THE MACFARLANE TRUST

GRANT ALLOCATIONS

Payments from the Trust will be of two kinds:

1 Single payments

2 Regular payments – towards the cost of heating, diet or laundry, etc.

Single Payments

Single payments will cover a wide range of items within the terms of the Trust Deed. Payments must be related to need, but this does not mean only financial need. Help is often needed to relieve the stress of living with HIV infection and payments will be made where there is such a need. Holidays or family outings are two examples, but there are many other things which could be considered. There will be payments to assist with costs related to managing illness and maintaining good health; examples of these would be clothing, bedding, washing machines or driers.

Single payments will be made on the basis of need in a broad sense, not based on income. Many families which seem "better off" find that their standard of living has fallen, giving rise to difficulty. It is hoped that these families will make application to the Trust, when there is a need.

Single payments will be available to:

a People with haemophilia who are HIV positive, and to the families and dependants of these people.

b Wives and children of those people who had haemophilia, were HIV positive and who have died. Children will be eligible for single payments until they complete full-time education, or reach 18 years, whichever is later.

c Parents caring for a son with haemophilia who is HIV positive, provided the son lives with them. If the son has died, payments may be made where the need is related to HIV.

All grants are authorised by the Allocations Sub-Committee of the Trustees, which normally meets once each month. However, this Committee has delegated authority to the Administrator and Social Worker to make immediate payments of up to £500 which fall within certain guidelines.

Requests for larger sums or which fall outside the routine guidelines will be dealt with at the next monthly meeting, except in extreme urgency when special arrangements can be made for early payment.

Payments will not be made for items normally provided by the local authority or Department of Social Security. In the case of funeral costs, single payments will be considered for reasonable costs not covered by Social Fund Payments, and also towards the cost of providing a simple headstone.

Payments from the Trust will not affect entitlement to Social Security benefits and need not be declared to the Department of Social Security. Claimants applying to the Social Fund shall not be asked about payments from the Trust, nor should they be told to apply to the Trust instead of the Social Fund.

Frequency of payment – each application will be considered on its merits, therefore there will be no restriction as to how often a person may apply.

Applicants may ask that a decision be reviewed. Review will be by the full board of Trustees.

Regular payment

This system of payments is intended to top-up the income of people on low income, whether from low wages or from benefits. It is aimed at assisting those people who are finding it difficult to meet the cost of heating, diet etc, particularly those on benefit who were unable to obtain an additional allowance for these costs.

The regular payment is meant to relieve the constant worry over basic day to day living costs that some families are experiencing. It will be assessed on the basis of weekly income and expenditure, but will probably be paid on a monthly basis.

Regular payments will be available to people with haemophilia who are HIV positive and meet the conditions explained below. They may also be available to dependants of people with haemophilia who have died as a result of HIV/AIDS.

People who qualify for the regular payment will still be eligible for single payments.

The amount of the payment is based on trying to ensure that the net **(disposable)** income of a household will not fall below a level which allows adequate heating and diet and some balance to maintain the quality of life.

The actual net income is the sum of money which the person, or family has to live on after deduction of housing costs, and fares to and from work. It is the "Take home" pay after deduction of Income Tax and National Insurance which is used in this calculation. Family Credit and Child Benefit will be taken into account together with income from any other source. Attendance Allowance and Mobility Allowance are **not** included.

In the case of a single person living with his family, the calculation could be based either on the finances of the family as a whole, or on the financial circumstances of the person with haemophilia, taking into account his contribution towards the costs and rent or mortgage and rates. Whichever method seems most appropriate for each applicant will be used.

Initially the maximum regular payment will be £20.00 per week, the minimum will be £5.00 per week. **The qualifying figures and maximum sum of the regular payment will be kept under review to monitor the effectiveness of the system and to take account of inflation.**

Decisions will be made by the Administrator and Social Worker on the basis of the guidelines set down. These decisions will be reviewed by the Trustees if requested by an applicant.

At the outset, a lump sum will be paid to those receiving a regular payment. It will be equivalent to backdating the regular payment to 16th November 1987, provided the applicant would have been eligible from the time. If the person was not eligible for all of that time, the lump sum will be adjusted and related to the point at which the applicant would have become eligible.

In the case of a person who has died, but who would have met the criteria for this payment, a lump sum will be paid to his widow/dependants, whether or not they qualify for weekly payments in their own right.

