

THE MACFARLANE TRUST

Minutes of a meeting of the Trustees held at Alliance House on Thursday 28th September 1989 at 11.00 am.

Present: The Rev. Tanner, Mr Grinsted, Mrs Guy, Dr Jones, Mr Knight, Mrs Leitch, Mr Palmer and Mr Stevens.

In attendance: Wg Cdr Williams, Mr Williams and Ms Turner.

AGENDA

General Session

- 89.65 Apologies for absence
- 89.66 Minutes of meeting held on 27th July 1989
- 89.67 Matters arising
- 89.68 Report on Meeting with Dept of Health
- 89.69 Annual Report
- 89.70 Administration
- 89.71 Information & Public Relations

Finance

- 89.72 Grants Expenditure
- 89.73 Investment Report
- 89.74 Half year budget & 1990/91 Section 64 Grant

Allocation Session

- 89.75 Case review
- 89.76 Allocation Policy - Assessments
- 89.77 Allocation Policy - Widows
- 89.78 Mortgage Policy

Closing

- 89.79 Any other business
- 89.80 Future meetings

GENERAL SESSION

The Chairman welcomed all to the meeting and particularly welcomed Ms Susan Turner who was meeting Trustees for the first time since her appointment as Assistant Social Worker.

89.65 APOLOGIES FOR ABSENCE.

The Administrator reported that the appointment of Mr John Cashman had recently been confirmed but that Mr. Cashman had been notified too late to be able to attend this meeting, for which he sent his apologies. Apologies were also received from Mr Taylor.

89.66 MINUTES OF PREVIOUS MEETING held 27th July 1989.

Some errata to the draft minutes were noted, and minor additions or changes made to 89.61c, 89.62 and 89.63. Subject to these corrections it was proposed by Mr Stevens and seconded by Mr Grinsted that the minutes be accepted as a true record. This was agreed unanimously.

89.67 MATTERS ARISING

The Administrator drew attention to the paper tabled for this agenda item which summarised the agreements reached at the previous meeting on the subject of holiday grants (89.58d.) but for which no formal approval had been given. After a further brief discussion it was proposed by Mr Stevens and seconded by Mr Palmer that the resolution be adopted as a statement of current policy on holiday grants. This was carried unanimously. The statement is at Annex A to these Minutes.

It was accepted that all other matters would be covered by the day's Agenda.

89.68 REPORT ON MEETING WITH THE DEPARTMENT OF HEALTH

The Chairman reported that with the Deputy Chairman and the Administrator he had visited Mr Strachan Heppell, Deputy Secretary (Policy) at the Ministry on 7th September. Mr J Canavan, Principal of Health Services division had also been in attendance.

The Chairman gave a resume of the meeting and said that a written report would be circulated with the minutes. He reported that it had been a friendly and helpful meeting which showed that Ministers were satisfied with the work of the Trust and that the Department had no points of concern to raise.

On the subject of extra funding it had been made clear that the way was open for a future application but that the time was not right at present. The advice was that at least half the fund would need to be spent and a firm forecast be made of the fund running out within 2 to 3 years.

The possibility of total rather than partial funding of management costs via the Section 64 Grant, or other means had been discussed.

The possibility of further Government help on the matter of insurance, either in cash terms or by other means, had been discussed but appeared remote.

The Chairman said that apart from this latter point he regarded the meeting as very successful in terms of the general tenor of relations with the Department and in maintaining personal contact at the highest level. This assessment was endorsed by the Deputy Chairman.

The meeting expressed satisfaction with the report.

89.69

ANNUAL REPORT

It was reported that the final text of the Annual Report had been passed to the designer and that a text proof was now available. Mr Knight said that once the text had been proof-read it should be possible to obtain a first design-proof in under a week and if this was cleared rapidly the Report could be ready in as little as two weeks.

There was discussion on the subject of distribution of the Report, in particular different views were expressed on whether the Report should be automatically sent to all people registered or simply made available on request. Since there was no consensus the Chairman put this matter to the vote. It was decided by 5 votes to 3 that the Report would be available but not sent automatically.

The Haemophilia Society request for 500 copies, which would provide for distribution to members of the Houses of Parliament who had supported the campaign was approved. It was agreed that the report should be available to the media on request but otherwise only sent to those who had shown recent interest. It was agreed that 2 to 3 copies would be enough for Haemophilia Reference Centres and that copies should also be sent to organisations such as the Lighthouse and Terence Higgins Trust.

It was agreed that 5 copies would be sent to each Trustee unless they informed the office of a higher requirement.

On the basis of this discussion and guidance it was left to Mr Knight and the Administrator to agree the final print run.

