THE MACFARLANE TRUST

STRATEGIC REVIEW 1998

INTERIM REPORT
JULY 1998

MACFARLANE TRUST - STRATEGIC REVIEW

INTERIM REPORT TO THE DEPARTMENT OF HEALTH

1. INTRODUCTION

(i) 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.

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 heamophilia 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.

(ii) 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.

Trustees appointed by the Secretary of State for Health must include a Haemophilia Centre Director and Social Worker. The appointments are made for terms of 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 UK and not exceed two terms in office except as an emergency measure.

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

(iii) Trust Staff Establishment

Day to day administration of the Trust is delegated to a small staff team led by an Administrator\Chief Executive and 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 made after specific decisions by Trustees.

(iv) Finance

(a) HM Government Funding

Since the Trust was set up with an initial grant of £10 million, there have been three further top-up grants of £5,000,000 in 1993; £2,500,000 in 1996 and £3,000,000 in 1998, making a total funding to the Macfarlane Trust for the ten year period ended 31st March 1998 of £21,500,000.

(b) Payments to Trust Registrants

Payments made to registrants in the ten year period to 31st March 1998 have totalled £20,126,349 and comprise the following:

Regular Monthly Payments:	£12,633,767
Single Grants:	£ 4,270,147
Winter Payments:	£ 3,222,435
Total:	**£20,126,349**

(c) Total Assets at 31st March 1998

By reason of prudent investment The Trust is able to report that as at 31st March 1998 it retained funds equalling (at market value) £6,287,117 to which, during the last days of March 1998, the top-up grant of £3,000,000 was added, making total assets held at 31st March 1998 of £9,287,117.

(d) Investment Management

Over the ten year period money not required to meet immediate cash demands has been invested. At present funds are lodged with Principal Investment Management Ltd and COIF Charity Funds who have discretion to invest within parameters set by the Trust. The strong asset position that the Trust is able to record is due to both investment returns and capital appreciation. The Trust holds Equities, Fixed Interest stocks and Cash on deposit.

(e) For the sake of completeness, it should be recorded 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 of these awards under provisions set out in separate Special Payment Trust Deeds.

(v) Past Reviews of the Macfarlane Trust

There have been two previous major Reviews of the Macfarlane Trust:

(a) the first was an independent survey commissioned by Trustees and carried out by Public Attitude Surveys Ltd in 1995 aimed at finding out how effective the Macfarlane Trust was seen to be by its Registrants, and whether their needs could be better met by the Trust. [Appendix 5]

(b) 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 administration and financial aspects of the organisation and concluded that the management and administration of the Trust was to be commended. [Appendix 6]

Both the previous reviews were conducted at a time when it was generally believed that Trust Registrants were:

'a small and diminishing client group for whom it would remain critical to support and assist the remaining individuals and their dependants.'
and
'It was recognised that the Trust would need to continue at least until the end of the century, providing a service for a reducing number of individuals but continuing to support families'. (CAF Survey 1996)

Both Reviews recognised a steady and predictable reduction in membership leading to an reduction in the overall task of the Trust. The next section illustrates how these expectations may be changing.

(vi) A Changing Outlook for Macfarlane Trust Registrants.

Since the two reviews referred to above were carried out there have been very significant changes in the treatment of HIV/AIDS for all those in the United Kingdom and other developed countries.

Combination therapy - involving the use of three or more drugs to attack the virus at different stages of its life cycle - has dramatically reduced the death rate from AIDS and improved the quality of life of patients with HIV infection. In turn, this has changed the outlook for many Trust Registrants from one of imminent terminal illness to that of an uncertain but extending life expectancy dependent on a rigorous regime of drugs and supportive therapies. [Appendix 1]

For example in 1995, 90 Trust Registrants died; in 1997 the number had fallen to 33 and in the first 6 months of 1998 only 7 Registrants have died.

Despite the obvious medical benefits, the new multiple drug therapies bring with them a number of demands, particularly in the form of side effects such as vomiting, abdominal pain and diarrhoea. There is also recent evidence to suggest that haemophiliacs taking these therapies may experience an increased incidence of soft tissue bleeding. [Appendix 2]

Whether patients treated with combination therapy will continue to derive clinical benefit is uncertain as the previous pattern in HIV treatment has been for the virus to become resistent to drug therapy. There are recent reports of a small number of AIDS patients becoming resistent to combination therapy and this could mean that the improved quality of life being experienced by these patients might not be sustained.

There are significant issues for those patients who have also been infected with the 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 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 in HIV).

A formidable medical challenge for these HIV\HCV infected patients therefore is to provide them with effective therapy against HIV which does not impair their already inflamed livers. [Appendix 4]

Although medical treatment has improved, the practical difficulties and side effects of combination therapy - together with uncertainties about their long-term effectiveness - continue to leave HIV infected patients in a state of emotional turmoil as well as physical disablility. These symptoms are exacerbated by the co-existence of hepatitis virus in these patients, since this virus is also associated in itself with long term poor health. [Appendix 3]

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

(vii) The Case for a further Strategic Review

These complex patterns of medical and health related changes in the lives of Trust Registrants, combined with newly emerging 'psycho-social problems' related to a significantly altered life expectancy for hundreds of young men who, up until very recently, had felt they had no future, make it essential to carry out a fresh in-depth Review of how the changes will affect the Registrants and the future of the Macfarlane Trust.

Many Registrants were young children at the time of infection; they received substantially lower payments from HM Government in 1990 and 1991 because it was not expected that they would live to take on reponisibilities of family life. Many of these young men are now married and struggling with poverty, debt and social exclusion due to their HIV status and unemployment.

The Trustees have therefore decided to carry out another Strategic Review which will place particular emphasis on gathering up-to-date information on Registrants' current state of health and treatment regimes, as well as seeking to discover their own views of their changing needs at this time.

2. AIMS OF THE REVIEW

(i) The review will aim to identify the changing medical and psychosocial needs of Registrants in the light of recent scientific developments in the management and treatment of people with haemophilia and HIV, and the altered life expectancy and quality of life arising from these developments.

(ii) The Review will gather medical and statistical information available now in an attempt to forecast future demands on the Trust and a likely timescale for its duration.

(iii) The Review will also report on Trust expenditure in the ten years since its formation, and estimate future funding requirements if Trust Registrants are to receive similar levels of support in the future.

3. PROPOSED METHODOLOGY

(i) It is proposed that much of the work of the Review will be carried out 'in-house' by Trustees and staff of the Macfarlane Trust assisted by the HIV Worker of the Haemophilia Society.

