## THE MACFARLANE TRUST

Minutes of a meeting of the Trustees held at Alliance House on Thursday 22nd March 1990 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

90.13 Apologies for absence

90.14 Minutes of meeting 18th January 1990

90.15 Matters Arising

90.16 Ex Gratia Payment - Progress Report

90.17 Administration

#### Finance

90.18 Grants expenditure.

90.19 Investment and Finance Report.

90.20 Charges to Special Payments Trust

90.21 Accounts 89/90 and Budget 90/91

## Allocation Session

90.22 Case Review

90.23 Allocation Policy
A Implications of ex gratia payment
B Other items as requested

## Closing

90.24 Information and PR

90.25 Any other Business

90.26 Future meetings

## GENERAL SESSION

Opening Remarks

The Chairman welcomed all present. He informed the meeting that there were only nine Trustees at present as the Haemophilia Society had decided not to invite Mr Simon Taylor to serve for a further period and had not yet agreed on another appointment in his place. It was confirmed that all Trustees present had received letters of reappointment.

The Chairman said that because Mr Stevens had to leave the meeting early some of the Agenda Items would be taken out of order so that Mr Stevens could take part in the discussion.

### 90.13 APOLOGIES FOR ABSENCE.

Mr Cashman had given his apologies at the previous meeting.

90.14 MINUTES OF PREVIOUS MEETING held 18th January 1990.

No comment was raised on the minutes. It was proposed by Mr Grinsted and seconded by Mrs Guy that the minutes be accepted as a true record and this was carried unanimously.

#### 90.15 MATTERS ARISING FROM MINUTES.

M90.11 Embargo on benefits to Trustees. The Chairman advised the meeting that following their previous decision a special dispensation had been sought from the Charity Commissioners but they had been unable to make the exception sought. Further discussion had then been held with Paisners who had given their opinion that the Commissioners reply gave no leeway for further action.

The Administrator reported that the discussions had shown that the discretion of the Commissioners was minimal in this respect and applied only to interpretation of general trust law. The Commissioners had no power to override the specific conditions of any trust deed, such as applied to the Macfarlane Trust. Furthermore since the view of the Commissioners was increasingly firm in support of the general rule they would be unlikely to welcome a move to alter the Macfarlane Trust deed or to make any exception that might still be necessary under the general law.

The meeting expressed disappointment at the rulings given but agreed with the Chairman that no further

action should be taken in seeking legal change or exception. Instead, alternative means should be examined to ensure the continued participation of persons eligible who might need to accept financial assistance from the Trust.

The meeting expressed their support for the Trustee directly affected by this situation and their thanks and admiration for his continued participation, for however long this may be.

## 90.16 EX-GRATIA PAYMENT - PROGRESS REPORT

The Administrator reported for formal record that negotiations had been completed shortly after the January meeting and the Macfarlane Special Payments Trust Deed had been engrossed on 29th January 1990. A Copy of the Deed had been sent to all Trustees. He further reported that, on the basis of the rate of expenditure forecast, the Government had paid the full £24 million in a single tranche and this had been received on 31st January.

1000 payments had been made by 16th February. Since then progress had been slower while more complicated cases were dealt with and due to difficulties with the Post Office. At 21st March 1110 payments had been made and with new registrations still being completed the expected total of 1200 could well be exceeded.

In reply to a question the Administrator said that approximately £200,000 had been earned in interest but that tax would be payable on this sum.

There was some general discussion. The meeting agreed to place on formal record their congratulations and thanks to the Staff for what had been achieved.

Further Campaign. In reply to a question the Chairman stated that the Society was continuing the campaign for further redress. A series of small group meetings with members of the Houses of Parliament was now in progress with the aim of maintaining the level of support previously achieved.

## 90.17 ADMINISTRATION

a. Registrations The Administrator reported that 1176 registrations had been confirmed and 24 applications were being verified. Further applications continued to arrive so the figure of 1200 was likely to be reached in the near future.

b. Statistics There were now 28 known infected marriage partners. The list of deceased was now 174 but the increase was more due to posthumous registration than to any marked increase in deaths reported. Of the 24 registrations being validated 6 were for deceased persons. 96 of the deceased had left widows. A more complete statistical summary would be circulated as soon as possible. (Annex A).

