THE MACFARLANE TRUST

STRATEGIC REVIEW

FINAL REPORT

JANUARY 1999

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CONTENTS

Executive Summary and main Recommendations

Strategic Review – Main Report

MACFARLANE TRUST - STRATEGIC REVIEW
EXECUTIVE SUMMARY

1. The Macfarlane Trust was created in 1988 following a campaign by the Haemophilia Society on behalf of those people with haemophilia who had contracted HIV infection through NHS treatment with contaminated blood products in the late 1970s and early 1980s. Without conceding liability, the Government with all-party support , recognised the special case of these people and a grant of £10,000,000 was announced in Parliament on 16th November 1987, when Government stipulated that a new Trust should be set up to administer the fund. The Macfarlane Trust has, since 1988, been an effective means of support, and is a resource on which they have come to depend.

2. Around 475 people registered with the Trust are still living, and a further 175 families of deceased registrants are being helped by the Trust under the terms of the Trust Deed.

3. This detailed, in-depth Strategic Review has identified changing patterns of needs and expectations of registrants who are benefiting from more effective treatments which increase life expectancy.

4. Recent advances in treatment of HIV/AIDS through multiple drug therapy has markedly reduced the death rate, but the rigorous drug regime may bring severe side effects which are more complex for people with Haemophilia, particularly those 95% of registrants also infected with HCV.

5. The extra costs of maintaining a reasonable quality of life, or managing sometimes prolonged terminal illness mean that this group of people are still a 'special case' as was recognised by Parliament in 1987, leading to the establishment of the Macfarlane Trust in 1988.

6. The Trustees need to be flexible in meeting the changing needs of people registered, and have identified areas of future support that can be achieved by the Trust alone. In addition the Review has highlighted priority projects for development in partnership with the Haemophilia Society and other voluntary organisations and has identified actions needed by the Health Service and other Government Agencies. Much but not all of the latter as part of a National Framework of care for people with HIV/AIDS.

7. The Trust needs continued financial security to achieve any part of this programme of support, and Trustees see little prospect of a reduction in annual expenditure for at least five years, with a definite prospect of some level of support being needed for ten or more years.

8. At 30th September 1998 the Trust had assets remaining of £7,711,675. If support to registrants continues to be given at an anticipated annual expenditure of not less than £2 million a year for the next five years total assets of not less than £10 million will be required. Indeed, if further needs identified by this Review are to be met, additional resourcing will be necessary.

9. In 1997 The Trust confirmed to the Department the need to keep investment levels up to £4,000,000 in order to maintain payments. This suggests that it would be necessary for the Trust to receive further funding from Government in 2000 and again in 2003 to top up the Trust Fund.

10. It would also be necessary to continue to fund the administration of the Trust with Government assurance of Section 64 Core Funding or similar funding mechanisms.

11. Feedback and reassurance would be given to all Trust registrants'; future needs would be monitored and further reports made to Government at regular intervals.

12. Main Recommendations:-

To Macfarlane Trust

12.1 **To provide a cost effective and efficient administration to ensure that provisions of the Trust Deed and agreed policies are pursued with probity, diligence and accuracy, providing a high quality and responsive service to registrants.**

12.2 **To respond to newly identified areas of need including support for carers respite, lifestyle choices and take up of education and training opportunities.**

To Ministers/Department of Health

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

MACFARLANE TRUST

STRATEGIC REVIEW 1998 - FINAL REPORT

1. INTRODUCTION AND BACKGROUND

1.1 Background to the Macfarlane Trust

The Macfarlane Trust was created in 1988 following a campaign by the Haemophilia Society on behalf of all those people with haemophilia who had contracted HIV infection through NHS treatment with contaminated blood products in the late 1970s and early 1980s. Without conceding legal liability, the Government with all-party support, recognised the special case of these people and a grant of £10 million was announced in Parliament on 16th November 1987, when HM Government stipulated that a new Trust should be set up for the purpose of administering the fund.

The objects of the Trust were and remain 'to relieve those persons suffering from haemophilia who as a result of receiving infected blood products in the United Kingdom are suffering from Acquired Immune Deficiency Syndrome or are infected with human immunodeficiency virus and who are in need of assistance or the needy spouses, parents, children or other dependants of such persons and the needy spouses, parents, children or other dependants of such persons who have died.'

The Macfarlane Trust Deed was signed on 10th March 1988.

1.2 Governance of the Trust

The Trust is governed by the Trust Deed (as amended) and under the control of ten Trustees, six of whom are appointed by the Haemophilia Society and four by the Secretary of State for Health. Trustees appointed by the Haemophilia Society serve for a term of two years and are then eligible for re-election. In practice most Haemophilia Society appointed trustees have served for at least two terms of office.

The Structure of the Trust is shown at Annex A

1.3 Funding of the Trust

In the ten years since the Trust was established, grants totalling £20,500,000 have been received from Government. At 31st March 1998 the Trust had paid out £20,126,349 to registrants. By careful husbandry and investment, by March 1998 there was capital remaining of £6,287,117, to which was added, during the last days of March 1998, the most recent payment from Government of £3 million, (included in the £20,500,000 above) making total assets held at 31st March 1998 of £9,287,117.

1.4 Payments made to Registrants

Payments to registrants may be broken down as follows:

Regular Monthly Payments [to assist with additional costs of living with HIV]	£12,633,767
Single Grants [to meet specific one-off costs – see Annex C.]	£ 4,270,147
Winter Payments [to meet additional winter costs related to HIV: heating, food etc]	£ 3,222,435
Total:	£20,126,349

Significantly, it should also be noted that in 1990 the Government made available the sum of £24 million so that an ex-gratia payment of £20,000 could be made to each registrant, and in 1991 to avoid litigation, a further £42 million was made available. The Trustees undertook the disbursement of both these awards under provisions set out in separate Special Payments Trust Deeds.

2. THE NEED FOR A STRATEGIC REVIEW

2.1 Previous Reviews of the Macfarlane Trust

Since the Trust was set up in 1988 there have been two major reviews of its work:-

The first Review, carried out in 1995 by Public Attitude Surveys Ltd on behalf of Trustees aimed to discover how effective the Macfarlane Trust was seen to be by the registrants, and whether their needs could be more effectively met by the Trust.

The second Review of the Trust was carried out by CAF Consultants on behalf of the Department of Health in 1996 and looked more closely at administrative and financial aspects of the Trust's work.

[Summaries of both these reviews are included in the 'Working Papers' binder appended with this Report.]

2.2 A Changing Outlook – Medical and Psychosocial Aspects

On the basis of experiences in the early years, both previous Reviews deduced that Trust registrants were a diminishing group with a steady reduction in numbers leading to a predictable scaling down of Trust activities and funding. However, the introduction of new treatments for HIV/AIDS has significantly changed the situation for all those with HIV infection in the UK. **Life expectancy for Trust registrants has been well beyond earlier projections. This has considerable implications for the future of the Macfarlane Trust as a grant giving body for their benefit, and for substantially longer Government funding for both administration and grants.**

Combination therapy using three or more drugs to attack the virus at different stages of its lifecycle has dramatically reduced the death rate from AIDS and improved the quality of life for patients with HIV infection. This has changed the outlook for many Trust registrants from imminent terminal illness to an uncertain but extending life expectancy dependant on a rigorous regime of drugs and supportive therapies.

As a consequence, the forecast decline in numbers of Trust registrants has not taken place. Significantly, in 1995, 90 trust registrants died; in 1997 there were 33 registrant deaths; and in 1998 only 22 registrants died. Therefore the death rate has fallen from 133 per 1000 in 1995 to 46 in 1998.

However, despite the obvious medical benefits and reduced numbers of patients dying from AIDS related disease, the new multiple drug therapies may bring severe side effects such as vomiting, abdominal pain and diarrhoea, peripheral neuropathy and for some people with haemophilia, increased incidence of soft tissue bleeding. **Accordingly, medical care and financial needs are likely to grow.**

It is uncertain whether or not patients treated with combination therapies will continue to derive clinical benefit as the pattern of HIV therapy to date has been for the virus to become resistant to drug therapy. There are recent reports of a small number of AIDS patients becoming resistant to combination therapy which could mean that the increased quality of life experienced by patients may not be sustained.

There are significant issues for those patients who have also been infected with hepatitis C virus as a result of their previous treatment with blood products. Nearly all Macfarlane Trust registrants with HIV have been doubly infected with hepatitis C in this way. Combination therapy for HIV appears to be to be particularly toxic to the liver in these patients and in a number of cases, combination therapy has been withdrawn because of deterioration of liver function.

