

FINANCIAL AND INVESTMENT REPORTS

CASE WORKER'S REPORT

**REQUIREMENTS FOR FUTURE FUNDING OF THE EILEEN TRUST
BASED ON AN ANALYSIS OF THE LIKELY NEEDS OF THE
REGISTRANTS
AUGUST 2012**

Introduction

Even with considerable experience, which the Trust obviously has, it is difficult to gaze into the future with any certainty. Certain issues are obvious and this report will cover the aging of the registrants, and of course their spouses (partners) who are often their main carers.

It is far from clear that all of the registrants who may be eligible to join the Eileen Trust have, as yet, been identified. Whilst new registrations are not a usual occurrence, eight have occurred since the turn of the century and more will obviously swell the population of the Eileen Trust community, which will clearly affect the requirement for extra funding. There are two cases under consideration at the time of writing, one of which seems quite likely to be eligible for registration with the Trust.

The aging of the community of the Eileen Trust is causing registrants to be even more vulnerable, with infirmities and other problems of old age allied to their already difficult medical condition. This is particularly relevant to those recently registered, whose late diagnosis of HIV had led to a severe deterioration in their health both mentally and physically.

HIV has generally led to loss of earnings, for both the infected registrants and their partners, who have been unable to work in order to provide care. All these registrants and partners have thus been severely financially disadvantaged. This has affected a wide range of financial areas including pensions, housing and savings and has left registrants feeling financially vulnerable and insecure about the future, adding to their natural concerns about the medical condition of their partners.

GRO-A 5091 (**GRO-A** 1961) – this registrant is severely disabled having contracted HIV whilst having his leg amputated; at the same time he contracted hepatitis C (he is currently the only registrant known to be co-infected). Although he is currently able to manage on the funds he receives from the MFET payment and additional help from the Trust, his future needs will inevitably increase, as he is now middle-aged and unlikely to improve as he moves into his later years.

GRO-A 5011 (GRO-A/1963) – this registrant is a good financial manager but inevitably her capacity to handle her affairs may become less as the aging process takes effect.

GRO-A 5090 (GRO-A/1942) – this registrant was diagnosed many years after contracting the HIV virus. The infection has affected his brain which means he needs constant care. His wife, also in her 70s, was diagnosed with lung cancer a year ago and her prognosis is poor, which means that his principal carer may well not be able to provide care in the near future.

If the registrant died first, an annual income from the Trust to his surviving wife, of, say, £6,000 per annum, would help with the reduction in income, which is mainly made of MFET payments; also a one off payment of £7,000 to help defray the costs of funeral and probate expenses. If his wife pre-deceased him, he would probably need to move into some form of managed or sheltered accommodation. His MFET income would probably suffice but a similar bereavement payment would be most likely be necessary.

GRO-A 5058 (GRO-A/1959) – this registrant is one of the younger registrants and is professionally qualified, which enables her to cope adequately at the moment. It is not possible to say whether the HIV virus will cause difficulties as she ages.

GRO-A 5074A (GRO-A/1937) – this registrant is now entering her 70s and may well require assistance in the future.

GRO-A 5072A (GRO-A/1933) – this is a particularly sad and complicated case, as this registrant contracted the disease during his first marriage, his wife being the initial registrant. She has since died and her husband has become a registrant in his own right. He is elderly and has remarried. However, his second wife is also disabled and is unable to care for him. He is himself frail. **A grant of £2000 has been provided for the deposit on a motability car.**

This is a good example of the financial disadvantages that have manifested themselves. Having contracted the disease from his wife, the registrant was unable to work, his income fell, and he is now left with a £70,000 interest-only mortgage, with no way to settle the debt. It is likely that the Trust will need to provide for this mortgage to continue to be serviced and to provide help with further care needs. Due to the HIV infection this registrant was unable to obtain any life assurance.

The immediate needs of this couple are a grant of £2,000 to assist with the purchase of a "motability" car.

