' needs, had requested considerably higher increases.

Be referring to the "remaining registrants" the Minister clearly indicated both her failure to comprehend that the number of ET registrants is rising year by year, and her failure to grasp the Government's responsibility for all ET's registrants, even those who have not yet been identified.

### Conclusion

ET is a discretionary charitable trust, not a vehicle to deliver a tariff of compensation payments. The circumstances of those that it supports are such that ET should be their primary source of help, not a scantily-funded source of top-up.

ET is undoubtedly small, with few registrants. There could be different means of providing that support, but they would require a greater acceptance of responsibility than successive Governments have shown. However, there is little doubt that the current indications of policy of the DoH towards ET and its registrants show even less understanding of its responsibility than hitherto.

Successive Governments have chosen not to provide levels of true compensation that would match their responsibility; they have instead opted to provide ongoing support through ET whose Board of Trustees are charged with the duty to relieve the needs of its beneficiaries. They cannot perform that duty unless adequate funding is provided.

The Government must recognise both the fundamental change brought about by the long-term survival of victims and their families, and the fact that the number of ET registrants is growing and is likely to continue to grow. A commitment to substantially increased funding for the Trust and to substantially enhanced capital payments for its registrants is not just essential but also morally irrefutable.

Peter Stevens  
Chairman, The Eileen Trust  
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