HIV has a profound influence on the course of hepatitis C infection, in that HIV promotes hepatitis C replication thereby worsening the liver disease. In a number of centres patients are dying of liver disease rather than of AIDS as the treatment of hepatitis C remains essentially ineffective, with no drugs of proven benefit and no effective way of monitoring levels of virus in the blood stream (unlike the situation with HIV).

A formidable medical challenge for these HIV\HCV infected patients therefore is to provide them with effective therapy against HIV that does not impair their already inflamed livers.

Although medical treatment has improved, the practical difficulties and side effects of combination therapy, together with uncertainty about their long-term effectiveness, continue to leave HIV infected patients with haemophilia in a state of emotional turmoil as well as physical disability. These symptoms are exacerbated by the co-existence of hepatitis virus in these patients, since this virus itself is also associated with long term poor health.

Finally, many patients find that the level of support that they have received from Haemophilia Centres in the past is decreasing in quality as resources are withdrawn by Health Authorities in order to pay for combination therapy.

2.3 The Case for a Further Review

Many Trust registrants were children at the time of infection and were not expected to survive to adulthood and take on the aspirations and responsibilities of family life. Payments made by HM Government to these registrants in 1990 and 1991 were significantly lower than those made to more mature men, particularly those with families.

Many of these registrants are now in their 20s and 30s. They are often living with poor health, unemployment and increasing poverty combined with uncertain life expectancy and coping with a demanding drug regime, sometimes with unpleasant side effects. Some of these men and their partners would like to start families, but risk reduced conception is difficult and costly; and for most patients this treatment is not available on the NHS.

Many older men who were established in life when they became infected with HIV have lost employment, families and good health. They have lived with an uncertain life expectancy, seeing many of their friends and colleagues die of AIDS related disease.

With due sympathy for all AIDS sufferers and for those without Haemophilia who have contracted HCV, it is clear that the extra burden of the interaction between AIDS and Haemophilia, and especially when HCV is also present, is a heavy one. It is therefore argued that those people registered with the Macfarlane Trust are still a 'special case'.

2.4 Terms of Reference

A Strategic Review of the Trust had originally been planned in the Autumn of 1996 and work on this began early in 1997; however, due to administrative changes within the Trust and emerging new medical information the Review was temporarily postponed.

At the end of 1997, in the light of changing needs and life expectancies of registrants, Trustees decided that it was essential to continue the Strategic Review and agreed that more emphasis should be placed on needs as perceived by registrants themselves. This would allow Trustees to inform Government of these needs and enable the Trust to effectively use its resources within the scope of the Trust deed to reflect changes of emphasis revealed by the Review.

Trustees approached the Department of Health in October 1997 with a proposal to carry out a Strategic Review, and funding from a Section 64 underspend the previous year was approved to allow work to begin.

In response to a letter from the Trust's Chairman in the Spring of 1998, The Minister of State for Health at the time, Baroness Jay welcomed the proposal to carry out a review.

An Interim Report was submitted to the Minister of State for Health, Baroness Hayman, at the end of July 1998. At that time a request was made to the Department for further funding to complete the Review. A schedule of research activities was in progress, and it was anticipated that work to the Review would be complete by early November, in line with an anticipated submission of the Final Report to the Department of Health by the end of 1998.

[The Interim Report is included the Working Papers binder]

3. AIMS OF THE STRATEGIC REVIEW

The Review would provide a brief historical perspective on the first ten years of the Macfarlane Trust. The main emphasis of the Review would be on finding out as much information as possible from registrants themselves about their current situation in order to determine whether their needs were being adequately met by the Trust and/or other statutory and voluntary service providers. Registrants would be encouraged to become involved in the Review, providing the Trust and its researchers with information based on their own experience of living with haemophilia, HIV infection, and for the majority, hepatitis C as well. The Review would seek information on all aspects of their lives, and would identify needs as perceived by registrants themselves.

The Trust would involve the Haemophilia Society and specific interest groups in the Review.

Information so gathered would be presented to The Department of Health together with recommendations from Trustees of the Macfarlane Trust to the Department.

The Report would also be made available to relevant statutory and voluntary bodies, and, in an appropriate format, to the registrants themselves.

Trustees recognised the importance of emphasising that the role of the Review was to identify needs, whilst not necessarily being able to meet all needs so identified from the current limited resources of the Trust. However, it would be opportune to make recommendations to Ministers/Department of Health as well as to Local Authorities and to the Haemophilia Society and other voluntary organisations.

4. METHODOLOGY

4.1 Monitoring and Supervision

The work of the Review was supervised by a Group chaired by the Trust's Chairman, and include Trustees and staff of the Macfarlane Trust and the Haemophilia Society.
A Psychosocial Needs sub-group supervised the research process. This Group included two Trust registrants, two Trustees appointed by the Department of Health

and staff of the Macfarlane Trust and the Haemophilia Society. The Review Group reported regularly to Macfarlane Trustees.

[Strategic Review Group and psychosocial needs subgroup composition are shown in Annex D.]

The Review was planned during the early months of 1998 and research work was carried out between June and October 1998.

4.2 Registrants' Participation

Trust Registrants were advised of the proposed Review by Newsletter in May. A letter and request to complete a new Census form to update existing database information was sent to each registrant in June.

A postal Questionnaire was circulated to registrants in late June offering them three levels of participation in the Review:

(i) completion of the Postal Questionnaire

(ii) joining in a Focus Group

(iii) taking part in a One-to-One Interview

Registrant participation in the Review secured the return of 159 completed Questionnaire forms; participation by 14 people in four Focus Groups held in London, Liverpool and Birmingham; and a further 15 people meeting the Haemophilia Society's HIV Worker in One-to-One Interviews. All registrants who wished to become involved in the Review were encouraged to do so.

A small seminar for 'Positive Women' was held at the end of October ensuring that those partners who had become infected with the virus through intimate relations with Trust registrants also had an opportunity to express their needs and concerns as part of the Review.

Members of the UK Haemophilia Centre Directors Group were also invited to contribute their views of the particular needs of patients living with haemophilia, HIV/AIDS and if relevant, hepatitis C infection .

Detailed Reports were received from consultants who analysed Questionnaires and facilitated Focus Groups. A full report was also received from the HIV Worker at the Haemophilia Society on the One-to-One Interviews conducted by him in September and October 1998.

[All Reports are included in Working Papers binder accompanying this Report]

This Final Report summarises the main findings of the research.

5. RESEARCH FINDINGS

Findings from the Questionnaire, the Focus Groups and the One-to-One Interviews each have strengths and weaknesses in obtaining a true picture of registrants needs, but all contain the essential elements as perceived by them.. Whilst there are differences in needs identified by each research tool, there is a much greater degree of commonality. It is the Trust's view that between them they represent as a complete and reliable picture of current registrants' need as it is possible to obtain. Findings from all three Reports are summarised under four main headings:

Medical Needs and Information;

Financial Needs and Information;

Information and Support Needs;

Psychosocial Needs.

5. 1 Medical Needs and Information

During the period covered by the Research, (June – October 1998) 480 of the original Trust Registrants (34.5%) were still living. Allowing for some duplication of research tool response, it is estimated that at least 37% of current Registrants were involved in the Review.

The following information summarises responses from 188 people to questions related to their current state of health, their medication and adverse side effects experienced:

5.1(i) Combination Therapies

Just over 63% of all registrants involved in the research were on combination therapy of one type or another (115 people). Amongst these 75% felt the same or better than they had 6 months ago. However, 17% of those on combination therapy actually felt worse than 6 months ago. Some of these registrants may have been adjusting to the new drug regime, and some may have been suffering such serious side effects that they might have to abandon new treatments if a satisfactory combination of drugs cannot be found.

Of those registrants not on combination therapy, 70% felt the same as 6 months ago; it is likely that most of these people were asymptomatic . But 27% of the sample of those not taking combination therapy felt worse than they did 6 months ago. It is likely that this group contains many who were either unable to go onto combination therapy due to their impaired liver function, or have had to come off anti-retroviral therapies due to severe side effects and increased risk of illness.

Severe side effects of combination therapy recorded include nausea; diarrhoea; abnormal weight loss or gain; peripheral neuropathy with extreme pain in lower limbs and feet, and in some cases temporary or impaired use of hands; hair loss and

acceleration of liver disease. Some registrants had experienced mental health problems including severe depression.
A special feature of giving this treatment to people with Haemophilia is an increase in soft tissue bleeding.

Adherence to a demanding drug regime proved challenging not only to the Trust registrants, but also to families because drugs required food and drink regulation throughout waking hours and at interval frequencies that did not fit into family programmes easily.