(ii) The Review work will be guided by a Steering Group made up of Trustees supported by staff of the Trust and the Haemophilia Society.

(iii) There will also be a small sub-group responsible for consideration of the 'psycho-social issues' of the Review and organisation of feed-back from Registrants. This Group will include a Department of Health appointed Trustee and will be supported by the Macfarlane Trust Social Worker, the Haemophilia Society HIV Worker and representatives of Trust Registrants.

(iv) The work of the Review will fall into three main areas:

A. Identification of Registrants Needs through:

Focus Groups
One to One Interviews
A Postal Questionnaire
A revised Census Form
Use of the Conference Programme

B. Medical and Statistical Information from:

A Literature Search
Statistical Analysis of Causes of Death for people with Haemophilia and AIDS
A Letter to UK Haemophila Centre Directors

C. Financial Information from past records:

Grants to Registrants	- Details of grants made 1988 - 1998 and
Estimated Expenditure	- 1999 and beyond

4. EXTERNAL SUPPORT

(i) Medical Information

The Centre Director Trustee has undertaken to write to the Haemophilia Centre Directors Group to advise them of the Review and ask Directors and their staff to help gather relevant medical and social information for the Review.

Reference will also be made to the annual Report of "Causes of Death for People with Haemophilia and AIDS" which is produced in Oxford for the Haemophilia Centre Directors Group.

(ii) Psychosocial Needs

Staff of the Haemophilia Society and representatives of a Self Help Group for people with haemophilia and HIV, together with two Macfarlane Registrants and an external Consultant are working with the Sub-group to design questionnaires and set up Focus Groups and One to One Interviews.

It will also be necessary to recruit external help to assist with facilitating 'Focus Groups' and One to One interviews with Registrants.

(iii) Research and Administrative Support

It is recognised that as well as specialist support required to carry out a literature search and analyse results from a postal questionnaire, it will also be necessary to provide additional administrative support to the small Macfarlane Trust staff team for the duration of the Review.

It had been hoped that it would be possible to recruit such external help through the Civil Service 'Interchange Programme' but unfortunately we have been advised that the NHS Central Secondments Budget is already committed.

5. BUDGET

Whilst a large part of the work of the Review is to be carried out by Trustees and staff of the Trust, the specialist work referred to in Section 4(iii) above will incur costs not included in the Macfarlane Trust budget for 1998/99, and in excess of funds provided for in the Section 64 Grant for the current year, and the Section 64 'underspend' sum of £3,553 for 1996/97, approved for Review expenditure by NHS Executive in 1997.

Because the Review is about gaining as full a view of Registrants needs as possible, it will be necessary to use external facilitators to conduct Focus Groups and analyse findings from the Questionnaire.

The budget outlined below shows estimated costs for these activities:

BUDGET

FOCUS GROUPS:	£
Facilitator costs	4,000
Travel & Subsistence	4,000
Hire of meeting rooms/facilities	1,500
ONE TO ONE INTERVIEWS:	
Travel & Subsistence - 20 meetings	1,500
LITERATURE SEARCH	500
QUESTIONNAIRE & DATA ANALYSIS	4,500
ADMINISTRATIVE ASSISTANCE	3,000
OVERALL TOTAL	**£19,000**

TIMESCALE

(i) All Trust Registrants have been advised of the forthcoming Review, and have been asked to complete a new Census Form to update the Macfarlane Trust database.

Registrants have also been sent a Questionnaire offering them three levels of involvement in the Review:

(a) Participation in Focus Groups
(b) Having a One to One Interview with a Researcher
(c) Completing and returning the Postal questionnaire

(ii) It is hoped that all Questionnaires will be returned by mid-August. Those who wish to participate in Focus Groups or One-to-One Interviews will be chosen by random selection.

(iii) Focus Groups and Interviews will take place during September. Findings from these meetings and from the postal questionnaires will be analysed in the autumn.

(iv) The Literature Search will be conducted between July and the end of September, and responses from Centres will be summarised in October.

(v) It is planned to prepare a first draft of the Report by early November, and to have a final Report ready for submission to the Department of Health by the end of November 1998.

NOTES AND APPENDICES

(1) a. History of HIV Therapies;
    b. Problems with New Classes of Drugs, HAART.
    [These two Handouts have been provided by the Haemophilia Centre of The Royal Free Hospital, London.]

(2) A Personal Account of living with Haemophilia, HIV and Combination Therapy from a Macfarlane Trust Registrant

(3) Psychosocial Issues facing Macfarlane Registrants

(4) A Medical Viewpoint from a Haemophilia Centre Director

(5) Executive Summary of Main Findings - PAS Survey 1995

(6) Executive Summary - CAF Review for Department of Health 1996

Macfarlane Trust - Interim Report to The Secretary of State for Health.

July 1998

Appendix 1a

History of HIV therapies

Mid 1980s	Zidovudine (AZT) A nucleoside reverse transcriptase inhibitor (NRTI)
Late 1980s/ Early 1990s	Other NRTIs Didanosine (ddI), Zalcitabine (ddC),Stavudine (d4t) Some marginal benefit in combination with zidovudine, or if zidovudine failed
Early 1990s	Lamivudine (3TC) NRTI shown to be more effective in combination with zidovudine than zidovudine monotherapy
Mid 1990s	Protease inhibitors (PIs) Saquinavir,Ritonavir,Indinavir Nelfinavir
Late 1990s	Other PIs, NNRTIs and NRTIs

Appendix 1b

Problems with new classes of drugs / HAART

- Dosing schedules
- Large numbers of tablets on daily basis at obscure times of day → poor compliance
- Drug-drug interactions
- Side effects
  - Liver problems
  - Bleeding
- RESISTANCE / CROSS RESISTANCE

MACFARLANE TRUST STRATEGIC REVIEW - APPENDIX 2

A PERSONAL ACCOUNT OF LIVING WITH HAEMOPHILIA, HIV AND COMBINATION THERAPY.

The following account was kindly submitted to us by a registrant to give a picture of what he lives with on a day to day basis.

Current Medication:

1. Indinivar 3 x day (Combination anti-retroviral therapy drug)
2. Lamivudine 2 x day (Combination anti-retroviral therapy drug)
3. Stavudine 2 x day (Combination anti-retroviral therapy drug)
4. Bottled water 2L per day (minimum)
5. Co-Trimoxazole 3 x week (prevents Pneumocystis pneumonia)
6. Oilatum Hydromol Emollient (Bath additive, for HIV related skin problems) 2 x daily
7. Unguentum Merck (for HIV related skin problems) 2 x daily
8. E45 Cream (for HIV related skin problems) 2 x daily
9. Fluconazole (to prevent/ control thrush infection in mouth & throat) daily
10. Acyclovir (to prevent and control herpes infections) daily
11. Clarithromycin (broad spectrum antibiotic) daily
12. Factor Vlll (haemophilia prophylaxis) intravenously 3 x week.
13. Co-Dydramol (pain relief) 4 x daily
14. Chlorpheneramine (anti-histamine)

In addition, I occasionally take recreational drugs to manage stress and counteract weight loss, swim twice a week, have physiotherapy twice a week (both to strengthen joints and maintain muscle tone), and have a weekly hydrotherapy session. I also have to perform muscle toning exercise twice a day.