#### FINANCE

### 90.18 GRANTS EXPENDITURE

A summary of grants to 28 February had been circulated. Some errors in the paper were pointed out and these are corrected in the revised version attached at Annex B. A summary of grants made from 1st to 21st March was circulated at the meeting.

### 90.19 INVESTMENT AND FINANCE REPORT

A summary of the Stocks Portfolio and other Capital Investments was circulated, and is reproduced at Annex C.

Mr Grinsted reported that the dialogue with MANEX had continued on the lines discussed previously (M90.08). Because of continued high interest rates the Gilt Stock market continued to stagnate and there was little prospect of selling or buying Stock in the foreseeable future. MANEX had not been prepared to make any concession on fees and therefore after consultation with his fellow members of the Investment Committee he had written to MANEX terminating the management contract with effect from 28th February. It was hoped that in due course at least some of the book loss on the Stocks held would be recouped. In the meantime their yield was very close to the current market and did not justify selling at a loss. A watch on progress could be kept without MANEX's help. If the need for a more active investment programme became apparent, the case for professional advice could be reconsidered.

The meeting concurred with the action taken and the Chairman thanked the Investment Committee for their work.

# 90.20 CHARGES TO MACFARLANE SPECIAL PAYMENTS TRUST

At the request of the Chairman the Administrator introduced the discussion paper (Annex D). He said that it had been agreed that the Special Payments Trust would reimburse the Macfarlane Trust for the costs of all services rendered. The majority of these costs fell in the current financial year and hence an early agreement was needed.

Because of the short timescale the Trustees of the MSFT had seen the calculations first and he could therefore report that charges of this order would be met without question. It had been agreed that it was not feasible to produce itemised costs and the proposed basis of costing and charging had therefore been discussed with the Auditors (Pridie Brewster) who had given their opinion that the method was satisfactory and would not be liable to any adverse comment during audit.

The calculations were reviewed and accepted by the meeting. It was proposed by Mrs Guy and seconded by Mrs Leitch that charges be levied on the Special Payments Trust at the rate of £15.00 per payment and that a first payment of £16,5000 be requested in current financial year. This was carried unanimously, and the Chairman signed the letter requesting payments.

## 90.21 ACCOUNTS 89/90 AND BUDGET 90/91

The Administrator introduced the paper (Annex E) pointing out that this reproduced the figures agreed in September 1989, updating those for the current year.

- a. 1989/90 Previous forecast expenditure of £120,000 was only covered by £100,000 of Section 64 Grant, leaving a cost to the Trust of £20,000. Although expenditure now rises to £122,500 the offset payment of £16,500 from MSPT leaves the debit to Trust Funds reduced to £6,000.
- b. 1990/91 The Administrator reported that the Section 64 Grant approved for the year was £150,000 which was the full amount requested to cover inflation and the addition of the VSW project. He said that one major item in the budget covering the fees which would have been payable to MANEX would now be much reduced, possibly even to no cost. He recommended that notwithstanding this observation the budget remain unchanged for the present and the meeting agreed this recommendation.

#### ALLOCATION SESSION

### 90.22 Case Review

a. Personal Grants Mr Williams presented 20 grant applications for a total sum of £42,998. The Trustees approved 14 grants totalling £12,975. Five applications were rejected as inappropriate and one was referred back to the staff for further inquiry.

Two of the applications rejected had resulted from a representation by a Centre Director of a need for personal compressors for nebulisers for administration of Pentamidine. It was agreed that such equipment ought to be available from Health Service resources but that in emergency the Trust would cover costs to ensure that individuals did not suffer delays. Dr Jones agreed to speak to the Centre Director concerned.

[Post meeting note: resulting from Dr Jones's discussion the block request was withdrawn for further consideration].