5.1 (ii) Co-infection – Hepatitis C and HIV

To date 225 registrants out of 480 have responded to a specific questionnaire asking whether or not they have hepatitis C infection:

214 registrants confirmed that they did have hepatitis C; 6 state that they did not have hepatitis C infection and 5 registrants said they did not know whether or not they had hepatitis C.

This suggested that out of a sample of 47% of Trust Registrants, over 95% of the sample were co-infected with HIV and hepatitis C viruses.

There was little indication that many of those with hepatitis C infection were receiving treatment, and many respondents were concerned that there was little information about hepatitis C infection or treatment available to them. Many registrants were increasingly concerned about the complications of being dually infected, and wanted to know whether treatment with combination therapies caused more adverse side effects if they had both infections. There was a widely held belief that hepatitis C was "making their HIV worse".

Those registrants who were receiving treatment were taking the drug Interferon, and some had experienced such severe side effects that treatment had been discontinued.

Recommendation to Macfarlane Trust and Haemophilia Society:

To promote the development and dissemination of up-to-date and clear information related to treatments for people with haemophilia, HIV and hepatitis C infections.

5.1 (iii) Complementary Therapies

Under a third of Questionnaire respondents reported use of complementary therapies, whilst two thirds of Interview participants and many Focus Group members had accessed a range of complementary therapies including
aroma therapy
hypnotherapy
homeopathy
reflexology
neuro-linguistic programming
and shiatsu

Many registrants said they would use complementary therapies more often but they found the costs involved prohibitive. They reported that whether or not complementary therapies had a physiological effect, the psychological gains were tangible, leading to a decrease in stress and a greater sense of well-being.

Complementary therapies were not generally available under the NHS despite general recognition of their beneficial effects and relatively low cost. It appeared that many registrants were unaware of the existence or benefits of complementary therapies.

Recommendation to Macfarlane Trust and Haemophilia Society

To promote the use of alternative therapies to complement traditional medical treatment for people with HIV and haemophilia.

5. 2 Financial Needs and Information

All participating registrants reported that money received as Special Payments from Government in the early 1990s had been spent. A few people had invested all or part of the payments in their homes, and a few others had invested the money to provide a small income each year. However, the vast majority of those questioned had not believed their life expectancy to be more than a few years at best, and spent payments on holidays and an enhanced quality of life for a few years. This reflects a general inability to finance special needs and confirms the increase in requests for single payments from the Trust.

The table below shows the extent of registrant dependence on State benefits:

Disabled Living Allowance (Mobility)	91%
Disabled Living Allowance (Care)	70%
Income Support	44%
Invalidity Benefit	23%
Job Seekers Allowance	2%

It would appear that at least 70% of registrants who responded to the Review are largely dependent on State Benefits and Macfarlane Trust funding for their financial needs.

This is well over twice the national average of people living at or below the ‘poverty line’.

Poverty and despair about money were common features in Questionnaire responses, particularly from those at peak earning age and had taken on responsibilities of a mortgage and a family.

Although many people on benefits were sick, there were others who were relatively well and in work but without the usual access to provisions of life assurance, permanent health insurance, mortgage protection at all or at a reasonable cost. This was due to restrictive practices related to HIV infection.

Respondents frequently expressed fears that the Government would change the rules in forthcoming welfare reforms, affecting their entitlement to future Benefits.

Those who were severely incapacitated were entirely reliant on State Benefits, Macfarlane Trust payments and other grants from charities.

Many registrants were bogged down by debt, and most were concerned that their essential outgoings were covered by their income, leaving no leeway for holidays, unexpected bills, house repairs, changes in rent or council tax rates, let alone repaying debts.

Many registrants expressed a genuine desire to get back into some form of employment. However, none was well enough to sustain full time work, so part time work would have to be very well paid to compensate for loss of benefits. If health deteriorated and they had to give up work, the benefits system took so long to be re-instated, during which time their only income would be that from the Macfarlane Trust, that returning to work was not really an option. The benefits system was seen as a deterrent to those wanting to return to work. In most cases, men were desperate to do something constructive with their time, but were forced to be idle.

Recommendations to Ministers / Department of Health

To ensure that current Welfare Benefits reviews include recognition of the nature of chronic illness with periods of respite typified by those with haemophilia and Hiv. In particular to enable such people to pursue further education and training and to take up part-time employment without loss of benefit entitlement.

The main service people had used for financial support had been the Macfarlane Trust. A few had used other sources as well such the DSS Social Fund and HIV charities, but had found these sources of help took a long time to reach decisions and had difficult forms to complete to access grants.

Many registrants were very concerned about the future of the Macfarlane Trust and wanted confirmation that the Trust would be there to support them for as long as necessary, and that payments would keep pace with inflation.

All respondents valued the role of the Benefits Adviser; Eight out of 14 people interviewed had used this service recently, and commented that the Adviser had been very helpful, especially with regard to the Benefits Integrity Project, applying for new benefits and 'back to work' issues.

[Benefits Adviser's Report is included in Working Papers binder appended to this Report]

Recommendation to Ministers/Department of Health

To ensure ongoing funding to Macfarlane Trust to enable continued support to Trust registrants to meet existing and emerging special needs, and with the Trust to review types and extent of provision required.

5. 3 Information and Support Needs

5.3 (i) Medical information

Many registrants were concerned at lack of information available to them about treatments and their possible side effects, particularly with regard to co-infection with hepatitis C and if and when they should seek treatment for hepatitis C.

Respondents were also concerned that communication between Haemophilia Centres and HIV (Genito-Unrinary Medicine) Centres about their treatment was sometimes very poor, with little or no liaison between the two groups of specialists.

Some registrants felt that they were regarded as ‘possessions’ by their Haemophilia Centres and experienced reluctance to refer them on to HIV Services; others felt that their HIV status had meant that the Haemophilia Centre had lost interest in them.

One registrant reported that staff in the HIV Centre were ‘terrified of haemophilia’, another that the Haemophilia Centre was not up to date with treatment of HIV and hepatitis C, and when an in-patient for treatment related to haemophilia, he had suffered considerable difficulties maintaining his combination therapy drug regime.

Splitting of treatments between different centres for haemophilia and HIV could mean a lot of extra travelling when centres were sometimes hundreds of miles apart.
This was stressful and costly for sick people.

Information about treatment for hepatitis C and how this might affect haemophila and AIDS related health conditions was virtually unobtainable.

Recommendation to Ministers/Department of Health

To take measures to coordinate services and ready provision of appropriate information.

5.3 (ii) Macfarlane Trust Information

A few registrants indicated that they wanted more information on what the Macfarlane Trust was for and the extent of its brief.

Some respondents would like to see more specific information about grant-making policy, and felt that the application process could be simplified and standardized.

Registrants would like more Newsletters from the Trust, and some felt that the Handbook could be presented more clearly.

Recommendation to Macfarlane Trust:

To improve explanations to registrants and set out clear grant giving policies.

5.3 (iii) Support Needs

The Questionnaire respondents overwhelmingly regarded Macfarlane Trust as the single most effective organisation to meet registrants' needs.

There was a tendency to use external support if possible for fear of burdening partners and other family members.

Support from Haemophilia Centres was variable, but mainly good. However, some Centres were many hours travel from home so development of local support networks that were accessible to people with haemophilia and HIV was essential.

The Haemophilia Society was not seen as a main source of support. There was limited use of the Society Bulletin as a source of treatment and other information.. Some registrants had attended events or been active in local Society Groups. One respondent felt that the Society's services and events were " good, but only seemed geared up around parents and young children with haemophilia."

Some respondents regarded The Society as being 'paternalistic'; others felt that those infected with HIV were 'treated as second class citizens' by The Society.

Peer support was seen as valuable by some registrants, but others were not interested or against this. Organised meetings were unpopular, with a preference for non-illness related social gatherings or smaller informal meetings.

Some registrants expressed isolation due to their diagnosis and asked for establishment of small groups where they could meet other 'positive haemophiliacs'.

Recommendations to Macfarlane Trust in partnership with the Haemophilia Society:

To develop conferences and seminars to enable registrants to support each other and gain and share information on all aspects of their changing life expectancies and needs.

To promote the development of local support services accessible to people with haemophilia and HIV through partnership with statutory and voluntary organisations.

A telephone support network to enable contact with other men living with haemophilia, hepatitis C and HIV was suggested as a means of reducing isolation.

Many registrants felt they had nobody outside the family to talk to who was in a position to understand what they were going through. Some men had had bad experiences with counseling services including breaches of confidentiality. Others indicated that counseling, when available, was beneficial to them.

Some registrants felt they needed guidance on what they could/should expect from support services offered by Local Authorities and Treatment Centres.