A TYPICAL DAY

My typical day would normally start around 6 a.m. when I am gently woken up by the gentle throbbing of our ever punctual milkman's diesel engine outside our bedroom window, which is very convenient, as it is the time to take my first dose of medication (Indinivar, Lamivudine, Stavudine), with my first 500ml of bottled water. I then spend ten minutes on muscle toning exercises to prepare myself for getting out of bed, and to check my joints for any bleeds which may have started in the night.

All being well I head downstairs to have my first bath of the day, with no soap, just two capfuls of Oilatum (for my HIV skin condition). A twenty minute soak, minimum, is needed before getting out. By this time - 6:45 a.m. - there is the strong, nauseous taste of metal in my mouth, (like chewing a piece of silver paper). This remains until I am allowed to eat, 1 - 2

hours after taking the morning tablets. Getting out of the bath in my slippery state can be very dangerous, so I let the water out first, and dry myself in the bath.
After drying I make sure I use the toilet before I leave (as it will be in constant use by other members of the family until 8:30).

At 7:30 tea and toast seem to help relieve the nausea and the metallic taste in my mouth, but leave me still feeling faint from leaning over the bath to clean it. The next job on my agenda is to apply Unguentum Merck and E45 creams. Then, while that's soaking in, I give myself my Factor V111 injection.

At 9 a.m. it's time for more tablets, Co-Trimoxazole and Co-Dydramol, with a second 500ml of bottled water. By this time I could go back to sleep and give in to the constant fatigue and tiredness, but a visit to the toilet is needed, so I get dressed and go downstairs, taking any bedding that may need washing if we have had a bad night with sweating. I try and keep myself moving by helping to tidy up after breakfast.

At 10 a.m. my sister-in-law takes me swimming at the local baths. After one hour's exercise I arrive home at around midday, feeling like shit, but pleased I had completed my hour of exercise. It's now time to eat a light snack before sleep takes over until 3 p.m., when it is then time to take some tablets (Stavudine, and Co-Dydramol again), then ten minutes muscle toning before getting back off the bed to help with anything that needs doing around the house. This part of the day is the period when I battle most with the urge just to sit down and rest. I keep going and try not to think to much about the health situation I find myself in. It is a constant struggle to keep convincing myself that I am making the best choice by taking the drugs. The doctors tell me my viral load results are improving but my body (which I have always tried to listen to) is telling me that things are failing. Maybe the fatigue will be better with time, it's still early days (only four months since starting the new drugs).

Must remember to drink plenty of water to stop kidney stones forming (a side effect of triple combination). I am already getting days when it's painful to pass water.

By 6 p.m. it's time for the main meal of the day, followed by a second bath (Oilatum, Unguentum Merck and E45 again). 7:30 to 10 p.m. is quality time with my family or friends. I may even have a glass of wine some evenings (not often, as it makes my liver painful - a complication of Hepatitis C).

10 p.m. and it's the last dose of tablets (Indinvar, Lamivudine, Stavudine and Co-Dydramol). I must wait an hour now for a light snack with a hot drink to try and relieve the nausea and metal taste from my mouth. At 11:30 p.m. we retire to bed, hopeful of a good night's sleep, with no interruptions from night sweats, the need to use the toilet or just being unable to sleep.

As well as the above drugs, I might also be taking treatment for opportunistic infections. The side effects from all this medication that I am currently dealing with include headaches, nausea, diarrhoea, allergic rash, muscle pain, fatigue and peripheral neuropathy.

I make three regular visits to the hospital every week, apart from a monthly blood test, picking up medication, and visits for any other HIV or haemophilia related problems which may have developed.

My typical day starts around 6 a.am. when I am awaken by the gentle throbbing of our ever punctual milkman's diesel engine....... and so it goes on.

I would just like to add that my wife is also HIV positive, and taking the same triple combination therapy as myself, with all the HIV related problems above (plus a few female only ones).

Bye for now

From a very patient Patient.

MACFARLANE TRUST STRATEGIC REVIEW - APPENDIX 3

PSYCHOSOCIAL ISSUES FACING MACFARLANE REGISTRANTS: AN OVERVIEW

INTRODUCTION

There have been a number of changes that have affected those who are living with haemophilia and HIV over the years. Some of these are to do with the impact of living with a terminal but indefinite diagnosis for many years, but increasingly they are to do with recent radical advances in anti-HIV therapy. Changing social priorities, the subsequent changes in political and economic health and social care agendas and policies have also had a significant impact. However many of the fundamental issues facing registrants are the same as they ever were.

This document attempts to highlight some of the main issues that face this Haemophilia & HIV Community. It is hoped that the full review will provide more complete evidence of these needs and also strategies to combat difficulties in a positive and responsive way.

KEY ISSUES

* HEALTH SITUATION: IMPACT OF COMBINATION THERAPY

New anti-HIV therapies have brought mixed blessing. Various statistics show decreases not only in the rate and number of deaths from HIV related illnesses, but also in measures such as frequency and length of inpatient stays on wards. For example, in London there has been a marked reduction in HIV dedicated beds, and several dedicated wards have actually closed.

However the treatment regimes that most patients have to live with represent a huge intrusion and pressure on day-to-day life. People must adhere to **stringent regimes of medication** that can be disruptive to daily life. The **side effects** for these drugs include nausea, diarrhoea, vomiting, abdominal pain, headache, fatigue, hair loss and muscle pain, amongst others. For those people trying to maintain employment this is a nightmare, and in all cases has serious implications for quality of life.

Some drugs used in combination therapy have added side effects for haemophiliacs. Also the effects of co-infection with **Hepatitis C Virus** (affecting the majority of registrants) cannot be ignored. Both HIV and HCV seem to speed each other's disease progression. Additionally, **chronic liver damage** from active hepatitis affects drug metabolism, and thus access to life saving therapy.

Therefore, although prognosis has improved greatly for many registrants, it is at the cost of drug regimes and side effects that often affect quality of life markedly.