#### b. Block Grants.

- (1) A request had been received from the Haemophilia Society for assistance with the funding of a Women's weekend seminar for which they had been unable to gain funding elsewhere. The Trustees agreed to provide the support for spouses and carers of persons registered with the Trust to a maximum of £100 per person and an overall maximum of £7,500, being half the projected cost.
- (2) A request had also been received from Leeds for group payment for up to four sessions of therapy for relaxation and stress reduction. Allocation would be against a list of nominated persons registered, totalling £60.00 per session.
- c. Applications to Register. Five applications to register with the Trust were presented. Two applications by widows for posthumous registration of deceased persons were refused on the grounds of lack of proof of HIV status. One application by a female carrier was referred for further evidence from a Centre Director. In the case of two applications by persons with undisputed HIV status resulting from treatment for Acquired Haemophilia no decision was taken pending consultation with the Department of Health.

## 90.23 ALLOCATION POLICY

a. The implications of the £20,000 ex gratia payment

The Chairman said that this was a subject which the Trustees had set for themselves to debate at the earliest opportunity, and he drew attention to a communication from the Executive committee of the Haemophilia Society dated 16th February 1990 (text reproduced at Annex F). The Chairman invited views from everyone present and the subject was extensively discussed.

The major considerations raised, sometimes by more than one speaker included the following:

'At the time the ex gratia payment was announced the Secretary of State also expressed the intention/hope that the Macfarlane Trust could also be more generous'

'Since the Departments of Health and Social Security were prepared to disregard the payment the Trust should do likewise'

'Where Grants were for capital improvements the ex gratia payment should be taken into account'

'The Trust had not previously taken account of applicants capital/savings and should not now do so'

'If it were intended to take account of the payment there were practical problems in knowing what had been done with the grant'

'Taking account of grant and savings would be a disadvantage to the thrifty'

'Since there was no absolute guarantee of further funding, ignoring the lump sum payment could be viewed as failure to take an opportunity to be more selective in allocation of diminishing resources.'

'Difficulty of an equitable system which took account of only certain types of payment - hence ignore for all'

'Many excluded from legal aid were having to use the payment for litigation costs'

'A basic review of grants policy was desirable and the ex gratia payment was only one factor in such a review'.

The final majority view was that no direct account should be taken of the ex gratia payment in assessing grants by the Trust, and this was seen as a continuation of existing policy. At the same time it was recognised that it would be difficult to guarantee that Trustees' awareness of the grant could be entirely set aside, and hence may affect their view of some requests for assistance, such as mortgages or house improvements.

The suggestion by the Executive Committee of the Haemophilia Society that anyone had been or would be "penalised" as a result of receiving the grant was entirely refuted.

It was recognised that although grants policy had been regularly reviewed and developed this had been an evolutionary process and there was a case for a re-examination of the principles to see whether they still matched the needs of the people served taking account of likely resources available. Trust numbers had increased and the ex gratia applications had provided further demographic data. The Trust also now has over two years of grant making experience. The Administrator and Social Worker were asked to prepare preliminary discussion papers on this subject.

A reply to the Haemophilia Society was drafted and approved. The text is recorded at Annex F.

### b. Holiday Grants

It was agreed that although no formal paper had been prepared the subject of holiday grants needed an early decision and that the next Trustees' meeting would be too late to be effective for the summer of 1990.

The desirability of making an annual holiday grant was generally agreed though with a minority dissent, and several Trustees spoke of the strong feeling of registered people on this point. The major point of debate was therefore on the cost of further grants, the priority of such costing and whether other savings could or should be made to offset this expenditure.

It was generally agreed that holidays should be one of the highest priorities for grant expenditure and that the current policy not to make holiday grants in consecutive years should be reversed. This principle was put to a vote, five Trustees voting in favour and one against. Carried.

The nature of the holiday grant and the degree of funding that could be allocated was then discussed. It was agreed that the Trust could not be committed to any particular type or style of holiday and also that a good contribution towards costs should be the aim as opposed to total funding. At the same time the grant should be sufficient to provide some form of holiday even when the applicant had no other It was further agreed that the grant should be directed mainly towards the registered person and the partner or carer with less assistance to other members of large family groups. It was recognised that few holiday grants were paid at the single person rates and the majority were for two people, with still a sizeable minority including one or more other family members.