The probable financial needs of this couple are similar to those of 5090 above. If the registrant died first, an annual income from the Trust to his surviving wife, of, say, £6,000 per annum, would help with the reduction in income, which is mainly made of MFET payments; also a one off payment of £7,000 to help defray the costs of funeral and probate expenses. There would also be a need for an additional annual income to cover the modest (at present) interest on the mortgage; this would cost approximately £2,000 per annum at current interest rates, which are historically low. Clearly this sum may be greater if interest rates rise over the years.

If the wife died first, the probable needs would be a bereavement grant but no further income supplement.

GRO-A 5022 (GRO-A/1942) – whilst the registrant and his wife have managed fairly well financially, he has been in and out of hospital over many years and is now extremely frail. He is fortunate in having an able carer but she is also now moving into her later years and after many years of caring for her husband is finding it more difficult to cope.

A bereavement grant might be necessary on the first death to assist with funeral costs and probate.

GRO-A 5088 (GRO-A/1984) – this is a case where the responsibilities of the Trust extend for many years as he is in his late 20s. Currently his relative youth enables him to deal with the medical situation but he has a low level manual job which will become more difficult as he ages and if the medical condition deteriorates, which is reasonable probability.

GRO-A 5054 (GRO-A/1968) – although this registrant is one of the younger registrants, he is in poor physical condition. He suffers from angina as well as diabetes on top of his HIV positive status. So far his mother has been his primary carer but she is now in her 60s and has recently suffered from breast cancer which has resulted in a mastectomy. Their financial situation is poor as his mother has been unable to have a normal job due to her caring responsibilities. As he is only middle-aged, it is likely that the Trust will have an increasing responsibility for many years to come.

This registrant currently receives £3,000 per annum from the Trust, in addition to the MFET payment, to help with living expenses as the household income is very low.

GRO-A 5086 (GRO-A/1967) – this registrant currently enjoys reasonable health but is very concerned about her HIV status becoming known in her local community, which has limiting effects on her life style.

This registrant currently receives £1,800 per annum from the Trust to help with living expenses.

GRO-A 5092 (GRO-A/1985) – this is a young registrant, who is also profoundly deaf. He is currently unemployed and has suffered very considerably with the principal medical and physiological effects of HIV infection. Presently, he lives with his brother but there is little doubt that he will require greater medical care as he ages. Due to the fact that he was not informed about the existence of the Eileen Trust until very recently, he has also been significantly financially disadvantaged.

This registrant currently receives £4,800 per annum from the Trust to supplement the MFET payments.

GRO-A 5023 (GRO-A/1978) – this registrant is unable to care for herself or maintain an independent existence; she has various medical problems other than HIV, including heart problems and Noonan's syndrome. She currently lives in a specialised HIV community at considerable cost, which will inevitably increase. Her medical situation leads to almost constant hospital visits on which she has to be accompanied. This registrant will need considerable care for perhaps 20 to 30 years. Most of the costs of her care are provided by the local authority. **GRO-A is moving into a flat next door to the therapy centre, she will still receive care from the centre. A grant of £5000 has been agreed to assist her with furnishing the flat and moving expenses.**

This registrant is moving to an attached flat, adjacent to the therapy centre, and will receive a one off payment of £5,000 to help with moving costs.

GRO-A 5087A (GRO-A/1997) – this registrant was infected when born, by her late mother. Her principal carer is her aunt, with whom she lives. Clearly this registrant will be a responsibility of the Trust for a very considerable period, but is unlikely to need financial support for the foreseeable future.

GRO-A 5085 (GRO-A/1962) – this registrant has two young children (8 and 12) and is not in a robust condition. She is unable to work due to the HIV infection and a blood condition, which requires numerous hospital visits. This family require a large amount of financial support from the Trust because they have a young family and only one salary, which is fairly low. The need for financial support will last for many years as the childrens' needs will increase.

This family receives £9,600 per annum in addition to the MFET payment to enable them to defray the high costs of bringing up a family on only one modest income.