- **RANGE OF NEED**

The practical support needs are many and varied. HIV symptoms and drug side effects allied to the well-known problems associated with long-term haemophilia will mean many **mobility difficulties.** Requests for help with adaptions (for example for hoists into baths) have become frequent. The rapidity at which need can change is often marked, whilst the response time of local authorities may be too lengthy.

A whole range of **mental health problems** are now surfacing. Most people who were told they were HIV positive were given the prognosis that they would not survive past two to three years. Some did die this quickly, most did not. Fifteen years later, the survivors have now **lived with uncertainty** for a very long time. A lot of people are reflecting on the years gone by and the people they have lost along the way. There is a large group of people doing a lot of **delayed grief** work. Only now they are dealing with the sense of loss they have been living with for so long. This loss might be to do with people who have died, but might also be due to the loss of life that they could have had in different circumstances.

In a material sense most people, feeling that they only had a short time to live, have spent the original money that was given to them by the Trust. This money was spent on the problems that faced them at that point. They are now looking at having a limited, medically regimented life for a longer time than they could ever have expected, whilst living in **financial hardship** and with **chronic need**

- **ISOLATION**

The isolation of this group has, if anything, increased over the years due to the ongoing stigma that still exists within society. Most people have continued to communicate their status to a very limited number of people, if any. This leads to an **unwillingness to access local services** due to fears of **confidentiality.** This isolation is exacerbated by the reducing size of the haemophilia and HIV population, which has led a lot of people to isolate themselves further. Reaching out to this group requires specialist knowledge and understanding.

- **BEREAVEMENT**

The Macfarlane Trust still has a duty to support the dependants of those who have died. The isolation, that a lot of people dealt with when their loved ones were alive, carries on after they have died. A lot of people therefore are not able to tell family, friends, relatives or neighbours about the real reason for a loved one's death. In some cases children from families, where a member has died in these circumstances, will have special educational and other psychological needs due to these confidentiality problems.

* LOCAL VARIABILITY OF SERVICES & ACCESS TO TREATMENT

Access to combination therapy is variable across the UK at this time. **"Prescription by post code"** means that where you live, and not clinical need can often be the criteria for accessing combination therapy. Likewise, areas with higher HIV incidence will often have better statutory and voluntary services (medical and psychosocial) than areas with low incidence.Service provision for registrants is very **"patchy"** across the UK. Even with London, the variability between boroughs and health authorities can be marked. Furthermore, the awareness of haemophilia issues is often poor in mainstream HIV services, and many, if not most, are **not perceived by haemophiliacs as "haemo-friendly"** - most are seen as gay, drug-user or African focused.

* EROSION OF SERVICES

The progressive loss of ring-fenced funding for HIV treatment and care, the cost pressures of combination anti-retroviral therapy and the increased cost pressures of other areas of medical technology (including recombinant blood products) means less money is available for those HIV specific services that do exist. Specific services for those with HIV and haemophilia are now almost non-existent. Furthermore as the numbers of co-infected haemophiliacs have decreased, so dedicated services are disappearing.

* ROLE OF THE MACFARLANE TRUST

A lot of people in many ares are not able to access emotional or practical support in the same way as before. This leaves the Macfarlane Trust as the main central body dealing with the HIV and haemophilia community. The Trust, in the early years, had to concentrate its' efforts on providing and administering financial support. Increasingly however, the psycho-social needs of the registrants are coming to the attention of the Trust, and they are being asked directly to provide or organise support for people. It is felt by the Trustees and staff alike that this represents an ongoing challenge and that the full review of the work of the Trust will demonstrate that these needs will, if anything, increase.

The Haemophilia Society has recently appointed a new haemophilia and HIV development worker. Close links with this worker are already being built up and it is envisaged that through this partnership people will have a central specialist resource to turn to for help. The knowledge and information regarding both treatment and effects of haemophilia and HIV/ HCV co-infection is increasing all the time and it makes sense for this information to be held centrally. A lot of people do not have access to this knowledge and information elsewhere and need a point of contact to answer queries.

There is now in the general HIV population a lot of expertise, resources and potential support for this group amongst both the voluntary and statutory sectors. The role of the Trust is increasingly to use this network to access confidential, HIV specialist support for people and provide a bridge for people living in isolation to the expertise that can be found within reach.

Psychosocial Needs Subgroup

1998

MACFARLANE TRUST STRATEGIC REVIEW - APPENDIX 4
A Medical Viewpoint from a Haemophilia Centre Director

Recent Developments in HIV treatment and care

There have been a number of recent scientific developments in both the management and specific treatment of those with HIV infection and these developments are having a significant impact on the quality of life of these patients.

For many years, the most sensitive way of assessing the damage being caused to the immune system by HIV was to monitor CD4 cell counts, these being the white blood cells destroyed by HIV. There was a precise and meaningful inverse correlation between the level of the CD4 cell count and the likelihood of progression to clinical disease and treatment decisions were to a large degree based on these parameters.

Quite recently, HIV viral load testing has been introduced and this represents a very accurate way of measuring the amount of HIV virus in the bloodstream at any one time. This has proved to be a much more sensitive predictor of impending clinical deterioration than the CD4 cell count and the availability of this test also means that the effect of treatment on the viral load can be assessed more accurately. From the laboratory perspective therefore there are now much more sensitive means of assessing both the state of the patient's virus infection (and its impact on the immune system) and the response of the immune dysfunction and viral load to treatment.

Parallel with this, there have been significant developments in the field of anti-retroviral therapy. The MRC Delta Study indicated that combination therapy - using two or more anti-retroviral agents - was clearly more effective than monotherapy and this has evolved into the concept of 'triple therapy'. In these regimes, two anti-retroviral agents that affect an essential viral enzyme - Zidovudine and Lamivudine - are combined with a particularly powerful and newly available group of drugs called protease inhibitors. These drugs work in a different way on the virus and seem to be synergistic in their actions.

Both from the clinical and immunological stand point, the implementation of this new combined therapy has had an extraordinary impact. There has been at least a 50% decrease in patient mortality and a number of patients who had begun to prepare themselves for death are now feeling so much better that they are able to consider retraining and are having to cope with a number of different medical and psychological problems in their lives. The immunological response to this therapy is dramatic, in that patients who may start with a viral load in excess of 50,000 copies/ml are found to have undetectable virus in the bloodstream when the viral load test is repeated after only a few weeks of therapy. In other words, the new therapy has the ability to effectively clear HIV from the bloodstream.

To date, response to this new therapy appears to be sustained although from the medical point of view one clearly needs further information before being able to say that the dramatic improvements seen so far are likely to be long lasting.