89.70

ADMINISTRATION

A. Registration. The Administrator reported that the recent circulation of letters via Reference Centres had received very good support and cooperation from most directors and was producing further registrations and also some statistical information on a number of people who were choosing not to register. A statistical summary was circulated and is attached as Annex B.

b. Staff. Ms Caroline Evans had resigned as Assistant Social Worker and had left on 6th September. During the period of notice the post had been readvertised and Ms Susan Turner appointed. Fortunately Ms Turner had been able to start on 18th September so the post had not been vacant for very long.

c. Data Network. The Administrator reported that one outcome of the steady increase in information being recorded was that one of the network stations was increasingly used for loading and updating purposes and this was conflicting with the use in wordprocessing. Funding of a proposal to add a fourth station had been approved by the Deputy Chairman and the equipment was now on order.

d. Donations. Two donations were reported:

£700 from Mrs GRO-A, who had raised the money by sponsored running in the London Marathon.

£25 from Patrick MacNamee and Partners (lately neighbours in Alliance House) in recognition of temporary assistance in shredding waste.

The Trustees expressed their gratitude for this help.

89.71

INFORMATION AND PUBLIC RELATIONS

a. General the Administrator drew attention to the latest list of visits (Annex C) and also to the following events and meetings:

1. World at One broadcast (BBC Radio) 11 August 1989. An interview with the Administrator had been included in this item, which had reported the issue of writs for compensation and had been mainly concerned with the subject of compensation. There had been no other media interest prompted by this item. The Chairman said that both the Haemophilia Society and the Trust had been well reported in this broadcast.

2. Consultation with Executive Officer of the Australian Haemophilia Foundation on 7th September 1989 (Administrator & Social Worker) as part of her visit to the Haemophilia Society. (Australia may create a similar organisation to the Macfarlane Trust).

3. Informal briefing on the work of the Trust to the Australian Minister of State for Health on 22nd September 1989. (Given by the Administrator as the Chairman was out of town.)

b. Haemophilia Society Campaign.

The meeting took note that the Society campaign aimed at seeking a compensation settlement out of court was due to be launched in 2 or 3 weeks time. It was agreed that this reinforced the decision that the Annual Report should be issued on a low profile basis so as to avoid any clash with the campaign.

Dr Jones asked whether statistical data from the Trust could be made available for use in the campaign. There was some discussion on the principles involved and it was decided that although such information would be totally impersonal it still would still break the Trustees' previous decision that information given to the Trust would be used only for the purpose of Trust business. Since this type of statistic had not to date been prepared and released by the Trust it had not become free to use for other purposes, and this applied irrespective of Trustees' support for the use intended.

Dr Jones also asked whether the Trust could or would handle a further or second sum of money under different rules from the present Trust Deed if this became an option during the campaign. After discussion it was agreed that this was an 'academic' point and that the Trustees should not give credence to it by offering any view as to the principle or the practice.

FINANCE

89.72 GRANTS EXPENDITURE

The summary of grants expenditure to 31st August is Annex D. to these Minutes. (The summary of payments made in September prior to the meeting will be consolidated into the Summary for 30th September).

89.73 INVESTMENT REPORT

The portfolio summary for 31st August is at Annex E to the Minutes.

Mr Grinsted pointed out that since the previous meeting two short term stocks (11 3/4% Treasury 1991 and 10 1/2% Treasury 1992) had been sold. These had not recovered to their purchase price but MANEX advice had been that in view of the continuing high bank rate they had probably reached as high as they would go. The advice to sell had therefore been accepted and they had been sold on August 17th. The money realised was now in Bank Certificates of Deposit and giving a significantly higher yield (at over 13.7%).

There were no comments or questions and the meeting expressed support for this action.

89.74 ANNUAL BUDGETS AND SECTION 64 GRANTS

The Administrator introduced the budget papers which had been circulated. He informed the meeting that the Section 64 Grant for 1989-90 had been approved at £100,000, the same level as the year before and requested approval of the revised 1989-90 budget and of the forecast budget for 1990-91 as a basis for the further Section 64 application which was now due.

There were no questions. Mr Stevens expressed satisfaction that the current year's budget was being contained well within the earlier forecast. Notwithstanding this comment he suggested that a greater allowance should be made for 1990-91 particularly since the Rates may be much higher and there had not yet been time to refine the costs of the Visiting Social Worker Programme. He proposed that these items and appropriate contingency items should be raised to bring the total budget to £150,000, and subject to this modification he proposed that the budgets be accepted. The proposal was seconded by Mr Grinsted and carried unanimously.

Annex F includes the changes as proposed.

ALLOCATION SESSION

89.75 CASE REVIEW

The Social Worker introduced the cases for review. 29 cases were put forward under 11 headings, the total sum applied for was in excess of £48,000. All applications but two were supported by the office but a reduced sum totalling under £31,000 was recommended.

The Trustees approved 24 applications but with 6 of these subject to further enquiry by the staff. A total sum of £28,602 was approved. Two applications were rejected and three deferred for further enquiry and resubmission.

In reviewing four applications for assistance with central heating the Trustees requested that the office should produce a paper giving more information on typical costs for various types of home, and alternative methods of heating, so that a consistent response to further requests could be guaranteed.