Regular payments from the Trust will not affect Social Security benefits and need not be declared to the Department of Social Security.

The Macfarlane Trust, PO Box 627, London SW1 0QG. **October 1988**

CONFIDENTIAL

THE MACFARLANE TRUST

GRANT ALLOCATIONS POLICY

FOR PROFESSIONAL USE

Payments from the Trust will be of two kinds:

1. Single payments
2. Regular payments – towards the cost of heating, diet or laundry, etc.

Single Payments

Single payments will cover a wide range of items within the terms of the Trust Deed. Payments must be related to need, but this does not mean only financial need. Help is often needed to relieve the stress of living with HIV infection and payments will be made where there is such a need. Holidays or family outings are two examples, but there are many other things which could be considered. There will be payments to assist with costs related to managing illness and maintaining good health; examples of these would be clothing, bedding, washing machines or driers.

Single payments will be made on the basis of need in a broad sense, not based on income. Many families which seem "better off" find that their standard of living has fallen, giving rise to difficulty. It is hoped that these families will make application to the Trust, when there is a need.

Single payments will be available to:

a People with haemophilia who are HIV positive, and to the families and dependants of these people.

b Wives and children of those people who had haemophilia, were HIV positive and who have died. Children will be eligible for single payments until they complete full-time education, or reach 18 years, whichever is later.

c Parents caring for a son with haemophilia who is HIV positive, provided the son lives with them. If the son has died, payments may be made where the need is related to HIV.

All grants are authorised by the Allocations Sub-Committee of the Trustees, which normally meets once each month. However, this Committee has delegated authority to the Administrator and Social Worker to make immediate payments of up to £500 which fall within certain guidelines.

Requests for larger sums or which fall outside the routine guidelines will be dealt with at the next monthly meeting, except in extreme urgency when special arrangements can be made for early payment.

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Frequency of payment – each application will be considered on its merits, therefore there will be no restriction as to how often a person may apply.

Applicants may ask that a decision be reviewed. Review will be by the full board of Trustees.

Regular payment

This system of payments is intended to top-up the income of people on low income, whether from low wages or from benefits. It is aimed at assisting those people who are finding it difficult to meet the cost of heating, diet etc, particularly those on benefit who were unable to obtain an additional allowance for these costs.

The regular payment is meant to relieve the constant worry over basic day to day living costs that some families are experiencing. It will be assessed on the basis of weekly income and expenditure, but will probably be paid on a monthly basis.

Regular payments will be available to people with haemophilia who are HIV positive and meet the conditions explained below. They may also be available to dependants of people with haemophilia who have died as a result of HIV/AIDS.

People who qualify for the regular payment will still be eligible for single payments.

The amount of the payment is based on trying to ensure that the net **(disposable)** income of a household will not fall below a level which allows adequate heating and diet and some balance to maintain the quality of life.

This required net income will be calculated initially on the following basis.

Householders – couple £65.00

Householder – single £45.00

Additional members of the household/family

Single adult £35.00

Children under 18 years £20.00

A figure of £35.00 will be added for each member of the family who is HIV positive.

The actual net income is the sum of money which the person, or family has to live on after deduction of housing costs, and fares to and from work. It is the "Take home" pay after deduction of Income Tax and National Insurance which is used in this calculation. Family Credit and Child Benefit will be taken into account together with income from any other source. Attendance Allowance and Mobility Allowance are **not** included.

If the **actual** net weekly income is less than the **required** figure, the difference (up to a maximum of £20) will be paid by the Trust. The following example should illustrate what is meant:

Mr and Mrs Smith have three children aged 9 years, 13 years and 15 years. Two children are HIV positive.

Qualifying figure for this family.				
Parents – couple (householder)		£65.00		
Children – £20 x 3		60.00		
2 family members HIV positive		70.00		
				£195.00
Actual Income (weekly)				
Take home pay		£220.00		
Child Benefit		21.75		
	Total		£241.75	
Deduct (weekly rates)				
Rent/Mortgage		£35.00		
Rates		15.00		
Fares to work		10.00		
	Deduct		£60.00	
	Actual Net Income			£181.75
Deduct Actual Net Income		£181.75		
from qualifying figure		£195.00		
				£13.25

In the example shown, a regular weekly payment would be made of £14.00 (ie £13.25 rounded up).