AIDS has thus become a chronic and manageable illness with patients undergoing complex laboratory and immunological tests and taking complicated drug regimes but with substantial clinical benefit.

M WINTER
Haemophilia Centre Director 24th February 1998

Appendix 5

2.0 EXECUTIVE SUMMARY OF MAIN FINDINGS

2.1 Members Survey

2.1.1 In general, members taking part in the survey felt that the Trust did a good job overall (60% thought that the Trust did its job *very well* and a further 34% felt that the Trust did a satisfactory job). Most (88%) felt that Trust staff dealt with enquiries sensitively, and the majority (82%) were satisfied with the Trust's procedures on confidentiality.

2.1.2 One in ten respondents had not had any contact with the Trust (other than receiving regular payments and Newsletters). Of the remainder, most had contacted the Trust by telephone, or by letter. Only 9% of the sample had contacted the Trust in person.

2.1.3 Of those contacting the Trust, most felt that the Trust replied to letters and telephone calls within a reasonable period of time (97% in both cases), and that it was easy to find someone at the Trust to deal with them (36 out of the 40 respondents who had contacted the Trust in person).

2.1.4 A fifth of the sample were not aware of any of the services offered by the Trust. Of those who were aware of the Trust's services, a third had never used any.

2.1.5 The most popularly used of the services offered by the Trust was information on available DSS benefits, and help with applications for benefits. Each of these services were used by around a third of the sample.

2.1.6 Twenty four percent of members responding to the survey had not contacted any organisations for help, information or advice in relation to their HIV. Of the 335 respondents who had contacted an organisation over half (52%) had contacted the Macfarlane Trust. A further 46% had contacted the Haemophilia Society - national, and 36% had contacted their GP.

2.1.7 Those who had contacted an organisation had been seeking the following help, information or advice: information on DSS benefits (45%), information on existing and possible future treatments for HIV (44%), foreign travel advice (38%), assistance with applications for or appeals with, DSS benefits (36%) or a chance to share their views with others in the same situation (22%)

2.1.8 The organisations contacted appeared to differ depending on the type of advice and information sought. For example, respondents were slightly more likely to consult the Trust on practical matters (such as information on benefits, and mortgage and housing advice), than the Haemophilia Society (national or regional).

2.1.9 Respondents were asked to indicate in which areas they felt more services should be provided for people living with haemophilia and HIV. The service mentioned most frequently by respondents was the provision of information about existing and possible future treatments for HIV which was mentioned by 65%. A further 45% mentioned advice on alternative or complementary therapies and 40% information on DSS benefits.

2.1.10 Twenty seven percent of respondents felt that they were not reasonably well informed about the HIV treatment options available and 25% did not feel that they were given the chance to be involved in deciding the best treatment for themselves. Considering this, it is perhaps not surprising that the service required by the largest proportion was the provision of information about existing or possible future treatment options.

2.1.11 Respondents were then asked how the services they felt were required would best be provided. Again, there appeared to be a perception that different types of services were best provided by different types of organisations; with the Trust seen as the most suitable provider of help and information on practical issues (such as applying for benefits, and issues concerning debts and money management), and Haemophilia Centres as the best providers of information on treatments for HIV and complementary/alternative therapies, and the opportunity to talk with a qualified counsellor.

2.1.12 Respondents were asked to indicate which form of payment provided by the Trust was their most important form of variable financial help. The most important form of variable payment to members was the higher rate regular payment to those whose health was poor (named by 43% as their first priority for expenditure), followed by the higher rate additional payment to those on benefits (chosen as the most important priority by 21% of the sample). Long term regular payments for widows with children was named as the most important form of financial help by 13% (although this proportion was higher amongst respondents who are married/living as married, and those with dependant children).

2.1.13 Although the majority of the sample were able to identify their personal priorities for expenditure, there was also a general awareness of the financial constraints placed on the Trust. Half of the sample felt that there were no other types of payment that the Trust should provide, and most (86%) did not want the Trust to spend more on services if this meant reducing the amount spent on regular and single payments.

2.1.14 The majority of respondents (71%) felt that the Trust should have direct control over the services that it funded.

2.2 Dependants' Survey

2.2.1 In general, the findings of the dependants' survey were broadly similar to those of the members survey. Most respondents (97%) felt that the Trust did its job *very well* (65%) or *satisfactorily* (32%), and most (88%) were satisfied with the Trust's procedures on confidentiality.

2.2.2 As with the members survey, most dependants had some form of contact with the Trust, whether by 'phone (56%), by letter (73%), or in person (8%). Of the respondents who had contacted the Trust (either in person, by 'phone or by letter), 90% felt that their enquiries were dealt with sensitively.

2.2.3 In general, dependants were happy with the contact they had with the Trust: most felt that letters and telephone calls were replied to in a reasonable amount of time (97% and 95%), and 11 out of the 13 respondents who had contacted the Trust in person found it easy to find someone at the Trust to deal with them.

2.2.4 Although most respondents had sought advice, information or help since their partner's death, a sizeable minority (19%) had not contacted any organisations for help.

2.2.5 Of the 134 respondents who had sought advice or help 53% had contacted the Macfarlane Trust or their GP for advice or help since their partner's death. Twenty nine percent had contacted the Social Services department of their local authority.

2.2.6 The types of information and help which were sought included; general advice (48%), the opportunity to talk with a bereavement counsellor (31%), and information on DSS benefits (24%) and advice on applying for probate (16%).

2.2.7 As with the members survey, the organisations contacted for help and advice generally differed depending on the types of advice and information sought. The findings suggested that respondents were more likely to contact the Trust for general advice; their GP for the opportunity to talk with a bereavement counsellor; and the Social Services department of their local authority for information on benefits.

2.2.8 In terms of services for the future, there were some differences between members and dependants in the priorities placed on the variable forms of financial help provided by the Trust. For example, long term regular payments for widows with children, and long term regular payments for widows who were sick or disabled were named as the most important priorities by a larger proportion of dependants than members.

2.2.9 As in the members survey, however, respondents appeared aware of the financial constraints under which the Trust operated. Sixty one percent did not think that the Trust should provide any other types of payment, and only 14% felt that the Trust should spend more on services even if this meant reducing the amount spent on regular and single payments.

2.2.10 As with members, the majority (64%) of dependants felt that the Trust should have direct control of the services that it funded.

2.3 Staff Survey

2.3.1 The majority of staff (91%) felt that the Trust did a good job overall with 54% stating that the Trust did its job *very well* and 37% stating that the Trust did its job *satisfactorily*. Of the 52 respondents 4% felt that the Trust did its job poorly.