89.76 ALLOCATION POLICY - ASSESSMENTS

The Chairman invited discussion on the paper, prepared by the Administrator and Social Worker, which had been circulated and is attached as Annex G.

There was general support in principle for the recommendations of the paper, subject to some comments and queries. Dr Jones said that proposal was welcomed by the Social workers at his Centre but said it was important that good liaison be maintained with the Social workers who were already helping individuals, so as to maintain their cooperation. He also suggested that BASW should be kept informed of Trust plans in this respect.

In reply to a question from the Chairman, the Administrator said that subject to approval by the Trustees of the main principles of the paper, with the implicit commitment to the expenditure this entailed, the next stage would be for the office to develop (based on the notes to the paper and the comments received at the meeting), the procedures in detail and submit these for further approval. Further discussion would be held with the Family Fund and it would be the aim to circulate in time for consideration at the November meeting:

- a. Administrative Procedures for operation.

- b. Interview and reporting procedures
- c. A draft contract for VSW's.
- d. More detailed costings.

If these proved acceptable without major modification it should be possible to begin to operate early in 1990.

On this basis Mr Grinsted proposed that the recommendations of the paper be accepted and the staff authorised to proceed with the necessary developments. This was seconded by Mrs Guy and carried unanimously.

89.77 ALLOCATION POLICY - WIDOWS

The Chairman invited comments on the paper which had been circulated and is attached as Annex H.

The paper was welcomed as a valuable summary of what would become a major area of Trust activity, and one which posed a number of difficult problems. In this context the meeting took note of the three cases of representative individuals cases summarised anonymously.

The need for a statement of policy was recognised, and in particular that it was necessary to be able to give some assurance to sufferers that their widows and dependants would be taken care of. At the same time doubts were expressed on both the principles and the financial capability of long term care of widows, especially those without dependant children. The principle of a finite period of support after bereavement received some support though there were differing views of what such a period should be.

It was accepted that the development of criteria on the lines suggested in the Annex would have to be based on intuitive as well as logical considerations.

The Chairman said that the problem was too complex to expect to find a solution on this first discussion. He asked Trustees to give further thought to the problem and to let the Administrator have any comments or suggestions which would help to develop the set of guidelines in conformity with the intent of the Trust Deed.

89.78 MORTGAGE POLICY

There was no business on this agenda item.

CLOSING SESSION

89.79 ANY OTHER BUSINESS - None was raised.

89.80 DATES OF FUTURE MEETINGS.

Future meetings were confirmed as follows:

Monday November 20th
Thursday January 18th
Thursday March 22nd

all at Alliance House starting at 11.00am

An Allocations Committee meeting was agreed for
Thursday 26th October at 11.00am.

The Administrator asked that dates further into 1990
be considered as soon as possible so that
accommodation could be booked in good time. The
Chairman agreed to confer on this point.

The Chairman thanked all present for their contribution to the
meeting, which was closed at 5.15pm.

GRO-C

20th November 1989

The Rev. A J Tanner
Chairman

Annexes A to H

Annex A to
Minutes of
Trustees' Meeting
28th September 1989

The Macfarlane Trust

Allocation Policy - Holiday Grants

This short policy statement was prepared on the basis of discussion at the Trustees' meeting on 27th July, when the problems arising from the growing expense of this type of grant were reviewed.

On 28th September 1989 it was formally resolved that:

- a. The full family holiday grant (including parents siblings and dependants) would be paid once only.
- b. The maximum amount of the grant would be £350 per adult and £175 per child.
- c. Subject to the limitation per person no further limit would be fixed on the amount payable to a family.
- d. Applicants who have received a smaller holiday grant may be given a further grant up to the total allowed in b and c above.
- e. Second major holiday grants would not be made in the immediate future but smaller payments for outings or excursions (including families) would be considered.
- f. Short breaks (in UK) for convalescence or recuperation would be considered where strong medical grounds were offered, and such payments would not be classed as holiday grants. (Payment would be limited to the registered person and one carer/companion)

Proposed by Mr Stevens

Seconded by Mr Palmer

Vote carried unanimously

The Macfarlane Trust

Registrations Summary at 25th September 1989

a.	No of persons registered	1025	
b.	Infected wives/widows (additional to a)	23	
c.	No of persons deceased	116	
d.	Infected wives deceased (add to c)	1	
e.	Widows	63	
f.	Infected widows (incl in e)	3	

g.	No who have received financial help	755	% 73.65
h.	No who have received single payments	608	59.3
i.	No who have received regular payments	589	57.5
j.	No who have received both single and regular payments	442	43.1
k.	5 or more single payments	74	
l.	7 or more single payments	16	
m.	over £5,000 inc RP	36	
n.	over £5,000 excl RP	4	
o.	largest single payment	£9,500	
p.	largest total payment	£12,540	

The Macfarlane Trust

Deaths of Registered Persons 1989

January	nil
February	nil
March	2
April	3
May	1
June	6
July	3
August	3
September	3