Lacking more accurate costing the two person grant was taken as the average and 1000 as the number of people currently eligible to apply.

It was agreed without a vote that the grant for one person should remain at £350 but that the grant for a second person should be reduced to £250. On this basis the Trust would have to be prepared for an expenditure of around £600,000 in the coming financial year.

A ceiling for additions for other family members was put to the vote. For a maximum grant of £1000, two Trustees voted in favour and for a maximum grant of £750 three Trustees voted in favour. The latter proposal was therefore carried.

It was agreed without formal vote that anyone who had not received a holiday grant could still receive their first grant under the previous agreed terms (£350 per qualified adult, £175 per child).

## 90.24 Information and Public Relations

#### a. Visits

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The Administrator reported that a meeting had been held on March 1st hosted by the Lewisham Hospital but also including people from the Centres at Guy's, King's and St George's. Mr Grinsted had been accompanied by the Administrator and Social Worker. Some of the feed-back from this meeting had already been discussed in the Allocations session of the meeting. Mr Grinsted gave his view that the event had been most successful with a very open exchange of views and some const. Active suggestions. Whilst differing views had been expressed there had been no complaint laid at the Trust but many compliments at the helpful and speedy way in which requests were handled.

The Trust had also been represented at the BASW Haemophilia Group meeting held at St Thomas's Hospital on 16th March. The Administrator had given an update on the work of the Trust and a report on the Special Payments Trust and Ms Turner had remained for the session which provided a good chance to meet a large number of members since the meeting was very well attended.

The meeting took note of these visit reports.

### b. Annual Report

The Administrator said that the annual audit should be completed much earlier this year, and this would enable earlier publication of the Annual Report. Preparation could proceed in parallel with the audit and he invited suggestions or contributions from Trustees on subject matter for the report.

The meeting expressed their satisfaction with the previous year's report and agreed that no major change in style or content was called for. They agreed that the report should be completed as quickly as possible. Mr Grinsted agreed to draft the financial section and the other Trustees present agreed to let the Administator have any suggestions that they wished to make on content.

90.25 ANY OTHER BUSINESS None.

## 90.26 FUTURE MEETINGS

No changes or additions were proposed.

GRO-C

22nd May 1990

The Rev A J Tanner Chairman

#### Annexes

- A Trust Statistical Summary See note below.
- B Grants expenditure to 28 Feb 90
- C Investment Portfolio at 28 Feb 90
- D Costs and Charges to MSPT
- E Accounts and Budgets 1989/90 and 90/91
- F Ex Gratia Payment Correspondence with Haemophilia Society

#### Note

The next statistical summary was issued with the papers for the May meeting and is recorded there. Annex A was therefore not produced.

Annex B to Minutes of Trustees' Meeting 22nd March 1990

			22nd M	larch 199	90	
MAC	FARLANE TRUST					
Summary of Grants Made at 28th February 1990						
1.	To 31st March 198	39		8		
	Grants Regular Payments	935 406	496,909 564,490		*	
	Overall	Total		i d	<b>£1,061,399</b>	
2.	Financial Year 19	189-90				
Α	Single Payments					
	No	Total		Amount	Run.Total	
	Apr- Nov December 131 January 121 February 74	1081 1212 1333 1407		68,885 62,937 34,022	566,158 635,043 697,980 732,002	
В	Regular Payments.					
	No	Initial	Ongoing	Overall	Run.Total	
	Apr- Nov 217 December 25 January 10 February 7	322,571 23,598 19,012 5,401	366,357 57,365 56,678 59,890	80,963 75,690 65,291	698,928 779,891 855,581 920,872	
	2592		v x		*	
C	Totals Single Payments Regular Payments Winter Payments	February 34,022 65,291 4,400 £103,713	1989-99 732,000 920,87 389,20	2 2 0	Total 1,228,910 1,485,362 389,200 £3,103,472	
D	Loans Housing	39,649	39,64	9	39,649	
3.	Projected Annual	Rates for 19	89-90			
Sing Regu Ongo	er Payments gle Payments llar Payments - ping tial Back Payments	995,000	400,00 800,00			