In the case of a single person living with his family, the calculation could be based either on the finances of the family as a whole, or on the financial circumstances of the person with haemophilia, taking into account his contribution towards the costs and rent or mortgage and rates. Whichever method seems most appropriate for each applicant will be used.

Initially the maximum regular payment will be £20.00 per week, the minimum will be £5.00 per week. Should a family qualify by as little as £1.00, the minimum £5.00 will apply.

General Notes

The qualifying figures and maximum sum of the regular payment will be kept under review to monitor the effectiveness of the system and to take account of inflation.

Decisions will be made by the Administrator and Social Worker on the basis of the guidelines set down. These decisions will be reviewed by the Trustees if requested by an applicant.

At the outset, a lump sum will be paid to those receiving a regular payment. It will be equivalent to backdating the regular payment to 16th November 1987, provided the applicant would have been eligible from the time. If the person was not eligible for all of that time, the lump sum will be adjusted and related to the point at which the applicant would have become eligible.

In the case of a person who has died, but who would have met the criteria for this payment, a lump sum will be paid to his widow/dependants, whether or not they qualify for weekly payments in their own right.

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The Macfarlane Trust, PO Box 627, London SW1 0QG. **October 1988**

Spouse:

Surname

First names

Date of birth
day month year

Children:

Surname

First names

Sex
m/f

Date of birth
day month year

Surname

First names

Sex
m/f

Date of birth
day month year

Surname

First names

Sex
m/f

Date of birth
day month year

Surname

First names

Sex
m/f

Date of birth
day month year

Surname

First names

Sex
m/f

Date of birth
day month year

Any other dependents:

1. Surname

First names

Relationship

Date of birth day month year

1. Surname

First names

Relationship

Date of birth day month year

Please supply the address of any person who has a different address to that of the person named at the beginning of this questionnaire.

SECTION B

MORTGAGES AND LIFE ASSURANCE.

One of the objectives of the Trust is to help if possible, with life assurance and mortgages.

There are several sets of circumstances here:

Firstly, you may have tried and been unable to obtain any life assurance or mortgage finance at all; we want to see if there is a way to help you.

Secondly, you may have taken out assurance policies or a mortgage, but, because of the effect of being HIV positive on your income, are now having difficulty with payments; again we hope we can help.

Thirdly, you may not have a problem either because you are able to meet payments, or because of age of other reasons you do not have life assurance or mortgage finance; here we need to know so that we can be ready to help if your circumstances change.

Please, therefore, supply some information which will help us assess the possible calls on the Trust Fund to meet requirements relating to life assurance and mortgages:

HOUSING

Do you:

Own you house, flat, etc?	☐ Yes	☐ No
Rent your house, flat, etc?	☐ Yes	☐ No
If rented is it from a Council or similar public sector owner?	☐ Yes	☐ No
or other 'public sector' owner	☐ Yes	☐ No
or private landlord	☐ Yes	☐ No
or relatives	☐ Yes	☐ No
Live with your parents or somebody else who is responsible for paying for the property?	☐ Yes	☐ No

MORTGAGES

Do you have a mortgage?	☐ Yes	☐ No
When was this obtained?	☐ Year	
Are your payments up to date?	☐ Yes	☐ No
Is it protected by insurance, such as an endowment or a mortgage protection policy?	☐ Yes	☐ No
Have you been unable to obtain a mortgage because of being HIV positive?	☐ Yes	☐ No
When did you unsuccessfully apply?	☐ Year	

LIFE ASSURANCE

Do you have any life assurance?	☐ Yes	☐ No
When was this arranged?	☐ Year	
Are your premium payments up to date?	☐ Yes	☐ No
Have you been refused life assurance of being HIV positive?	☐ Yes	☐ No

EMPLOYMENT

Are you employed now?	☐ Yes	☐ No

What is your occupation/previous occupation? _

Please return completed questionnaire to:
The Macfarlane Trust, PO Box 627, London SW1 0QG.

October 1988

THE MACFARLANE TRUST

Thank you for completing the registration form.

For reasons of confidentiality we intend to register you under a code number. Until the Trust's office is fully equipped and staffed we cannot yet do this, so for now we will continue to need you to fill in your name and address in all correspondence.