Total	21

REPORTS/DEATHS

Annex C to
Minutes of
Trustees' Meeting
28th September 1989

The MacFarlane Trust

Visits and Liaison Programme 1989

<u>Completed</u>			To	From
April	19	Trustee, Social Worker, Administrator	London Hospital	
	20	Trustee, Social Worker	Liverpool	
	27	Social Worker	Lewisham Hospital	
May	4	Social Worker, Administrator	St Thomas's	
	14	Chairman/Social Worker	Birmingham	
June	5	Social Worker	Lord Mayor Treloar	
July	4	Social Worker	Kings	
August	24	Social Worker, Administrator	Family Fund	
	29	Social Worker, Administrator	Independent Living Foundation	
September	1	Social Worker	RCN AIDS/HIV Course	
	27	Social Worker, Administrator	Alton	
<u>Planned</u>				
October	24	Social Worker, Administrator, Trustee	Edinburgh	
	25	Social Worker, Administrator, Trustee	Great Ormond Street	
November		Social Worker, Trustee	Leeds	
December		Social Worker, Trustee	Sheffield	

MACFARLANE TRUST

Summary of Grants Made

at 31st August 1989

1. To 31st March 1989

Grants	935	496,909	
Regular Payments	406	<u>564,490</u>	
Overall Total			£1,061,399

2. Financial Year 1989-90

A Single Payments

	No	Total	Amount	Running Total
April-May	289			154,567
June	91	380	48,725	203,292
July	168	548	100,363	303,655
August	117	665	59,234	362,889

B Regular Payments.

	No	Initial	Ongoing	Overall	Running Total
April-May	107	168,168	63,862		232,030
June	19	35,374	33,826	69,200	301,230
July	35	55,227	38,414	93,641	394,871
August	9	14,692	51,610	66,302	461,173
	<u>170</u>				

C Totals

	August	1989-90	Total
Single Payments	59,234	362,889	859,798
Regular Payments	66,302	461,173	<u>1,025,663</u>
	<u>£125,536</u>	<u>£824,062</u>	<u>£1,885,461</u>

D Loans Housing	39,649	39,649	39,649
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3. Projected Annual Rates for 1989-90

Single Payments		871,000	
Regular Payments -			
Ongoing	707,000		
Initial Back Payments			
(est further 100)	200,000		
Annual Total		<u>907,000</u>	
Two year Total			£1,778,000
			£2,839,399

(SUMAUG)

MACFARLANE TRUSTPORTFOLIO SUMMARY at 31st August 1989

Name of Stock	Holding (nominal) Book Market	
		Clean Cost	Running Yield %	Value	Gross Ann Div
13 1/4% Excheq 1996	2,200,000	2,593,938	11.24	2,586,801	291,500
15% Excheq 1997	1,500,000	1,950,001	11.54	1,942,038	225,000
	-----	-----	-----	-----	-----
Stocks Total	3,700,000	4,543,939	11.37	4,528,839	516,500
Gain (Loss) on these stocks since previous month				4,993	
Overall Capital Gain (Loss)				(15,100)	
Certificates of Deposit					
Yorkshire Bank	1,000,000	1,000,027	14.00	1,022,790	Inc. accrued interest
Midland Bank	1,000,000	1,002,990	13.71	1,007,808	
Yorkshire Bank	1,000,000	1,008,440	13.71	1,013,305	

Overall total with MANEX				7,572,741	
Sterling at NatWest Bank		1,420,000	13.625	1,420,000	

Total Capital Investment				8,992,741	
Ref FINANCE/PORTFOLJ					

Annex E to
Minutes of
Trustees' Meeting
28th September 1989

Macfarlane Trust

Annex F to
Minutes of
Trustees' Meeting
28 September 1989

Budget 1989/90 & 1990/91 - Management Fund

1989/90

The first column of the attached paper shows actual costs for the first six months of the financial year (subject to additions 20-30 September and any late presented accounts).

This shows half year expenditure at £52,132.

The second and third columns show forecasts and estimates for the second half year. These figures are annotated where necessary.

These show a second half year expenditure of just under £68,000 and rounded figure total for the year of £120,000. A copy of the annual budget previously approved (14 March 1989) is attached for comparison.

The revised budget is reduced by £10,000 from the previous figure. This is mainly because most of the routine administration costs were based on very limited previous experience and were deliberately over-estimated so as to present a 'a worst case' figure in the application for the DH Section 64 grant.

Trustees are requested to approve the revised budget for 1989/90 for the total of £120,000 as presented.

1990/91

The Department of Health requires submission of claims for Section 64 grants for 1990/91 by 2nd October 1989.

The final column on the attached paper shows a projection of costs for 1990/91. Figures are again annotated. This shows a forecast expenditure of £150,000.

Trustees are requested to approve this outline budget of £150,000 for 1990/91 as basis for submission to the Department of Health for a further Section 64 grant.