Registrants also wanted to see Trust staff make more visits to registrants at home and in hospital, and would like to have regular opportunities to meet Trustees in local 'Surgeries'.

Some registrants felt that the Trust should do more to support widows and children, and make grants available to allow carers to have a respite break from this demanding task.

Recommendation to Ministers/Department of Health

To encourage effective partnerships between Government Departments and statutory and voluntary organisations supporting people with haemophilia and HIV infection. In particular to promote local support services that are accessible to heterosexual people and those with haemophilia.

5. 4 Psychosocial Needs

These needs manifested in four main areas of people's lives;

(i) Relationships, including making and sustaining them; children and families; risk reduced conception; making friends and socialising.

(ii) Disclosure, Confidentiality and Discrimination.

(iii) Isolation and constructive use of time: education, skills development and employment.

(iv) Respite care and support for partners and carers.

5.4 (i) Relationships

Responses in this area revealed great social isolation and loneliness. Many men found it very difficult to form close relationships with women because of their HIV status and suffered from rejection, loss of confidence and lack of fulfillment. Many registrants found they were unable to develop friendships or a normal social life because of fear of disclosure, breaches of confidentiality and rejection. This social exclusion could be as limiting to registrants as the medical effects of HIV/AIDS.

"I spend my time with no one...no family, no friends, they are not interested in anything to do with me...so I have been alone and completely isolated for the whole 13 years of being diagnosed. I wanted help to get through it...Yes, you get used to it, but the pain inside is intolerable".

Those registrants in stable relationships also found that HIV was a major difficulty. Many couples would like to start families but were deterred from doing so due to fear of infection of mother or child.
[The Macfarlane Trust has supported couples with grants for in-vitro fertilisation by donor, however, new methods of fertilisation using the registrants own sperm have not, to date, been supported by the Trust because the risk of co-infecting the partner has been regarded as being too great to support.]

One couple reported that they had practiced the 'reverse barrier method' whereby they had unprotected sex when the partner was most likely to conceive. This had caused a great deal of anxiety as the partner had to have an HIV test after each attempt, and stress levels for them both were high.

Attempts to conceive using 'artificial insemination by donor' was also stressful and very expensive; attempts to become pregnant often resulted in failure, followed by frustration and heartache.

Recommendation to Macfarlane Trust:

To provide guidance and policies, developed in cooperation with the Haemophilia Centres Directors Group.

5.4 (ii) Disclosure, Confidentiality and Discrimination

Fear of discrimination due to HIV status and breaches of confidentiality experienced by many registrants were a frequently recurring theme. It was a major factor that added to the social isolation experienced and often prevented (or was perceived to prevent) more involvement in local communities or moves to seek employment. Registrants and their families were often imprisoned in a life of lies and secrecy:

'In a Local Authority Housing Department a member of staff shouted to another "he's the one with AIDS".

A registrant described how he applied for a job, declaring his HIV status and didn't get it. He later applied for the same job and didn't disclose his status – and got the job. Another registrant reported a lot of harassment at his previous address on a Council Estate. The local youths found out his HIV status and "made my life hell." Forcing him to sleep at his parents' house until the local council rehoused him.

There was also perceived to be discrimination from others who were HIV positive including those in the Gay Community and people with haemophilia who were not infected with HIV.

Those who had not disclosed their status to friends and colleagues had invented 'cover stories' to deal with questions around medication or illness.

Some registrants had not told families, parents or in-laws of their HIV status, or had not informed their children because they were too young. Such secrecy placed a heavy burden on the couple, as it had to be maintained at all times outside the home.

Recommendation to Ministers/Department of Health

To promote policies to deter all forms of discrimination based on HIV status.

5.4 (iii) Isolation and Constructive use of Time.

Younger registrants, particularly those under 30, had lived with haemophilia all their lives, and with HIV infection since childhood. There was a lot of despair and isolation in this group of respondents, many of whom had missed out on further and higher education, and had never worked.

Research revealed that education was of considerable importance to registrants themselves. Some had recently left Higher Education and were currently seeking employment or wanting to retrain. It was also apparent that many registrants were highly intelligent; many others either had skills or could acquire them. Some of these may have never been developed, as in the case of young people.

Many registrants needed support and encouragement to use time constructively, particularly now that for some, life expectancy was increasing and planning a future could be regarded as a possibility for the first time.

Some mature men with families had adjusted well to loss of employment, particularly those with families who remained well enough to enjoy fatherhood.

5.4 (iv) Respite Care and Support for Carers

Many registrants expressed concern that their partner was also (or was becoming) their Carer. This could cause considerable stress to the relationship with partners becoming very exhausted and weighed down by the burden of uncertainty . Respite care had to be fought for, and lack of funding meant that holiday breaks for the family were seldom possible.

One partner had pointed out that she had lived with the expectation of becoming a widow for more than 10 years. This carried it's own stresses for her and the family.

Registrants were keen to have family around when they needed care, but did not want to be a burden to them.

Several respondents asked that the Trust pay holiday grants once more as a means of alleviating severe stress which registrants and their Carers were experiencing.

One man in his 50s reported having had no holiday for 20 years, another would like to afford more holidays while well enough to benefit. A Hindi registrant indicated that what would make the greatest difference for him was to make a Pilgrimage to India.

Recommendation to Macfarlane Trust:

To respond to newly identified areas of need including support for carers' respite , lifestyle choices and take up of education and training.

[Personalised comment and feedback from registrants are summarised in Annex G.]

6. RESPONSES FROM HAEMOPHILIA CENTRES

Dr Mark Winter, Centre Director of the Kent Haemophilia Centre and a Trustee appointed by the Secretary of State for Health, had written to members of the UK Haemophilia Centre Directors Group in August asking them to contribute to the Review by identifying the changing needs of patients with long-term HIV infection.

Detailed responses were received from Hampshire, Birmingham and Newcastle Centres. These reports present a picture which objectively endorses the subjective views of registrants themselves and in particular makes the following telling points on care:

'although people are living longer, their care needs have increased. The end stages are often prolonged and harrowing for families. Flexible ongoing care and support services are essential'.

'Carers are overwhelmed and extremely isolated and stressed. They need ongoing support to maintain their level of caring. Following the death of their loved one the bereavement process is usually prolonged and difficult. Bereaved carers do not usually access local services as they do not reveal the HIV connection. The lies and secrets that went on in life continue in death.'

These impressions from dedicated staff in Haemophilia Centres confirm many of the needs revealed by the User Research and help to identify priorities for recommendations to Government, to Trustees of the Macfarlane Trust and to the Haemophilia Society and other relevant statutory and voluntary organisations.

Overall, needs identified matched many of those included in the Report of the All Party Parliamentary Group on AIDS.

[Summary Report in Working Papers binder appended to this Report]

7. FEEDBACK FROM POSITIVE WOMEN'S WEEKEND

The main points to arise from the weekend for 'positive partners' – women who had become infected through intimate relations with their loved ones - were related to the extra burden of being the main carer of their partner with haemophilia as well as coping with their own illness. It was felt by many that 'the man always comes first – who cares for the carer?'

[Report in Working Papers binder appended to this Report]

8. ASSESSMENT

In the knowledge that resources present and future will never be unlimited and that many of the needs identified by the Review fall outside the remit of Macfarlane Trust, Trustees have selected and prioritised areas of need that could be met within the present terms of the Macfarlane Trust Deed provided that funding was available, and have also indicated areas of need that could better be responded to in partnership with or wholly by other organisations such as the Haemophilia Society.

Other needs might best be met through Government initiatives as part of a national strategy and many of these will reflect recommendations arising out of the All Party Parliamentary Group on AIDS/HIV hearing held during the Summer of 1998.

The Trust, as in the past, looks to Ministers/department of Health to continue to fund the essential tasks of the Trust, allowing Trustees to dispose of as flexibly as possible to meet the changing needs of registrants.

The Trustees record with thanks the actions of successive governments to honour the original promise to 'keep the future requirements of the Trust under review' but, since one of the major anxieties amongst registrants is the continued viability of the Trust, it would be a major reassurance to them if the guarantee of continued funding could be more specific, and established on a more permanent basis.

Recommendation for Ministers/Department of Health:

Ministers/Department of Health should recognise the changing profile of needs and give assurance of continued adequate funding plus administrative costs of Macfarlane Trust.

9. CONCLUSION AND FINANCIAL IMPLICATIONS

The Macfarlane Trust has been paying grants amounting to approximately £2 million a year to registrants or their dependants since the Trust was established in 1988. The nature of payments made has changed considerably over time. In the mid 1990s, bereavement payments and support to widows and children, together with payments to relieve those who were terminally ill predominated.