If it has not already arrived, you will shortly be receiving a Newsletter explaining our progress so far and our proposed basis of making payments from the Trust Fund. In the meantime we need to continue collecting some information to help us decide on these matters.

Whether or not you need help now or consider you may do so in the future, please complete and return this questionnaire for yourself or for your dependent who has registered with the Trust.

Name

Address

We now need some more general information about you to help us with our fundamental job of allocating the Trust Fund.

Please tell us your date of birth

day month year

SECTION A

DEPENDANT RELATIVES AND PARENTS OR PEOPLE TAKING CARE OF YOU.

Please provide some details of people who are dependent upon you or who look after you (these will generally be your parents, your spouse and your children). None of these people will be contacted by the Trustees without your consent or that of your legal representative.

Mother:

Surname

First names

Date of birth

day month year

Father:

Surname

First names

Date of birth

day month year

THE MACFARLANE TRUST

MAY 1988

From the Chairman of the Macfarlane Trust.

You will know from the HAEMOFACT leaflets produced by the Haemophilia Society that a Board of Trustees has been established to administer the £10m Fund made available by the Government to meet the needs of people with haemophilia who are HIV positive.

Until now the Case Committee of the Society has handled emergency applications on behalf of the Trustees and, since November, they have paid out grants totalling almost £50,000. The Trust now has its own Allocation Committee and you are welcome to write to the Trust, in total confidence, if you are being faced with any urgent or pressing financial problems.

We need to know how many people will qualify to be considered for grants and there is no way in which we can collect this information unless people with haemophilia who are HIV positive give us their permission to include their names on the Register which we are now compiling. As you may know, at the moment this information is only held by individual Centre Directors on a basis of strict confidentiality.

It is most important that we have accurate information about the numbers involved and we would be grateful if you could complete and return the enclosed card as soon as possible. We will, of course, require more detailed information and later we will send you another form which will help the Trustees to build up an accurate picture of the demands likely to be placed on the Trust.

We would like to reassure you that by sending us your name and address to be included in the register, the information will remain completely confidential although as you will see from the card, we will in due course, have your Centre Director confirm the diagnosis.

It has already been pointed out in HAEMOFACT 18 it is not possible to divide the £10m equally into 1,200 parts: apart from the fact that peoples' circumstances vary, for instance, number of dependents, the Charity Act 1960 requires the Trustees to take into account individual circumstances. Our interest as Trustees is to make a fair policy for the effective spending of this money. When we have our own register of members the Trust will be able to use its own mailing system, held in confidence apart from hospitals and other agencies, including, we must say, the Haemophilia Society itself.

You will also be interested to know that the Government has provided additional funding to enable the Trust to have its own staff and offices, again apart from the Haemophilia Society. This ensures that every penny of the £10m will be available to those for whose benefit it was given.

Please do register with us now: it is important. It is equally important that you encourage those of your family and friends who are eligible to register as well. More copies of this letter and the Registration Card are available from me, from the Society and through your local Haemophilia Centre.

I look forward to hearing from you

With all good wishes,

Yours sincerely,

GRO-C

The Revd Alan J Tanner
Chairman

THE MACFARLANE TRUST **REGISTRATION FORM**

SURNAME of person registering: ____________________

Mr/Mrs/Ms : First names ____________________

ADDRESS ____________________

____

Postcode: ____________________ **Tel No:** ____________________

Patients should give their own details. Dependents should give the details of the relative who had haemophilia and HIV:

HAEMOPHILIA CENTRE ATTENDED: ____________________

CENTRE DIRECTOR: ____________________

You should sign the following declaration on your own behalf (or as a dependent) and you should note that by doing so you are declaring that you/your partner or parent had haemophilia and came into contact with HIV through the use of blood products. You will by signing also give permission for HIV status to be checked with your Doctor.

Signed ____________________

TO: Dr ____________________

The patient/surviving dependents mentioned on this Registration Card has given permission to contact you in order to verify HIV antibody status. We would be grateful if you could complete the verification below by signing the statement.

I, the undersigned, *confirm* that the patient mentioned on this card has haemophilia and has come into contact with HIV through the use of blood products.

Signed: ____________________

PLEASE RETURN THIS CARD TO: **The Macfarlane Trust,**
PO Box 467,
LONDON, SE1 7HU.
marking the envelope **STRICTLY CONFIDENTIAL.**