2.3.2 Eighty seven percent staff had contact with the Trust with 71% having contact by letter, 65% by telephone and 33% in person. Nearly all (91%) of those who had contact with the Trust felt that their enquiries and assessments were dealt with sensitively.

2.3.3 Most members of staff were aware of some of the services provided by the Trust with 69% aware that the Trust provided information about what benefits were available, would help sort out practical problems and would help to identify possible sources of assistance. Sixty five percent knew that the Trust would help with applications for DSS benefits.

2.3.4 Twenty seven percent of staff had not used any of the services provided by the Trust, a proportion that is not significantly different from that among members.

2.3.5 Of those who had used services provided by the Trust the largest proportion (54%) had used the service providing help in identifying possible sources of assistance or specialist advice and information. Forty six percent had used the information service about the availability of DSS benefits and 44% had sought assistance with DSS benefit applications for their clients or patients. Forty two percent of the staff had sought help on practical problems on housing or hospital travel etc.

2.3.6 Staff were asked which organisations they had contacted for help, information or advice. Three quarters had contacted the Trust, 58% a local authority social services department and a further 58% mentioned the National Haemophilia Society.

2.3.7 The information that was most frequently sought by staff related to DSS benefits (53%) and assistance with applications or appeals for DSS benefits (45%). Other information that was sought included: mortgage or housing advice (35%), facilities for self-help or voluntary organisations (33%) and foreign travel advice(31%).

2.3.8 As with members and dependants, staff were asked to rank the variable forms of financial help provided by the Trust in order of importance. The largest proportion of respondents (38%) felt that higher rate regular payments to those whose health was poor was the most important form of variable financial help.

2.3.9 Respondents were also asked whether they felt there were any additional services that should be provided for people living with HIV and Haemophilia. Unlike the members survey, where the largest proportion (65%) mentioned information on existing or, possible future, treatments, or, the dependants survey, where just over half (51%) mentioned general advice, the largest proportion (50%) of staff felt that services providing information and advice on starting a family were important. In comparison this service was mentioned by 24% of members and no dependants.

2.3.10 As with the members and dependants surveys, staff generally suggested that financial help and advice would best be provided by the Trust and services concerning medical advice and information would best be provided by the Haemophilia Centres. In the majority of issues staff saw the provision of the service falling to either the Macfarlane Trust or the Centres with little mention of the Haemophilia Society or other agencies.

2.3.11 Seventy three percent of staff felt that the Trust should not fund service provision by reducing the amount of regular or single payments, a proportion which is broadly in line with the views of members and dependants.

2.3.12 Fewer than half (48%)of the staff responding to the survey felt that services financed by the Trust should be directly controlled by the Trust. This compares with 71% of members and 64% of dependants who felt that the Trust should control the services that it funded.[1]

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[1] The full report presents a complete analysis of the survey findings in addition to this summary.

Appendix 6

A REVIEW OF THE MACFARLANE & EILEEN TRUSTS FOR THE DEPARTMENT OF HEALTH 1996

1 EXECUTIVE SUMMARY

- CAF Consultants were commissioned to review the effectiveness of the Macfarlane and Eileen Trusts. As they share common staff, common procedures and some common Trustees, and as the Eileen Trust is now such a small operation, both Trusts have been evaluated together.

- The Trusts were established with an endowment from the Department of Health to offer help to people infected by HIV through donated blood or blood products. Their running costs are entirely met by government.

- The conclusion of the consultants is that both Trusts are well managed organisations, managing to meet need in an immensely complex environment.

- They are dealing with the needs of a small and diminishing client group, and also addressing the needs of the survivors, and in order to do this have developed procedures and policies for assessing need and determining eligibility that are, by and large, administered fairly and compassionately.

- There is some dissatisfaction among the membership, but much of this relates to the early days of the Trusts, and particularly the slow start up which, to many sufferers, seemed unacceptable.

- A decision about the future of the Trusts is a matter of some urgency because the nature of the client group means that the population of beneficiaries is declining in size. Additionally, Trustees are aware that they cannot keep their key staff forever and there is clearly a need for some careful succession planning, at the same time as the Trusts embark on a process of detailed strategic planning to determine future direction and needs. Together these two issues present the Trusts with major decisions and the need to operate strategically is paramount.

- The consultants examined:

  1. financial control
  2. investment management
  3. administrative systems
  4. social work capacity
  5. governance.

- In general, the consultants concluded that in all these areas the Trusts are operating effectively and efficiently.
- This report is an evaluation conducted on behalf of the Department of Health to inform its planning and assessment process. As such, recommendations are not included and would be inappropriate.

5. REPORTS FROM CENTRES

Dr Mark Winter, Haemophilia Centre Director, Kent and Canterbury Hospital, and a Trustee of the Macfarlane Trust, wrote to each Centre Director advising them of the Trust's Strategic Review and inviting comment from the Centres. These comments are summarised below:

Younger men

'...Have coped well with adolescence despite this additional dimension to their emotional and sexual development.'

'...Did well at school and went on to higher education and then became unwell and had to opt out of university courses, then started on newer treatments (e.g.: Protease inhibitors) have become well and been able to resume their courses. Not sure how they have coped with financial requirements, but it is important that they are able to return and complete their studies when health improves'.

'In younger patients, it is important to stress potential problems with secondary education and first employment. Again, with regard to HIV infected teenagers there are issues around leaving home and the emotional (and financial) impact this may have on parents.'

Birmingham.

Twenty-one year old male:

'Had found it difficult to make new relationships;

Had difficulty tolerating new drug regime, numerous allergies, many anti-retroviral therapies have had to be discontinued; there had been one episode of anaphylaxis = cardiac arrest; ongoing peripheral neuropathy was causing pain and discomfort. This young man had to make fortnightly visits to hospital for i.v. Pentamadine; He Had found it difficult to find and keep employment; and had been erratic when attending college courses;

He lived with parents who found it difficult to balance encouragement of normal life with over-protectiveness;

He was financially dependent on parents.

Young Male

Another young man had had difficulty accepting diagnosis; compliance was difficult, he now had HIV related illness; there were financial difficulties, and he had no employment;

He found it difficult to practise safe sex; and could be moody and aggressive at times, marriage broke down at one stage;

He was bitter at not being able to live normally, and resented his brother who had been able to reduce viral load down to undetectable levels.

Young Male

Another young man was living as normal life as he can; not on treatment;
His partner was aware of his diagnosis and safe sex was practised.

He was employed with good career prospects and financially 'as secure as most'.

Hampshire

'There are usually no respite facilities for younger people. A 20 – 40 year old does not want to go into a nursing home for elderly people. If the person has neurological symptoms the problem is exacerbated.'