However, over the past three years, 'Travel to Hospital' and grants to assist people move to more appropriate housing have remained the highest payment areas for single grants. Increasingly payments are also being made for equipment and adaptations to homes. These two types of payment are made when registrants are seriously or terminally ill, and help through local or health authority process is likely to be so slow to access that the registrant and family will have experienced much unnecessary suffering, before payments are made.

Of the 474 living registrants with haemophilia and HIV at the end of December 1998, 190 are below the age of 30. Whilst it is impossible to predict an estimated life expectancy for these people, it is perhaps worth noting that there have been no deaths in this age-group for 18 months.

There were 22 deaths of those between 30 and 70+ in 1998; leaving 284 people in this group still living. Whilst many of the 474 remaining registrants are living lives that are severely limited by ill health, it is possible to suggest that if current treatments continue to improve life expectancy, there will still be a considerable group of people with Haemophilia and HIV, of whom at least 95% also have hepatitis C infection, living well into the next century. It is therefore expected that the Macfarlane Trust will continue to be needed to provide financial and other support to these people for at least a further 10 years.

In the light of changing needs of registrants highlighted in this Review, it is suggested that financial support requirements of the remaining registrants are unlikely to diminish over the next 3 – 5 years and the current high levels of need will continue. Although the numbers of registrants are reducing – albeit more slowly than in earlier years, complex patterns of health needs mean that higher levels of support will be required for longer periods for survivors.

As numbers of registrants reduce, so the needs of widows and dependant children increase. It is incumbent on the Trust to assist dependents to become self-supporting where this is practical and to continue to support those who are sick or disabled themselves.

[see annex B(ii).]

At 30th September 1998, the Trust had assets remaining of £7,711,675. If support to registrants continues to be given at a similar rate to that provided over the past 10 years, a total sum of £10 million would be required to cover expenditure from 1999 to 2004.

If it is agreed that wider needs should be met, as concluded from this Report, there will need to be a commensurate increase in resources.

In 1997 the Trust confirmed to the Department the need to keep capital investments at or above £4,000,000 in order to maintain payment levels. It is therefore suggested that to support these levels it would be necessary for Government to provide further 'top-up' payments to the Trust in 2000 and again in 2003.

Recommendation to Ministers/Department of health

Ministers\ Department of Health should urgently consider the changing patterns and increasing financial demands and expectancies of Trust registrants. They should provide policy guidance and priorities along with commensurate resources to enable the Trust to meet the required level of services and increased needs of registrants..

10. RECOMMENDATIONS

10.1 The Macfarlane Trust

The outcome of the Review requires the following future commitments by the Trust to its registrants. These are placed in priority order with further comment as necessary.

(i) To provide cost effective and efficient administration to ensure that the provisions of the Trust Deed and agreed policies are pursued with probity, diligence and accuracy, providing a high quality and responsive service to registrants.

(ii) To maintain the principle of regular payments to registrants in response to their changing needs.

(iii) To continue to respond to the specific needs of registrants by payment of single grants, particularly related to increasing health needs.

(iv) To respond to newly identified areas of need including support for carers respite, lifestyle choices and take up of education and training opportunities.

(v) To continue to provide effective benefits advice and support to registrants.

(vi) To continue to offer advice on mortgages, pensions and personal finances including debt counseling.

(vii) To improve explanations to registrants and set out clear grant giving policies.

(viii) To provide guidance and policies on fertility treatment developed in cooperation with the Haemophilia Centres Directors Group.

(ix) To further develop an effective and responsive Helpline service to registrants.

10.2 in partnership with the Haemophilia Society and other organisations

(i) To promote the development of local support services accessible to people with Haemophilia and HIV through partnership with statutory and voluntary organisations.

(ii) To promote the development and dissemination of up-to-date and clear information related to treatments for people with haemophilia, HIV and hepatitis C infections.

(iii) To develop conferences and seminars for registrants to enable them to support each other and gain and share information on all aspects of their changing life expectancies and needs.

(iv) To promote the use of alternative therapies to complement traditional medical treatment for people with HIV and haemophilia.

10.3 Recommendations to the Department of Health/ Ministers

(i) **Ministers/ the Department of Health should consider the changing Patterns and increasing financial demands and expectancies of registrants. They should provide policy guidance and priorities and furnish the required level of resources.**

(ii) **To ensure ongoing funding to Macfarlane Trust to enable continued support to Trust registrants to meet existing and emerging needs, and with the Trust to review types and extent of provision required.**

(iii) **To continue to fund an efficient administration of the Trust.**

(iv) To encourage effective partnership between Government Departments and statutory and voluntary organisations supporting people with HIV and haemophilia;

(v) In particular, to encourage development of local support services for people with HIV that are open and accessible to heterosexual men and women and people with haemophilia.

(vi) To promote policies that deter all forms of discrimination based on HIV status.

(vii) **To ensure that current Welfare Benefit Reviews include recognition of the nature of chronic illness with periods of respite typified by those with haemophilia and HIV.**

(viii) To enable people with chronic illness and periods of respite to pursue further education and training without loss of benefit entitlement.

(ix) To encourage uptake of part time employment without loss of benefit entitlement.

(x) To encourage meaningful participation in development of local and national HIV strategies by people with haemophilia and HIV.

(xi) To provide research funding to ensure that the results of multiple drug therapies for haemophilia, HIV and hepatitis C viruses are closely monitored and information about adverse side effects made available to medical staff and patients to assist treatment decision-making.

(xii) **To ensure that adequate funding is available to support adequate 'Care in the Community' for those who return home to be nursed when terminally ill.**

(xiii) To encourage effective partnership and communication between Haemophilia Centres and HIV treatment Centres for people with Haemophilia and HIV.

(xiv) To ensure that adequate funding is available to enable Haemophilia Centres to continue to support psychosocial as well as medical needs of people with haemophilia and HIV

(xv) To consider proposals for development of information and support services specifically for people with haemophilia and HIV to be presented by the Macfarlane Trust in partnership with the Haemophilia Society.

11. CONTENTS OF ANNEXES

A. Structure of the Macfarlane Trust

B. Statistics Analysis

- (i) Age breakdown of those people who have died since 1995.
- (ii) Widows and Dependant Children – December 1998

C. Make up of Strategic Review Group and Psychosocial Needs Sub-group.

D. Personal comments and Feedback from Registrants.

E. Grants Information.

12. WORKING PAPERS BINDER

(I) Interim Report and summaries of previous Reviews

(II) Questionnaire Analysis and copy of Questionnaire used

(III) Focus Group Report

(IV) Report of One to One Interview

(V) Summary of Reports from Centres

(VI) Positive Partners Weekend Report

(VII) Benefits Advisers Report

ANNEX A.

MACFARLANE TRUST STRUCTURE

The Trust is governed by the Trust Deed (as amended) and under the control of ten Trustees, six of whom are appointed by the Haemophilia Society and four by the Secretary of State for Health. Trustees appointed by the Haemophilia Society serve for a term of two years and are then eligible for re-election. In practice most Haemophilia Society appointed trustees have served for at least two terms of office.

Trustees appointed by the Secretary of State for Health must include a Haemophilia Centre Director and Social Worker. The appointments are made for two years and whilst Department of Health appointed Trustees may be nominated to serve for a second term, it was the Secretary of State's intention that appointments should rotate around the areas of the United Kingdom and not exceed two terms in office except as an emergency measure.

From amongst the Trustees is appointed a Chairman and Deputy Chairman who at present also acts as Honorary Treasurer.

Day to day administration of the Trust is delegated to a small staff team led by an Administrator/Chief Executive. The team presently includes a qualified Social Worker, a part time Benefits Adviser and administrative and financial support.

The staff team is responsible for making approximately 80% of payments to registrants within established guidelines, which are regularly reviewed by Trustees. The remaining 20% of payments are made after specific decisions by Trustees.

ANNEX B. STATISTICS

(i) AGE AT DATE OF DEATH - 1995 – 1998.

AGE RANGE	1995	1996	1997	1998.	TOTAL
12 - 17	1	-	-	-	1
18 - 29	21	19	5	-	45
30 - 39	33	12	6	7	58
40 - 49	19	9	12	5	45
50 - 59	10	5	8	2	25
60 - 69	5	2	1	2	10
70+	1	1	-	-	2
TOTALS	**90**	**48**	**32**	**16***	**186**

ANNEX B

(ii) STATISTICS – WIDOWS AND DEPENDENTS

TOTAL WIDOWS KNOWN TO TRUST	221
WIDOWS STILL RECEIVING FINANCIAL SUPPORT	164
DEPENDENT CHILDREN RECEIVING FINANCIAL SUPPORT	148
TOTAL RECEIVING FINANCIAL SUPPORT	**312**

[NB MANY WIDOWS HAVE DEPENDENT CHILDREN]

ANNEX C.