Macfarlane Trust Management Fund

	----- 1989-90 -----			1990-91
	1st 1/2 Yr Actual	2nd 1/2 Yr Forecast	Annual Forecast	Annual Forecast
Salaries (Gross)	29,112	35,000	64,00	85,000 (6)
Fees				
Investment	5,414	5,500	10,900	10,000 (7)
Solicitors	-	5,000	5,000	5,000
Auditors	2,300	200	2,500	2,000 (8)
Bank & Misc	220	380	600	700
sub-total	-		19,000	17,700
Premises				
Rent	3,875	4,125 (2)	8,000	8,500
Rates	1,368	1,368	2,750	5,500 (9)
Services etc	578	650	1,250	1,500
sub-total			12,000	15,500
Equipment & Furniture	2,855	3,750 (3)	6,500	7,000 (10)
Stationery & Printing	1,228	3,750 (4)	6,500	7,000 (10)
Postage & Telephones	2,603	3,400 (5)	6,000	7,000 (10)
Expenses	2,291	3,200	5,500	6,000 (10)
Miscellaneous	288	300	600	700
	52,132	66,623	118,600	145,900
Contingency 2% on 1/2 yr			1,400	
2.8% on yr				4,100
			£120,000	£150,000

Notes

1989/90

- 1 Salaries Second half year figures are increased by:
- | | | |
|---|---------------------------------------------------------|--------|
| a | NALGO negotiated pay rise at 8.8% with effect from July | 3,600 |
| b | Annual scale increments to staff after 1 year service | 600 |
| c | First quarter 1990 visiting social worker costs | 1,800 |
| | Total | £6,000 |
- 2 Rent Increase due to some outstanding extra rent for meetings.
- 3 Furniture & Equipment Increase is due to cost of planned installation of a further terminal to the data network.
- 4 Stationery & Printing Increase allows for cost of Annual Report and for further order of printed stationery. There were no printed stationery costs in first half year as 1988/89 stock was still being used up.
- 5 Postage & Telephone Postage rates rise by over 5% with effect from 2 October. The increased figure also allows for the mailing of the Annual Report.

1990/91

- 6 Salaries Figure includes
- | | |
|----------------------------------------------------------------------------------------|--------|
| Salaries (including increments and allowing for further cost of living pay negotiation | 70,000 |
| Annual costs of visiting social workers (including expenses) | 15,000 |
- 7 Investment Fees These are based on % of sum invested and will reduce as invested capital is eroded.
- 8 Auditors Fees Second year will entail less work and fees should be lower than first year.
- 9 Rates We have as yet no indication of what the new 'commercial' rate will be after introduction of the Poll Tax. The % increase forecast may yet prove to be over-optimistic.
- 10 Administrative Costs New figures allow for inflation at 7-8%.

The Macfarlane Trust

The Use of Visiting Social Workers in Assessment of Claims

Introduction

It has been suggested that there is a requirement for the Trust to have the ability to obtain a first hand and objective assessment of the needs of applicants and the state of their current resources to meet these needs.

This possible requirement and the question of how it could be met were discussed at the Trustees' meeting on 27th July 1989 (M89.58c). A report was requested so that Trustees could further consider the various options.

Part I

Report on Investigation Visits

The Administrator and Social Worker visited the Family Fund (FF) on 24th August and the Independent Living Fund (ILF) on 29th August 1989. Both these visits were very valuable in general terms though this report is confined to aspects related to the use of visiting social workers.

Both these organisations **invariably** conduct a domiciliary visit to all new applicants. For both organisations these visits sometimes are needed to confirm eligibility, but in every case they also establish a good 'picture' of the circumstances of the family unit concerned.

Second visits are only conducted in exceptional cases but for both organisations the medical progression is more predictable than for the Trust, and since the sufferer is not the 'breadwinner' of the family the socio-economic conditions are also less likely to change.

Both organisations are national, operating from a single central HQ, and both operate a network of part-time visiting social workers (VSW). The economics of full time employed VSWs are not considered viable. The methods of operation are broadly similar but in general the FF provides the better pattern.

In each case VSWs are paid a fee per visit plus expenses. Inland Revenue allow FF to treat VSWs as self employed but at present ILF are having to contest a ruling (from a different area) that VSWs must be treated as employees. The fees paid are not the same in each case since the interview specifications are not identical. The costings of this system are dealt with later.

VSWs may have other full time or part time employment or may work on fees for more than one agency (a large number work for both FF & ILF). No conflict of interest is seen by either of the organisations since each individual VSW works to a direct brief from the organisation concerned, and neither operates in any way as agent for the other.

If requested FF would advise on and give the Macfarlane Trust introductions to some of their VSWs. Thereafter any arrangements made would be entirely between the Trust and the individual concerned. The FF would not be in any way involved (or wish to be).

Part II

The Principle Involved in an Assessment System

The basic question of principle is whether or not the Trust needs to have any system of individual enquiry and assessment. It is suggested that this question can best be resolved by consideration of two other questions:

- a. Some applicants appear already to be 'playing the system'. How can we identify whether this is the case or whether genuine need is being shown?
- b. The time may come (may already be here) when the Trust has not the financial resources to maintain current rates of expenditure. If economies have to be made how can it be ensured that resources go where they are most needed?