Newcastle

More Mature Men

'I feel it is important to stress that HCV is becoming a more important issue in these patients and that increasing numbers may become eligible for liver transplantation.'

Birmingham

Middle Aged Male with HCV

Employed but employer unaware of diagnosis; job security not good;

Financial difficulties associated with hospital visits; drug regime difficult to comply with;

Impaired liver function; finds it difficult to maintain weight;

Finds he is increasingly short-tempered with family.

Middle Aged Male

Will not disclose diagnosis, only wife and father know status;

Has had two children naturally – wife HIV positive;

Does not attend HIV clinic, uses back entrance to hospital;

Father disposes of all factor concentrate rubbish in London;

No financial problems, invested lump sum payments;

Had nasty experience with press some years ago, tries to maintain privacy and live a normal life.

Hampshire

Care Issues

'Our clients do not often 'fit in' with the Community Care assessment process; HIV clients are in competition with other service users. There can be long waits for assessments and services such as adaptations. Some local authorities are able to respond to practical needs, but are unable to offer on-going emotional support. Social needs of patients change rapidly, depending on their medical condition.

A recent example: A very ill man being discharged home to the community to be cared for by his wife and family and community services. The District Nurse did not see it as her role to bath the man. When hospital referred to local authority for assessment, we were advised that the case would be referred to panel the following week to decide whether a service could be provided. Centre applied to Macfarlane Trust for an agency nurse to bath the patient, as he could not wait for the local authority's decision.'

'Most local authorities do not provide a 'sitting service' (night or day). A recent case required night sitters. It was necessary to employ Marie Curie nurses as night sitters. The local authority could only fund this service 2 nights a week, which would have meant that elderly parents would have had to sit up with their very sick adult son five nights a week as well as be with him by day. Again, it was necessary to apply to the Macfarlane Trust to help fund other nights.

Although hospice care is excellent, it is not offered long term. Usually the care is shared with the community and it has been necessary to complement community care with private agency nurses to help families care for their loved ones.

6. POSITIVE PARTNERS WEEKEND

INTRODUCTION

There are 37 female HIV positive registrants of the Macfarlane Trust. Six had sero-converted after receiving contaminated blood products as NHS treatment for their haemophilia; all the others became positive through intimate relationships with male registrants of the Trust.
Six of the latter group, some widows of and some married to male registrants of the Trust, met together for a weekend seminar in October 1998. Areas of need highlighted as being specific to their particular group are included in this Report.

As the reason the women had assembled was not specifically connected with the Strategic Review, the women were invited to discuss only three Review related questions over a one-hour period. The questions were:

1. What is it like to be living with HIV as a woman?

2. What issues do we need to be aware of as workers?

3. What are your specific needs?

Other information for this report was gleaned from workshops that took place over the weekend relating to confidentiality, disclosure and treatments.

Most of the needs arising for this group were the same as those mentioned in the other three reports produced for the Review: 'The Voice of the Registrant' - analysis of the postal questionnaires and Reports of the Focus Groups and One-to-One Interviews. This Report will focus on the differences that arose in discussion.

ISOLATION

Most registrants said that isolation was a problem, with, in some instances, husbands preventing disclosure. It was felt that other HIV positive groups resented and rejected this group as they were seen as 'being provided for' by the Macfarlane Trust.

The problem of not knowing any other HIV positive women was also highlighted by most. Some wanted to meet other HIV positive women who shared things in common other than their HIV status.

Some solutions suggested to overcome the problem of isolation included a contact page in the MFT newsletter, a telephone network, use of the Internet and organised social events.

INFORMATION

Written and verbal information needed to be easily available – as it was thought not to be.

Where there was information, it was thought to be predominantly produced by the western medical profession with little or no regard to other treatments such as Complementary or Alternative Therapies which was of benefit to many women in their position.

Written information in the following areas was also considered lacking:

- Having children
- Sexuality and sexual relationships
- Transmission
- Menopause
- Effects of treatment

Concern was expressed about dealing with HIV and pregnancy. Those concerned felt they needed to be able to make informed choices about decisions around family planning. The lack of information as a basis of informed choices applied to most of the above issues.

PSYCHOSOCIAL

All the participants felt the need for relaxation time; half the group commented on the essential need for 'time off', not with other HIV positive people; at a location of personal choice and during a period of good rather than ill health.

The strain of acting 'everything is fine' and having to continue to live a lie with a cover story was felt by most of the women. This pretence was thought necessary as a response to the continued ignorance about HIV and Aids still prevalent amongst the general public.

OTHER AGENCIES

Some of the women were treated for their HIV alongside their husbands at Haemophilia Centres. A general feeling was that of being treated as 'wife of a patient' rather than patients in their own right. This was considered unacceptable and patronising, especially where participants felt their own knowledge of their illness was ignored. The fact that the MFT had details of the women on their husbands' files rather than their own seemed to echo this.

It was thought that Haemophilia Centres needed guidelines for and about positive women if they were to continue their care in areas such as 'management of menopause'.

Some women thought the centres were unaware of their needs, did not encourage questions from their patients and were lacking in issues of confidentiality.

AS CARERS

Being the wife/ partner or widow of a man with haemophilia who is/was HIV positive and, in most cases, was also hepatitis C positive, featured highly as a difficulty.

The following questions and problems were expressed and need to be appreciated:

- "The man always comes first"
- "Being a carer is burdensome, giving little time to 'look after' oneself as you take responsibility for yourself and others".
- "Who cares for the carer?"
- "Were female positive partners held as being as important at male registrants by the MFT? It was felt that maybe they were not'.

In the role of carer those with partners found they were the ones consoling other family members as well as acting in a counselling role to their husbands/partners. One commented on how she felt at the prospect of being left alone when her husband died – she asked who would care for and support her and felt angry at the amount of energy and commitment she had given as a carer.

As parents, those who had children felt the unfairness of seeing their children worry about them.

Whilst one woman felt that she was continuously educating non infected/unaffected people, others, fearing repercussions, were unable to engage in conversations about HIV.

Some women felt the immense strain of sustaining the lie intensified after their husbands' deaths as there was a further need to blame death on 'respectable causes'. The lies themselves caused great stress and needed to be prepared carefully in order that the details would not be muddled – as in remembering 'who was told what'.

The request that HIV should not appear on a death certificate was not always respected.

If a deceased partner did not want their HIV status known, it felt like a betrayal to disclose this information after death even though doing so would feel like the "lifting of a great weight from one's shoulders". Participants also did not want their partners 'blamed' for their own status.