(i) MAKE-UP OF STRATEGIC REVIEW GROUP

Chairman: The Reverend Prebendary Alan Tanner, OBE (Macfarlane Trust)

Deputy Chairman: Clifford Grinsted, JP (Macfarlane Trust)

Dr Mark Winter: DOH Trustees, Centre Director (Macfarlane Trust)

Mr Tim Hunt: DOH Trustee, Social Worker (Macfarlane Trust)

Mr Chris Hodgson: Haemophilia Soc. Chairman (Macfarlane Trust)

Mr GRO-A **(Macfarlane Trust)**

Mr John Williams: Retired Administrator (Macfarlane Trust)

In attendance:

Mrs Ann Hithersay: Administrator\CEO (Macfarlane Trust)

Mrs Fran Dix: Social Worker (Macfarlane Trust)

Mr GRO-A **HIV Worker (Haemophilia Soc.)**

(ii) PSYCHOSOCIAL NEEDS SUB-GROUP

Mr Tim Hunt

Mrs Fran Dix

Mr GRO-A

Mr GRO-A **: Trust Registrant; Trustee, Haemophilia Society**

ANNEX D.

PERSONALISED COMMENTS FROM REGISTRANTS

1. SIDE EFFECTS OF COMBINATION THERAPIES

"I have had to make several changes to my drug regime and to my diet and lifestyle to minimise liver problems caused by protease inhibitors".

"Palpitations and supra-ventricular tachycardia are alarming. Peripheral neuropathy especially on the hands limits any tasks you undertake. Increased bleeding also experienced".

"Consequences of taking drugs often unexpected and have been a surprise to doctors. Failure to grow and thrive; puberty has still not occurred (twins aged 14+) more bleeds."

"Twice in the past when hospitalised, certain prescribed drugs caused personality changes of a nasty and disruptive nature".

"When first starting on Indinivir I suffered what seemed to be a mini-stroke, which has left me with little feeling in my left hand. This was put down to the new drug."

"Peripheral neuropathy from D4T was much worse than I had been warned it could be. I ended up needing 60mg of morphine twice a day."

Drugs most commonly associated with adverse side effects for some patients included Indinivir, Sequinavir and Ritonavir. Sequinavir was said to make people feel worse, whilst Indinivir and Ritonavir were associated with more bleeds.

Adherence to a demanding drug regime proved challenging not only to the Trust registrants, but also to families because drugs required food and drink regulation throughout waking hours and at interval frequencies that did not fit into family programmes easily.

One registrant said "the day gets arranged around my drugs not me!"

Another said "it's difficult to take drugs with food and some without food and the sheer number of them is overwhelming".

And another "Dealing with illness has taken over my life"

2. COMMENTS ABOUT HEPATITIS C INFECTION

"Although I am not being treated now, I am experiencing extreme tiredness which my Consultant attributes to hepatitis C infection".

"Ask the question of yourself 'how long do I want to or will live? As it's HIV versus hepatitis C, which one will get you first?'"

3. FINANCIAL WORRIES

"Some weeks I get very worried and just wish I could end it all"

"Even though I have been unwell due to increased medication, I have had to work and work extra hours just to meet my financial commitments".

"I am at what would normally be my peak earning age – instead I find it difficult to make ends meet, let alone save anything".

"Although many people are on benefits and sick, there are still others who are relatively well and in work but without the usual access to provisions of life assurance, permanent health insurance, mortgage protection at all or at a reasonable cost. Are there other ways in which this sort of provision could be made through non life/health linked investments – but taking into account unpredictability of health and time required to access funds?"

"I worry about my family and what would happen to them if I get ill or die. My wife would lose a lot of benefits if I were to die. I think about financial security for myself. The Macfarlane Trust has been helpful in other ways – I would like to see that continue. Life would be much harder if the Macfarlane Trust were to go".

"I need to have confidence that the Macfarlane trust will stay around and that their financial support will continue".

"The Trust concentrates too much on medical needs. What about our other needs…?"

4. INFORMATION NEEDED

"I do not know if I am being treated for Hep C"

" I never had information before about Hep C, I didn't know until July 1998 that I had it".

"If I had known more about the 'potential' bleeding problems before starting combination therapy I could have made different decisions about which drug to choose".

"I don't really know what foods are good for HIV and Hep C".

"I never know which vitamins I should take".

5. SUPPORT NEEDS

"I would like some local professional support, but only on occasions though. It would be good to have someone to see as and when I wanted."

"What we need is someone like a 'change manager' to help you through all the changes caused by combination therapy. Existing counselling services are not about that. This needs to be a local service, and to be long-term and ongoing."

The Haemophilia Society was not seen as a main source of support. One Interviewee did use the Society Bulletin as a source of treatment and other information, other had attended events or been active in local Society Groups. One respondent felt that the Society's services and events were "good, but only seemed geared up around parents and young children with haemophilia".

Peer support was seen as valuable by some, but others were not interested or against this.

"One of the few positives to come out of being HIV positive is the friendships I've made with other positive haemophiliacs. These are, next to my wife, my closest friends."

"I don't want to meet up with others in case they are 'further down the road' than me. I've looked after people with AIDS in the past and it was scary."

"The only problem about meeting up with other positive haemophiliacs is that we all want something different. I'm still in touch with a few others, but think it's best that we only meet together occasionally."

6. RELATIONSHIPS

"I spend my time with no one…no family, no friends, they are not interested in anything to do with me…so I have been alone and completely isolated for the whole 13 years of being diagnosed. I wanted help to get through it…Yes, you get used to it, but the pain inside is intolerable".

"So called friends crossed the road in order to avoid me".

"My wife's parents keep their distance."

"The worst change has been not being able to mix with people in general."

" I don't have many friends. They ask too many questions, I just have my wife, my Mum and Dad."

One to One Interviewees were concerned about the major impact that HIV had on forming and sustaining sexual relations:

"Very few women will accept you if they know you are HIV positive."

"Girls tend to dump you when they know your status."

"Relationships with women are hard. They are impossible when things get serious, and even more so when the issue of children is raised."

"I haven't had a girlfriend in years. It's easier that way."

"Basically, I am a young man with needs. I need a girlfriend not just for sex, but more companionship. Going out etc…mention HIV and girls run a mile. Sex isn't a big deal for me, I just want someone to be with, to watch soppy movies with, just to love."

Even those in stable relationships found HIV a major issue.

"HIV is like a 'sword of Damocles' hanging over you all the time. It affects my moods – I get angry and depressed very easily, which affects my wife."

"I would dearly like children one day, but the risks of infecting my partner would be so great that my fear outweighs my desire to become a father."

7. DISCRIMINATION

Fear of discrimination due to HIV status and breaches of confidentiality experienced by many registrants are a frequently recurring theme. It is a factor that adds to the social isolation experienced and often prevents (or is perceived to prevent) more involvement in local communities or moves to seek employment. Registrants and their families are often imprisoned in a life of lies and secrecy:

'In a Local Authority Housing Department a member of staff shouted to another "he's the one with AIDS".

A registrant described how he applied for a job, declaring his HIV status and didn't get it. He later applied for the same job and didn't disclose his status – and got the job.

"Fear of discrimination puts limitations on what I would otherwise do e.g.: overseas travel."

"I had a lot of harassment at my previous address on a Council Estate. The local youths found out my HIV status and made my life hell. So much so that I had to sleep at my parents house until the local council rehoused me."

There is also perceived to be discrimination from others who are HIV positive:

"I feel discriminated against because I am straight and have haemophilia."

And from others with haemophilia but are not infected with HIV:

"The saddest thing has been bigotry from other haemophiliacs. Wanting all haemophiliacs to pretend they don't exist, better still, die. Admit how lucky we were to get HIV, and all haemophilia literature to ignore HIV."

A very few registrants have 'gone public' about their status:

"I put a story about myself, my wife and my first son in the News of the World, so nearly everybody in my area knows. I have had one or two incidents of people shouting 'HIV' at me, but I just ignore it."

8. CONSTRUCTIVE USE OF TIME

HIV has made many respondents withdraw from social life. Loss of work has reduced opportunities for socialising, and illness and disability made going out more of an effort:

"I can't get out very often, and even when I can, I just don't feel like it. HIV just makes me want to stay at home and concentrate on my music."

"I have nothing to get out of bed for."

"The change in view of life expectancy has led to re-evaluation. Now I don't know quite what to do with (possibly) many years to come."

