THE MACFARLANE TRUST
Alliance House 12 Caxton Street London SW1H 0QS
Tel: 0171-233 0057 Fax: 0171-233 0839

Our Ref:0730/AHCC

30th July 1998

M/s Christine Corrigan
NHS Executive
Health Services Directorate 1
Room 416
135 - 155 Waterloo Road
London SE1 8UG

Dear Christine

**MACFARLANE TRUST STRATEGIC REVIEW. INTERIM REPORT.**

I enclose copies of the Interim Report and letter from Alan Tanner delivered to Baroness Hayman at Richmond House today.

You will see from the Chairman's letter that he has suggested an early meeting with Baroness Hayman, if this is felt to be appropriate. However, it would be possible to wait for a meeting until the Autumn when the Final Report will be presented, if this would be preferable.

Meanwhile, it would be very helpful to have an indication of whether or not you think it likely that extra funds to complete the Review could be identified within the Department.
Dr Mark Winter had heard that Dr Mike McGovern might have some money available for research, but what we are doing may not qualify because it is more orientated to 'psychosocial research' than purely medical research. It will be essential to identify some extra funding from some source very soon if we are to complete this important study.

We were very sorry indeed to learn that you are soon to leave your current role, and hope that wherever you are going you will be appreciated! You will be sorely missed. I hope we may meet again before you move on, and wish you the best of luck with your next assignment.

With best wishes
Yours sincerely

GRO-C

Ann Hithersay
Administrator

cc: Alan Tanner OBE, Chairman

Registered Charity Number 298863

# 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 reponsibilities 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

Appendix 1a

# History of HIV therapies

| | |
|---|---|
| Mid 1980s | Zidovudine (AZT)<br>A nucleoside reverse transcriptase inhibitor (NRTI) |
| Late 1980s/ Early 1990s | Other NRTIs Didanosine (ddI), Zalcitabine (ddC),Stavudine (d4t)<br>Some marginal benefit in combination with zidovudine, or if zidovudine failed |
| Early 1990s | Lamivudine (3TC)<br>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 Vlll 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]

---

[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.