EMPLOYMENT

Problematic areas brought up in relation to employment were as follows:

- Fear to move to another job – due to issues of disclosure and confidentiality
- Tiredness at work
- Unpredictable future

Anger was shown at the huge areas of life missed/changed when ability to work was an issue and the choice of whether to work or not was taken away.

With the prospect of full-time employment ever diminishing, freedom about financial choices about credit, mortgages, loans etc. became increasingly reduced or non-existent if the person was not working at all. This was obviously more of an issue for this group where both partners were positive.

MACFARLANE TRUST (MFT)

The following comments were made abut the Macfarlane Trust:

- "MFT should be more flexible with grants"
- "They should anticipate need"
- "They should not act like the established Social Security Department and should be more aware of those not on benefits".
- "MFT should offer grants rather than us having to beg for them".

One woman spoke about her belief over the past ten years that she was the only HIV positive woman in the Trust. On learning that there were others she felt that a support network for positive women should have been set up long ago. This type of support need was echoed by practically all the women present.

It was interesting that although one woman was an "infected intimate", in MFT terms she had been widowed for a few years now and haemophilia was no longer part of her life. She felt this issue of positive widowhood also needed recognition.

It was thought discriminatory and unacceptable that "affected intimates" (positive widows) still had their husbands' MFT number rather than their own. This was questioned, together with the terminology "widow of haemophiliac" which was considered to be insensitive.

The lack of value that the MFT appeared to put on complementary therapies was deemed to be prejudiced and was reflected in the decision not to make more than a one-off 'taster grant' in this area.

One woman who had been widowed for many years felt forgotten by the MFT while another felt that her status as a long-term survivor was ignored by the Trust.

The question of how the MFT saw the future of this group arose. Forward planning and revisiting emerging new needs were suggested as important priorities for the Trust in years to come.

7. BENEFITS ADVISER'S REPORT

History

1) Correct and comprehensive advice about welfare benefits is essential for people with health problems for several reasons. Having serious long-term health problems gives rise to additional living expenses. The employment prospects of many Trust members are limited and they need to be able to access other sources of income. Members' circumstances change. They may start or stop work according to their changing state of health. Younger members have reached an age for moving out from home and setting up home on their own or with a partner. People enter and leave relationships. All of these changes affect the level of benefit. But in addition the level of monthly payments made by the Trust depends on what benefits are in payment to members: higher levels of payment are made to members receiving benefits payable because of incapacity or which are means-tested and there is a special supplement for members receiving the high rate of the DLA care component. Benefit maximisation therefore increases income in two important ways.

2) Members of the Trust have from the outset had access to advice about their welfare benefit entitlement and assistance with making claims. Originally this function was carried out by the Trust's Social Worker. In response to members' expressed need in the 1995 membership survey it was decided that a full-time benefits adviser should be appointed and the Adviser took up the post on 8th November 1995.

Remit

3) The job of the Benefits Adviser is to assist members and their families with claims at all levels. This may involve advice; help with completing forms; letters of support; pursuing a review of an unsuccessful claim; taking the case to an independent tribunal/Social Security Commissioner (or Housing Benefit Review Board). It also involves liasing with the Benefits Agency or local authority for example to resolve incorrect awards, hasten decisions along or negotiate repayments of council tax. The Benefits Adviser has also taken up individual issues at members' requests, for example misleading information about declaring MFT payments on a Housing Benefit form and incorrect information required in connection with a DS 1500 application.

4) Social Policy work

In addition to the day to day work with members the Benefits Adviser carries out a certain amount of social policy work.
i) She receives copies of consultation papers put out by the Social Security Advisory Committee (the body which advises government on proposed changes to legislation) and has always contributed where our members' interests are involved, for example when it was proposed to take away mobility awards from people in hospital and the proposed changes to the appeals system.
ii) She attends the meetings organised by the Disability Benefits Consortium to lobby on proposed changes to disability benefits.

iii) The Benefits Adviser also contributes a regular column to the Newsletter.
iv) She has also run a number of "take-up" campaigns focussing on a particular area where there may be underclaiming. This had included young people reaching the age of sixteen and able to claim benefit in their own right for the first time; people living alone and entitled to the severe disability premium as part of their Income Support and checking that members are claiming the appropriate levels of Disability Living
Allowance. At the request of the Trustees the Benefits Adviser has also carried out a review of every member's benefit, which was completed early in 1998.

5) Main areas of work

Disability Living Allowance

This is probably the most significant benefit for anyone with a health problem. It is also the one which takes up the most time largely because of the complexity of the claim form which involves forty pages asking detailed questions about the level of help required with mobility and/or personal care. It is paid to help with the unavoidable extra costs of disability and because it is "ring-fenced" and is not means-tested does not reduce entitlement to other benefits. It can in fact lead to higher rates of benefit. It can be claimed whether or not someone is working. The majority of our members receive the high rate of the mobility component and either the middle or high rate of the care component.

Giving up/returning to work

Because of the varying nature of both haemophilia and HIV (particularly because of the new treatments) work patterns change and advice about entitlement to benefits at all the different stages is essential so that members can make informed decisions.

House purchase

Many younger members are now reaching the stage of wanting a place of their own with or without a partner. The Benefits Adviser has worked closely in conjunction with the Trust's Consultant Mortgage Adviser to ensure that they receive the appropriate help with their mortgage costs.

Social Fund

This helps people on means-tested benefits with the cost of large expenses, which are difficult to budget for out of a fixed income. It is helpful both for those setting up home for the first time but also in replacing worn out items.

Young people and students

When young people reach the age of sixteen they are able to claim benefits (other than DLA) in their own right and advice is needed as to whether this is financially worthwhile for the family. Students also often need help claiming benefit, as this is an area of confusion for many Benefit Agency offices.

6) Results to date

In money terms the increase in members' income since the Benefits Adviser was appointed 3 years ago is in the region of £412,450. This is made up of one-off payments such as Social Fund grants and income increases of just over £300,000.

7) Future

Throughout this paper I have emphasised the importance of benefits income to Trust members and the continuing need for advice and assistance. It is rarely possible to reach a situation where an individual's situation is totally settled and impervious to change and when circumstances do change help should be available at each stage. This is particularly important at the moment when radical changes to the welfare benefit system are in prospect, particularly to benefits for people with disabilities. Previous changes have always been in the direction making entitlement less generous and, although having correct information may not necessarily alter an individual's decision, it will mean that any choice made is an informed one. These changes may come at a time when, due to the new treatments, many members are becoming more positive about their future and looking to the prospect of working. There is a continuing need to keep abreast of changes so as to be able to advise correctly at each stage.