Some mature men with families have adjusted well to loss of employment:

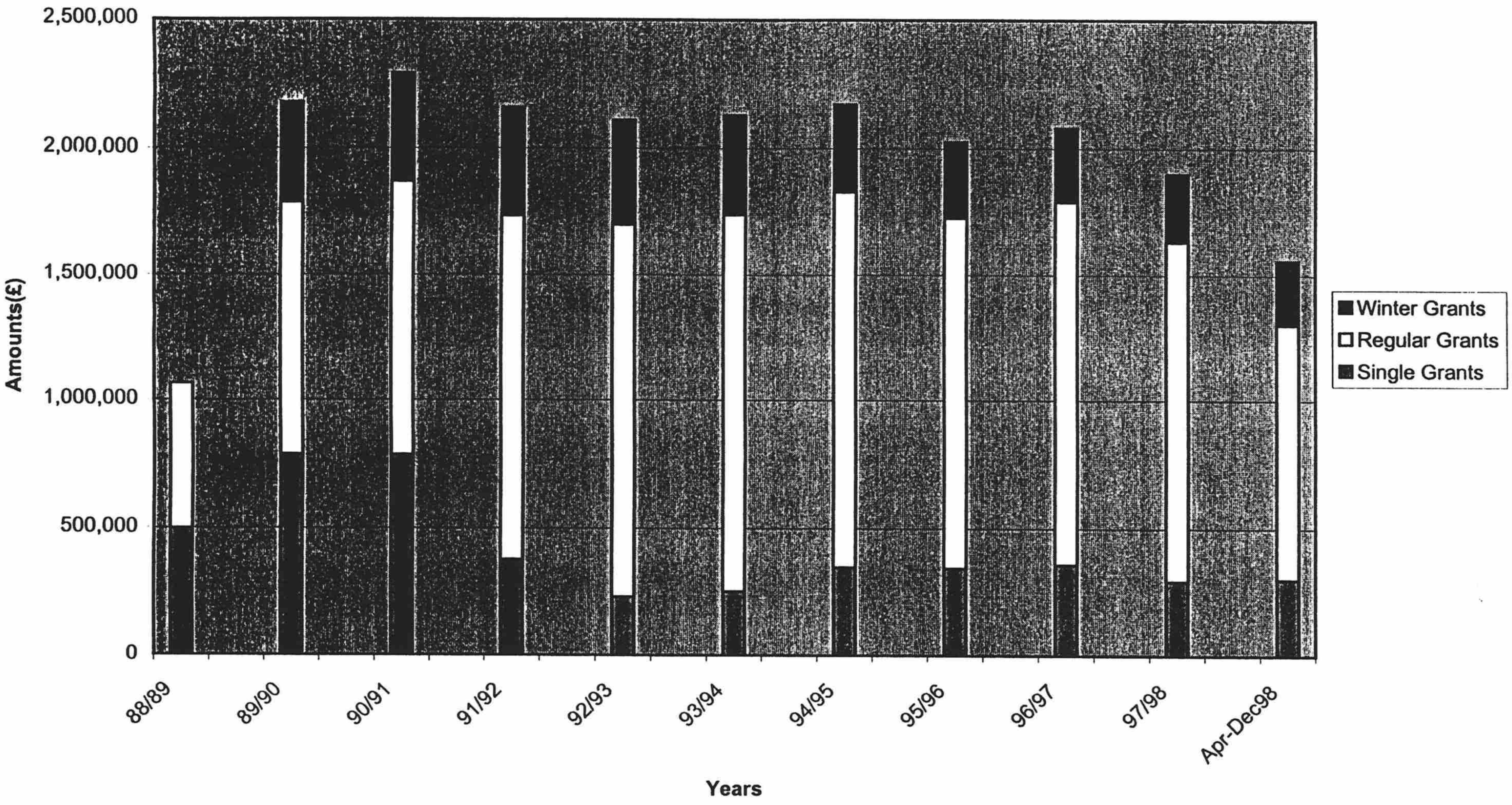
"I now have more time to spend with my 4 children, since I stopped working."

"I enjoy life more now because I have two wonderful children and they take up most of my time."

"Before I never had a view of the future, because I never knew when I was going to die, or become too ill to do anything. No even if I can't see many years ahead, I feel I can make plans for the next year or so."

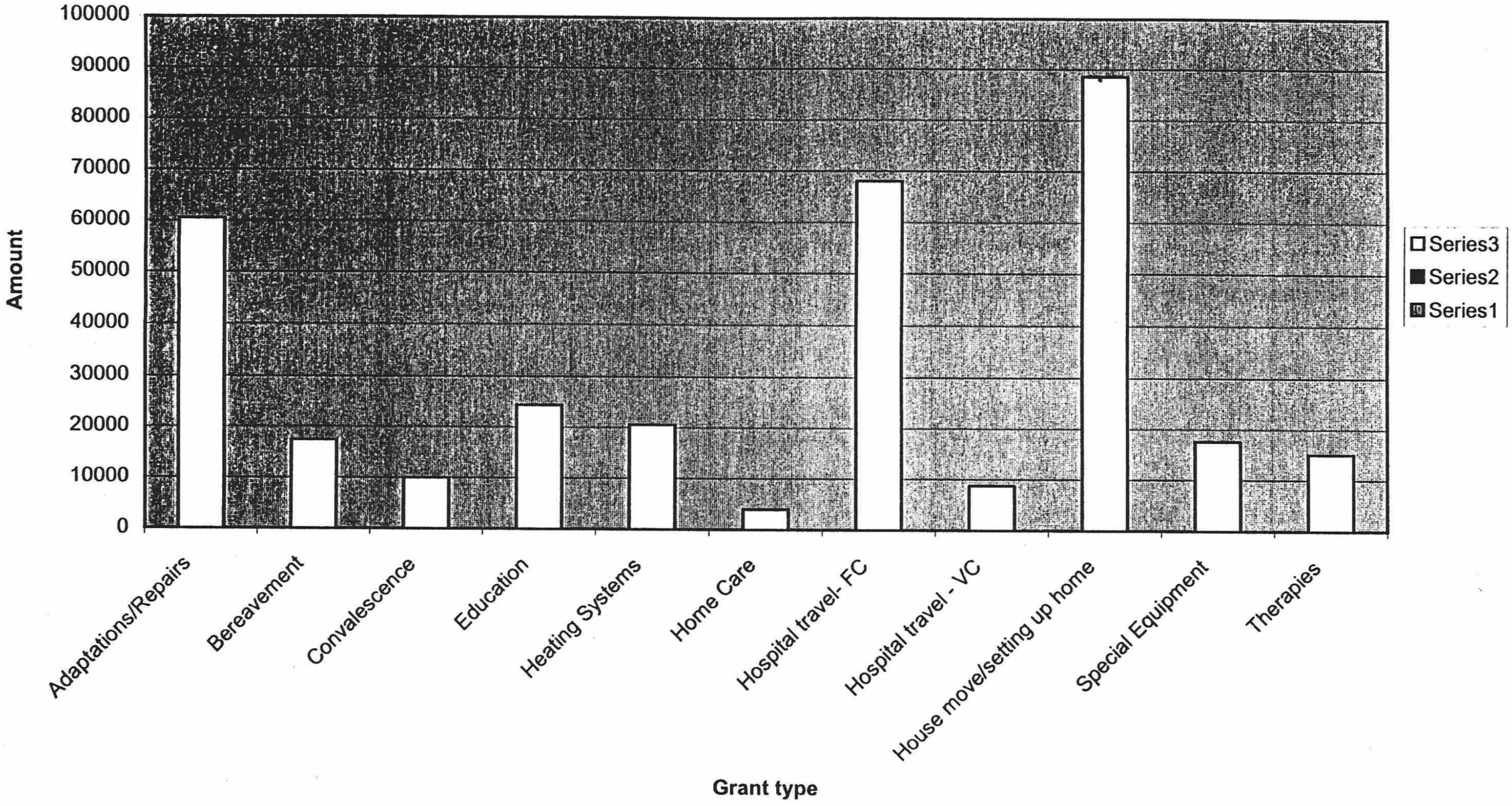
Annex E (i)