At present, assessment of need is based on paper applications, augmented in some cases by written or verbal reports by hospital or centre medical or social work staff. The Trust office then conducts enquiry or investigation as necessary but this is in most cases by telephone since there is no capacity (or procedure) for visits. This kind of enquiry is not always an adequate substitute for face to face contact.

Under such a system the best advocacy will often win the highest priority. Those acting as intermediaries at present quite naturally identify with the applicants and their advice tends to be subjective. They see their own local problems and not the overall task and problems of the Trust, and the Trust has no real right to expect otherwise.

In the worst cases the advice we receive is totally suspect and on the other hand many people registered have no advocacy at all. At best the reporting and advice is uneven across the country and the Trust administration has no reliable 'quality control' or system of mediation to ensure the level of even-handedness to which the Trustees have committed themselves.

Three other factors are worthy of consideration;

- a. Many people are surprised at our lack of enquiry, (not always favourably so). This applies both to their own requests and those of others, and leaves some doubts in people's minds on what 'proof of need' we require.
- b. The nature of the request is often not a true indicator of the actual need. Although we often sense such a situation it is difficult to test by direct question and even more so by telephone. Actual contact provides some of the answers and the opportunity to elicit others.
- c. Although we have now met many of the people registered this is mostly at group meetings and we are still a long way short of an adequate picture of our community. Home interviews provide an opportunity for some non-intrusive research into general conditions of living in the process of dealing with specific requests.

It is therefore suggested that without the ability to apply some system of assessment which is **under the direct control of the Trust**, the Trustees will find increasing difficulty in sustaining the principles of

- a. prudent management of resources
- b. catering for the whole community of the Trust
- c. consistency and even-handedness.

This is seen as a fundamental principle on which the Trustees would wish to make their decision unencumbered with discussion on ways and means.

Part III

If the need is recognised for the ability to make assessments it is then possible to go on to consider the second major point of principle - under what conditions should this ability be used? - which principle is to some extent bound up with the practical consideration of how-can it be done.

When should Assessments be conducted?

It is possible to argue that the principle of even-handedness should be applied to assessment as well as to the making of grants, and that if any form of assessment is applied it should therefore be 'across the board'.

However, the fact that a visiting assessment may be made need not mean that it will be made, and certainly not that there is any urgency. The use of visiting assessments should be to solve problems for the Trust or the client. Even-handedness can be served by publishing the fact that such visits are made when considered necessary.

In practice moreover a programme to visit all persons registered would take a considerable time to complete (at best 2 years) and hence a system of priority would be needed. Furthermore many people registered with the Trust have as yet made only straightforward requests for help or no demand at all. To propose any form of visit in such cases seems totally unnecessary intrusion on the privacy of the individual as well as making unnecessary work and therefore expense for the administration.

Some visits are already made by present staff. The capacity to expand the programme with present staff is minimal. Use of VSWs would not supersede the present visits but by taking over the more routine cases would enable the office staff to concentrate on those cases seen as potentially most difficult.

Five potential 'triggers' for a visiting assessment are suggested:

- a. Request for a large sum of money
- b. Repeated requests for financial assistance
- c. Requests involving clearance of debts
- d. Requests with a possible 'political' element.
- e. When the office has reason to feel concern that help may be needed even though not actually requested.

The degree of 'pressure' needed on each trigger is a matter for debate which this paper does not seek to pre-empt. It is suggested that there will be many occasions where the office should arrange a visit before bringing the case to the attention of Trustees, and some when the Trustees or Allocations committee should be asked to decide whether a visit is justified.

Visits in connection with housing or with employment projects are not seen as part of this framework but should continue to be handled by the office as at present.

The Size and Nature of the Task and Possible Means of Achievement

At present about twenty allocation requests are referred to the Trustees each month. Many of these are straightforward though outside the staff authority, but many others are referred because principles are involved or the exercise of Trustees' discretion is needed. In such cases the Trustees have frequently indicated that they would have liked more

information than has been available to the office. There have been occasions when the lack of information has been an inhibiting factor to effective decision making and many others where extra information would have been of considerable value. It is suggested that at present there are already as many as ten such cases each month; if the need arises for more stringent control of resources the number of assessments needed will also rise (probably in geometric progression).

The present task would therefore be around 120 to 150 per year but with every possibility of this growing to perhaps 250 per year until all persons registered had received one visit. There would then there would be a considerable falling off since second visits would be much less needed.

The Administrator and Social Worker could probably handle around 35 visits a year, and would need to continue to do so. The remainder would call for extra staff.

The smaller the team employed the greater the amount of travelling involved and this involves not only the direct travelling costs but the time of the individual(s) concerned. This is the main reason for the limitation on existing staff capability and similarly one of the greatest arguments against employing extra full time staff to do the work.