1,000,000

SUMFEB90

Annual Total Two year Total

£2,200,000 £3,261,000

## PORTFOLIO SUMMARY at 28th February 1990

Name of Stock	Holding (nominal)	Clean Cost Running Yield &	Market Value Gross Ann Div
13 1/4% Excheq 1996	2,200,000	2,593,938 12.055	2,312,750 291,500
15% Excheq 1997	1,500,000	1,950,001 12.112	1,711,875 225,000
Stocks Total	3,700,000	4,543,939 12.078	4,024,625 516,500
*	Gain (Loss) or	n these stocks since previous report	(229,625)
		Overall Capital Gain (Loss)	(519,314)

## Sterling at Nat West Bank

MACFARLANE TRUST

Period		Ma			
-				y	
1	month	23	March .	500,000	14.937
1	week	28	March	200,000	14.5
1	month	30	March	1,000,000	14.625
1	month	19	April	1,000,000	15.0
3	months		May	1,000,000	15.0
				3,700,000	
		46			

Ref FINANCE/PORTFOLM

Annex C to Minutes of Trustees' Meeting 22nd March 1990

## MACFARLANE TRUST

# Capital Assets - Financial Year 1989-90

		SMM	MANEX	Total (figures E million)
Apı	1	1.5		
	30	1.4	8.19	9.49
May	23	+ 1.4	- 1.4	Cash assets from Manex to Bank
	31	2.75	6.75	9.5
Jun	1	- 1.0	+ 1.0	TF to Manex for purchase of CD
	30	1.67	7.75	9.42
Jul	31	1.57	7.75	9.32
Aug	31	1.42	7.57	8.99 Stocks sold & CD purchaased
Sep	30	1.38	7.57	8.89
Oct	31	1.28	7.56	8.84
Nov	30	1.35	7.56	8.91 Stock dividend
Dec	14	+ 1.0	- 1.0	CD cashed. TF to SMM
	31	1.97	6.56	8.53
Jan	31	1.85	6.56	8.41
Feb	14	+ 1.00	- 1.00	CD cashed. TF to SMM
	28	+ 1.00	- 1.00	т
	28	3.7	4.56	8.26

With sale of last CD on 28 Feb MANEX management contract was closed. Stock is actually held by Nominees. Clean value at 28 Feb was £4,024,625.

Ref FINANCE/CAPFEB90

The Macfarlane Trust.

Costs to be levied by Macfarlane Trust on Special Payments Trust.

The figures below do not include fees (Solicitors/Auditors/Bank) which are paid direct from the MSPT account.

#### A. Staff.

Current Gross Salary Costs for the Trust run at £5,300 per month.

The Trust Office concentrated almost entirely on MSPT business during the month of February. It was heavily involved in preparatory work in December and January and is dividing its efforts about half and half through March.

There is therefore a good case that MSPT should pay two months worth of salary costs, i.e. £10,600 covering the work in the current financial year.

Additionally in recognition of the extra work and the lowered standard of working conditions, the Trustees wish to make bonus payments to the staff totalling £3,600 gross.

### B. Direct Expenses

Each payment has involved a minimum of 3 letters, for some the correspondence has been longer and for others there have been telephone calls and even visits. The establishment of MSPT records has called for special stationery and printing, and there have been costs in obtaining formal documents.

The absolute minimum cost per payment has therefore been £2.00 (not counting staff time). There have been varying extras running to perhaps £3 for ten percent and £7-10 for the top five percent.

Say	500	e.	£2.00	1000
7	500	e e	£2.50	1250
	100	e e	£3.00	300
	50	@	£5.00	250
	50	e	£8.00	400
			Total	£3,200

## C. Summary (Assuming work completed in current Financial Year)

Staff Costs:			10,600
	bonus	payment	3,600
Incurred exp	enditu	re	3,200
Total			£17.400

## D. Proposed Basis for Charging

This estimate of total cost of £17,400 averages out at a flat rate of just under £14.50 per payment. However the 'work per payment' is steadily rising as the complex cases have been left until last. We do not yet know what the final registration figure will be, or how long the work of the MSPT will last. It is therefore difficult to assess staff time costs for 1990/91, which would need to be added to the total costs listed above.