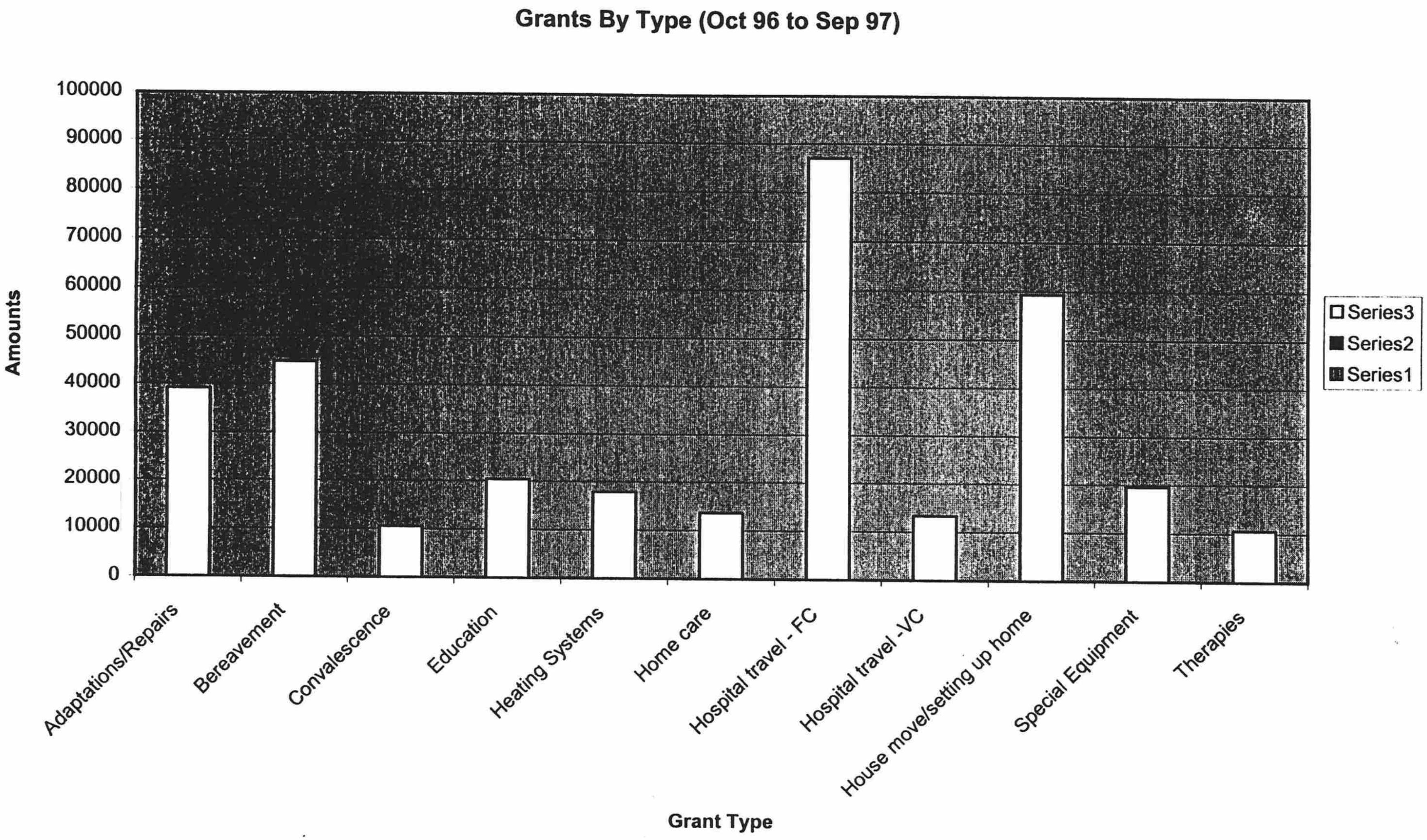
Grant Payments By Type Over a Ten Year Period



Annex E (ii)

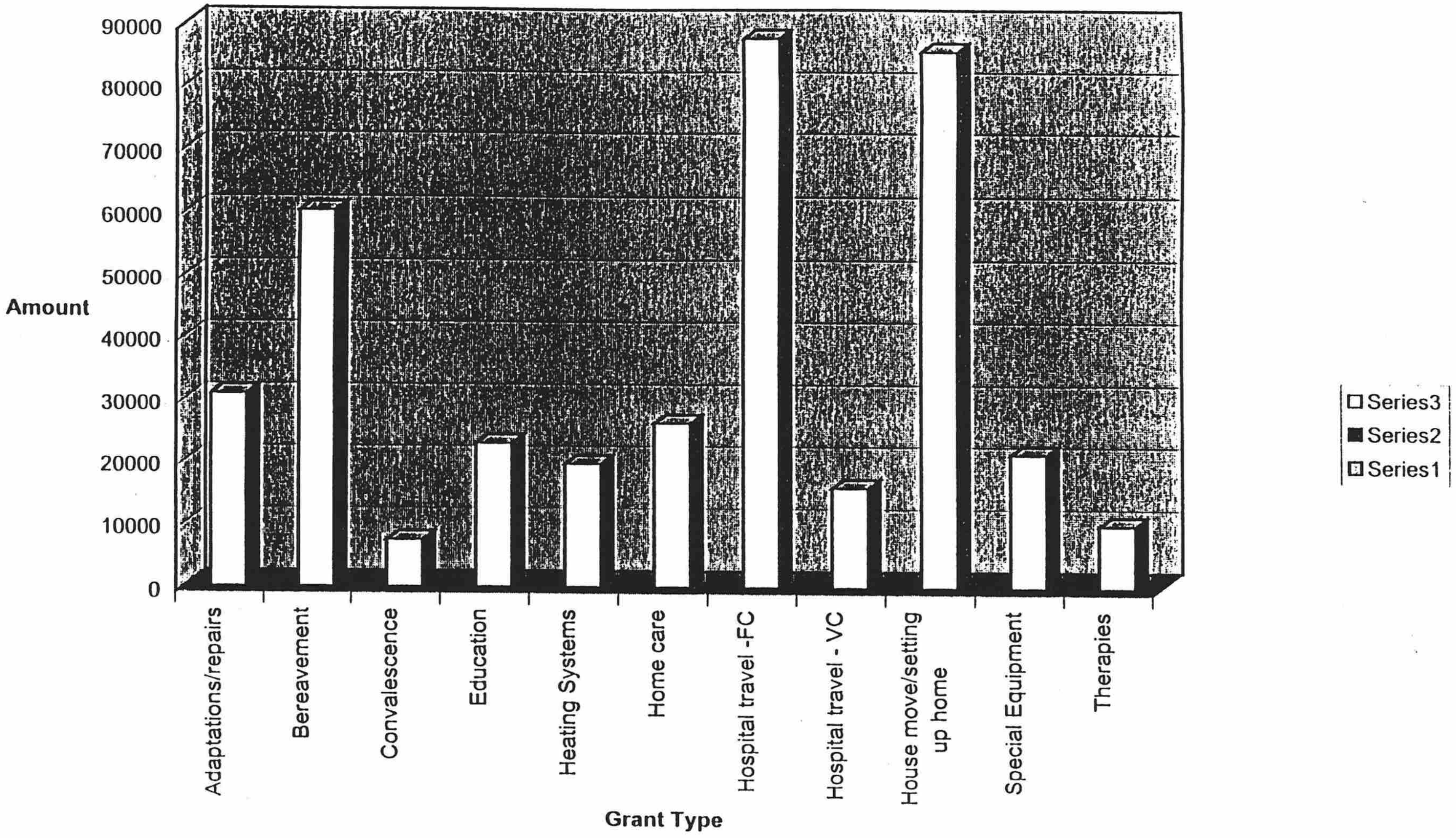
Grants by Type (Oct 97 to Sep 98)




Grants By Type (Oct 96 to Sep 97)
Amounts
100000
90000
80000
70000
60000
50000
40000
30000
20000
10000
0
□ Series3
■ Series2
▨ Series1
Adaptations/Repairs
Bereavement
Convalescence
Education
Heating Systems
Home care
Hospital travel - FC
Hospital travel -VC
House move/setting up home
Special Equipment
Therapies
Grant Type

Annex E (iv)

Grants by Type (Oct 95 to Sep 96)



ANNEX E (V)

Grant Types and Sub Types

Adaptation/Repairs
- Shower installation
- House adaptations
- Window replacement
- Redecoration
- Rising damp

Special equipments
- Reclining Chair
- Wheelchair
- Special bed, chair etc

Travel Costs (VC)
- Hospital travel costs
- Air fares

Travel Costs (FC)
- Motability
- Driving lessons
- Car Insurance and purchase

Heating systems
- Central heating system installation
- Boiler repairs and replacement
- Heaters

Home Care
- Clothing
- Portakabin rental charge
- carer costs

House move/setting up home
- mortgage arrangment fee
- Furnishings, removal costs, bed & linen
- legal costs, conveyancing fees

Bereavement
- Funeral costs and post bereavement costs

Education
- Registrants and Dependants course fees
- computer, school trip

Therapy
- Counselling fees
- therapies for registrant and partner
- Nam subscription by members

Convalescence
- Respite costs
- Convalescence costs