On the other hand confidentiality and cohesiveness argue for the smallest possible number of people to be involved. It would be essential that all persons acting on behalf of the Trust were under some form of direct contract with the Trust and that each visit were directly arranged from the Trust office and not through any other agency.

The optimum would appear to be between 7 and 10 part time workers well distributed across the United Kingdom. This would minimise travel whilst enabling good control to be maintained. General training and briefing would be done at the Trust office and briefing for specific visits would be by combination of a postal pack and a telephone discussion with the VSW

Some approximate costs of such a network will be presented. These are no more than guestimate at this stage, a more accurate costing would only be possible once the principles were established and the extent of the task thereby defined.

Rough costs for a permanent member of staff are also shown and even on this level of approximation the economics are clearly in favour of a dispersed team.

Part IV

Summary

On the matter of the needs and resources of persons registered with the Trust a decision in principle is needed as to whether there should be established under the direct control of the Trustees a system which gives the ability to make such assessments as are thought necessary.

If this principle is agreed two elements are needed.

- a. Procedures must be defined as to how and when visits should be required as a condition for approval of requests for grants.
- b. Expenditure must be approved to meet the costs of implementing such a decision.

Recommendation

It is the opinion of the Administrator and the Social Worker and our unequivocal advice to the Trustees that:

- a. The ability for the Trust to make its own assessments is a definite need at present and is likely to become even more pressing. Development of this ability should therefore begin as soon as possible.
- b. The best solution to achieve this ability would be to set up a small network of VSWs under the direct control of the Trust Office.

John Williams
Administrator

Tudur Williams
Social Worker

TRUSTEES/VSW

Macfarlane Trust

Widows and other Dependants of Deceased Persons

Some Considerations of Principle

1. The Deed requires Trustees to provide assistance for "the needy spouses, parents, children or other dependants of such persons who have died".
2. Leaving aside for this purpose any remaining ambiguity in the definition of what is a spouse there is a requirement for Trustees to agree on how, for all these dependants, the Trust will interpret "needy".
3. This basic policy decision is needed for two reasons:
 - a. This, sadly, is a growing community which represents a potentially growing expenditure of Trust funds, both as a percentage and in absolute terms.
 - b. This is the area of expenditure most vulnerable to criticism by our paymasters as encroaching on the grounds of compensation, and thus could in time affect any decision to allocate further funds.
4. The justification for the statement at 3b above is based on the arguments summarised below. However distasteful such arguments may seem they will almost certainly have to be answered sooner or later since, whilst they have not yet been pressed on us, they have at least been mentioned.
 - a. The Trust was established to cater for the special needs of people with haemophilia in connection with HIV and AIDS. Where these conditions no longer exist how is this special need defined in terms which exclude compensation for loss?
 - b. The state benefits system exist to take care of need (vs poverty). (Whatever we may think of the level it chooses). What basis do we choose for a higher level for our limited group of people? There is both a qualitative and quantitative element to this question.
5. Apart from the 'external' considerations mentioned above, for the future management of the Trust a policy needs to be decided. Whilst like other aspects of the Trust policy this can be developed over a period to meet changing

conditions it is a matter of some urgency that the overall aims and some general parameters are decided. This is needed to:

- a. Maintain equity and fairness in current allocation decisions and avoid entering commitments that cannot be sustained.
 - b. Plan and develop any necessary procedures.
 - c. Begin to forecast likely expenditures and resource needs.
 - d. Be able to give some information to our community on this important area of expectation.
6. Aside from this general policy it is suggested that some statement should be made on where the Trust will need to draw the line in interpretation of the term 'spouse'. We have quite a large population of young men of 'marriageable age', and many of them are embarking on steady (?) relationships but very few are marrying. Without taking any moral stand on this point it might perhaps be wise for the Trust to take some stand on the legal aspect of Trust responsibility. We know of cases even where the woman is unaware of the man's medical condition and this is a point on which the Trust perhaps should take a moral stance.

Some Practical Considerations

Regular Payments

7. The calculations on which the RP is based quite naturally apply a considerable weighting to the HIV factor. Lacking this £40 'income requirement' means that many widows on low incomes are excluded. This may be proper but the more serious anomalies exist in the differences between those who had insurance and those who had not, and in the matter of housing costs (e.g. someone whose insurance was paid in cash and still pays rent/mortgage may qualify for help whereas someone whose insurance paid off the house will almost certainly not qualify).
8. Even if the principle of regular payments to widows is upheld, it is suggested that neither the thresholds nor the maximum payments need be the same as the main scheme. There would be no administration problem in running the RP scheme on two parallel assessment systems.
9. It is for consideration whether any regular payment system for dependants should have some fixed relationship to the levels of state benefits. The eligibility might even be similar to the benefits system, particularly perhaps in taking capital into account.