It is therefore proposed that the costs throughout should be agreed at £15.00 (fifteen pounds) per payment.

MSPT\COSTS

## The Macfarlane Trust

Annex E to Minutes Trustees' Meeting 22 March 1990 Agenda Item 90.21

## Accounts 89/90 and Budget 90/91

Budgets for 89/90 and 90/91 were approved in September 1989 and recorded in M89.74 (and Annex F).

The Annex to this paper repeats the agreed budgets for the two years together with actual expenditure to 28 Feb 90 and a revised forecast expenditure to the end of the current financial year.

## 1989/90

Forecast expenditure is up from £120,000 to £122,500

This was the result of:

- a. Increased salary costs of £2,000 resulting from bonus payments for work of MSPT, partly offset by lack of any expenditure on VSW project.
- b. Increased equipment cost of £500 resulting from expansion of ADP network at a cost of approximately £1000.

Notwithstanding this increase, the reimbursement from the Special Payments Trust will reduce the expenditure of Trust Funds from £20,000 to £6,000. (Section 64 Grant was £100,000).

### 1990/91

A Section 64 Grant for 1990/91 of £150,000 has been approved. This meets the full bid resulting from the budget agreed in September 1989.

The one major change is that Investment Management fees will be significantly reduced, and could even be nil. We still do not know the Rates charge for the coming year.

It is recommended that the Budget for the year is not amended for the present.

## Macfarlane Trust Management Fund

		1989-90 -		1990-91
	Sep 89 Annual Forecast	28 Feb 90 Actual	Revised Annual Forecast	Annual Forecast
Salaries (Gross)	64,000	55,271	66,000	85,000
Fees Investment Solicitors Auditors Bank & Misc sub-total	10,900 5,000 2,500 600 19,000	8,041 4,623 2,559 935 16,158	10,175 5,000 2,750 1,050 18,975	10,000 5,000 2,000 700 17,700
Premises Rent Rates Services etc sub-total	8,000 2,750 1,250 12,000	7,800 2,736 <u>976</u> 11,512	8,000 2,736 1,649 12,485	8,500 5,500 1,500 15,500
Equipment & Furniture	6,500	6,934	7,000	7,000
Stationery & Printing	6,000	5,272	5,750	7,000
Postage & Telephones	6,000	5,625	6,000	7.000
Expenses	5,500	5,298	5,750	6,000
Miscellaneous	600	596	600	700
Contingency	119,600* 400*	106,666	122,560	145,900
	£120,000		£122,500	£150,000
Section 64 Grant		**	100,000	£150,000
From MSPT			16,500	
Required from Trust Fu	unds		6,000	
			£122,500	

<sup>\*</sup> Shows correction of previous misprint REF FINANCE\SUMMARY

Annex F to Minutes of Trustees' Meeting 22nd March 1990

# Correspondence with Haemophilia Society on Ex Gratia Payment

Text of letter from General Secretary of the Haemophilia Society to the Administrator, dated 16th February 1990.

"At the meeting of the Executive Committee of the Haemophilia Society held on Thursday 8 February 1990 deep concern was expressed that those benefitting from the £20,000 distribution through the Macfarlane Special Payments Trust were likely to be penalised when making applications for single items. The Executive Committee unanimously resolved that I should write to your trustees urging that the trustees policy be that of having no regard whatsoever to the payments when assessing requests for single payments."

Text of letter approved by Trustees 22nd March 1990.

"Thank you for your letter of 16th February regarding the ex gratia payment.

At their two-montly meeting on 22nd March the Trustees considered your letter and have asked me to make the following points in reply.

The Trustees have never enquired about the level of (savings) capital held by people requesting either regular weekly payments or single payments for particular needs. They do not intend to change their policy in that respect.

The Trustees have always kept under continuing review the forms in which help should best be given, in terms of the extent of weekly payments and the nature of the items for which single payments should be made. This review of the forms of help will continue but, as I have said, without regard to the level of capital held by individual applicants to the Trust.

This of itself refutes any suggestion that anybody is likely to be penalised following receipt of the ex gratia payment."