GRO-A 5093 (GRO-A/1961) – this is another registrant who was not notified of the existence of the Trust, thus once again he was financially disadvantaged for many years. He is unable to work and relies on his elderly parents for support. In his early middle age, he will require support for many years, particularly as his parents age and are no longer able to act as carers.

GRO-A 5089 (GRO-A/1955) – this registrant was a late diagnosis. Because HIV infection has damaged her brain, she has severe mental and physical problems. Her husband has been unable to work because she has needed constant care and is unable to cope with being alone. The strain on the family both emotionally and financially has been immense, with her husband trying to take his life some months ago. There is significant need for help in this family and the trust has provided financial and pastoral help. This situation will not improve and the Trust will have a financial commitment for many years.

This registrant currently receives £7,800 per annum to assist with the costs of care. In the event of either death a one-off payment of £7,000 would be made to pay funeral and probate costs. The surviving spouse would probably need to receive an income supplement to make up for loss of income, although this would be less if the husband pre-deceased the registrant.

GRO-A 5099W (GRO-A/1943) – this registrant is the widow of a registrant who died some years ago. Due to the fact he ran his own business, his provision for old age was minimal and his wife was left in a poor financial condition, with no occupational pension. This commitment could last for a significant number of years, given the current longevity of an aging population.

This registrant receives £6,000 per annum to help with living expenses. She is not entitled to MFET payments.

GRO-A 5005D (GRO-A/1991) – this is the son of a deceased registrant. The Trust has contributed toward his maintenance during his education, but will probably soon cease to provide him with any continuing support. **The payment of £250 per month is due to end this month.**

GRO-A 5076 (GRO-A/1979) – this is the most recent registrant, not having been informed of the existence of the Trust when he received his lump sum payment from the DoH. He is young and is unable to work, therefore represents a very long term commitment for the Trust. He currently lives in private-rented accommodation, the cost of which is rising rapidly. It might be that it would be beneficial for him to move into a small home of his own, which would provide him with security and could possibly prove less expensive for the Trust than providing him with sufficient income, on top of his MFET payments, to cover his rent and other living expenses; however, this would represent a considerable capital and on-going cost.

This registrant could receive £10,000 to assist in a move to a small home with help of up to £6,000 per annum being towards the costs of the mortgage.

GRO-A has now found a small house to purchase for £75,000 he is raising a mortgage of £55,000. Agree grant for moving costs.

Potential new registrants

There are currently two potential new registrants of the Trust, both awaiting confirmation from the National Blood Transfusion Service that they received an infected transfusion from the NHS.

On the assumption that the NBT confirms their eligibility, both of the above will join the Eileen Trust and receive regular payments. Additionally as they have been severely financially disadvantaged by non-discovery of their HIV infection, they might need considerable lump sum payments to cover accumulated deficiencies in their circumstances as well as income supplements additional to their MFET payments. There is no suggestion yet of mal-administration that might justify back-dating MFET payments. They will, if accepted, receive capital payments under the scheme.

Costs

It is difficult to provide an exact estimate of costs but these costs have been broken down into three categories, as follows:

- a) Younger registrants whose condition was diagnosed early and are currently coping with their condition, as best they can.
- b) Middle-aged registrants who need additional help.
- c) Older registrants who, in the writer's opinion, are the sector who will require the most help now and over the coming years. It is assumed that provision should be made for the deaths of two out of the five beneficiaries whose life expectancy now appears to be quite limited.

The figures below include winter fuel payments, an estimated cost of two funerals/probate, the annual ET event and the costs associated with potential new registrants.

For the future the registrants in categories a) and b) will move into category c), thus the needs of the Trust's community will inevitably increase.

Estimate

With all the difficulties of forecasting explained above, the figures would appear to be of the order of:-

1. A potential capital cost, in the next 12 months, of £51,000.
2. An on-going annual cost of about £100,000, as laid out above (this allows for a cost-of-living adjustment to the annual income payments being made to a few registrants).

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