Single Payments

10. Trustees have already agreed that after a year widows (& presumably by analogy other dependants) would not be eligible for holiday grants. This decision was taken on the basis that the holiday grant is given for "relief of stress" and that stress of bereavement could not be justified indefinitely.
11. Most people on benefits or low incomes have to cope with the shock of sudden expense by means of savings or borrowing. The scope for community grants is extremely limited. Dependants eligible for help from the Trust are neither better nor worse off than others in this respect. The consideration is that most of the typical single grants are for items that fall into this category and hence most occasional payments are a form of income support just as much as are regular payments. Without the 'special needs of HIV' clause it is very difficult to separate the two.

Expenditure

12. In the long term and worst case the Trust could be dealing only with widows and dependants. May that time be far away, but it is a theoretical point on the future path of Trust commitment. On present trends there could be as many as 700 to 800 widows (legal & common law) plus dependants. Every £10 per week to each family would cost the Trust £400,000 p.a.
13. The recent increase in regular payment was coupled with a rise in the 'income requirement' to cope with HIV from £35 to £40 per week. Widows on the 6 month continuation of their husband's payment will in most cases have received this raise but those assessed in their own right remain on the maximum of £20. At least until any new system for widows is agreed it is suggested that this situation should continue.

Conclusion - A personal summary

I had set out to write a paper which would contain some positive recommendations, particularly with regard to future regular payments for widows. This is what Trustees will have expected and I apologise that the paper falls well short of that aim. The requirement of the Trust Deed and the wish to find a compassionate solution are very difficult to meet on the basis of a consistent system which takes into account individual "needs" as required by general charity law.

Many individual aspects of the problem have been discussed in various contexts. It is suggested that the subject as a whole has not previously been the subject of debate and that this should not be further deferred.

I doubt whether any Trustee thought that this was a simple subject but I hope that the paper at least serves to show just how complex the problem is. I am not even sure that the solution will be in logical consideration of facts but rather in judgement the Trustees will have to make.

Two considerations may give weight on the side of compassion and provide some reply to any future suggestion that the Trust was giving special consideration to dependants over and above the criterion of need:

a. We have received no support from either the Government or the commercial side on the matter of insurance. Compared with the general public this lack may be representable as a need unconnected with compensation.

b. Worry over the future for their dependants is a major source of stress to the people registered with us. The Trust needs to be able to publish the basic principles of a policy which gives at least some reassurance on this point.

Whatever may be the policy of the Trustees towards widows, and other dependants, it is suggested that the criteria and calculations applied to registered person with HIV are not relevant to the consideration of dependants, and new set of criteria is needed.

The notes attached may provide a basis for such criteria.

Possible criteria for Payments to Widows and Dependants

The Principles

Overall aims might be stated in the following terms:

The Trustees aim to help widows and dependants through the period of bereavement and the subsequent problems of readjustment to the new life style occasioned by their loss.

Longer term assistance cannot be guaranteed and will depend on the resources of the Trust (after meeting the needs of those living with AIDS and HIV).

The Practice

A finite limit could be placed on the 'period of bereavement' (say 6-12 months) and the subsequent 'period of readjustment' (say a further 12 months).

Limitations in principle and/or in cash terms could be placed on 'longer term assistance'.

The Procedures - Suggested Rules

1. HIV infected widows should be dealt with as if they were registered in their own right, (But no dependants other than of the original registrant would be recognised.)
2. The Bereavement payment should continue and its value be maintained in real terms.
3. Regular payments should continue at the deceased's rate for six months as at present. Thereafter they should be tapered (over a period of up to eighteen months) to zero or whatever payment would be due under any scheme of RP for widows.
4. Single payments should be allowed for all expenses due to deceased's illness and for funeral costs as at present. Cost of damage or dilapidation due to deceased's illness should be viewed sympathetically in the 'period of bereavement'.

5. Thereafter single payments would not be recognised for household costs, either for running expenses or for replacement of appliances due to wear and tear. Special allowance might be made for accidents or 'acts of God' not coverable by insurance.
 6. Single payments could be considered to assist with needs arising from illness of widows or dependent children.
 7. Holidays. A holiday payment would be allowable to a widow up to 12 months after bereavement, whether or not she had received one with the deceased, but not necessarily to the same maximum agreed for other holidays. (say £200).
 8. Widows with dependent children. Special consideration might be given, especially for those with under 12's who cannot work without having the children taken care of. Some form of holiday or outings payment should continue and the children should be eligible for any Christmas payment approved in future years.
 9. Housing. As far as possible this should be left to be covered by whatever RP is approved and the state Housing Benefits. Where this is inadequate a high priority should be given to ensuring that widows (esp. with dependent children) do not lose the family home that they shared with the deceased.
 10. Resettlement Move. For a given period after bereavement (1 1/2-2 yrs) assistance could be given with the removal costs of a 'resettlement' (e.g. to more suitable accommodation, nearer relatives etc.). This would not include any capital costs of the new home, nor would the new premises be necessarily subject to the same protection offered to the original home (see 9 above) since an element of choice rather than circumstance had been introduced.
- etc.