

T H E M A C F A R L A N E T R U S T

Minutes of a Meeting of the Trustees held at Alliance House
on Thursday, 12th September 1996 at 10.30 a.m.

Present: The Reverend Prebendary Alan Tanner, Mrs Cowe,
Mr Grinsted, Ms Harrington, Mr ~~GRO-A~~ Mr Hodgson,
Mr Pudlo, Mrs Stubbs, and Miss Winterton

In attendance: Wg Cdr Williams, Mr Williams, Mrs Le Sage

AGENDA

Administration

- 96.28 Minutes of previous meetings - 21 May 1996
- 96.29 Administrator's Report

Finance

- 96.30 Expenditure summary to 31 Aug 1996
- 96.31 Administrator's Report to 31 Aug 1996

Assistance and Grants

- 96.32 Report on Regular Payment Review
- 96.33 Winter Payments 1996
- 96.34 Applications
 - a) Individual requests
 - b) Women's Weekend
- 96.35 Reviews
- 96.36 Guidelines

Policy Items

- 96.37 Feedback
- 96.38 Strategic Review
- 96.39 Meetings/Visits/Liaison
- 96.40 Newsletter 33
- 96.41 Any Other Business - to include:
 - a) Meeting dates: Sept 97 and Nov 97
 - b) Mini-Alloc dates: Sept 96 to Feb 97
- 96.42 Strategic Review (staff implications) - Trustees only

Apologies had been received from Dr Winter.

Opening the Meeting, the Chairman offered a warm welcome to Mr Paul Pudlo who, having relinquished his position with the Department of Health, had become a Trustee. He thanked Mr Pudlo for giving his services and looked forward to his contribution to the work of the Trust. The welcome was endorsed by the other Trustees present.

ADMINISTRATION

96.28 MINUTES OF MEETING - 21 May 1996

a. The Administrator introduced some small changes in M96.17, paragraph 2, and M96.18. It was subsequently proposed by Mr Grinsted and seconded by Miss Winterton that the Minutes be accepted. This was carried unanimously.

b. Referring to M96.20, the Administrator reported that the Annual Report had been cleared and promptly dispatched. He also reported that a Broadsheet incorporating information from the Annual Report had been produced and circulated to all members and that interestingly those members who had previously said they would like to receive a full copy of the Annual Report appeared to have been satisfied with this Broadsheet. In response to a question from Mr Grinsted, the Administrator reported that there was no feedback from the Broadsheet other than that fewer had commented that the Trust was sitting on large sums of money.

96.29 ADMINISTRATOR'S REPORT

The Administrator introduced the following subjects:

a. **Statistics.** The summary to 31 August 1996 had been circulated. The Administrator commented that despite the reservation expressed by Dr Winter at the last meeting, the number of deaths was still markedly fewer.

b. **Staff Matters.** The Administrator reported that Ms Hassan had given birth to a son on GRO-C and that they were both doing well. Ms Hassan would be returning to work on 4 November and in the meantime, Ms Beer was working as a temporary until her return. The Chairman asked that his congratulations be passed to Ms Hassan.

c. **National Westminster Bank.**

i) The Administrator circulated new terms of borrowing which had been sent by National Westminster Bank. He pointed out that the Trust had never borrowed from the Bank other than an accidental slight overdraft on two or three occasions. No formal borrowing was needed but the standard procedure as proposed by the bank was a useful facility in case of delayed credits or an urgent unscheduled payment. After some discussion it was agreed that the bank form could be signed.

ii) The Administrator reported that the Bank had been reviewing generally charity matters and consequently wanted the Trustees to renew their mandate as Clause 6(8) of the Trust Deed indicated that every cheque should be signed by two Trustees. As this would prove to be an administrative nightmare, it might be necessary for the Trust Deed to be amended. He was in the process of consulting Paisners during which time the Bank would accept the existing mandate.

The Chairman suggested that further discussion be deferred until the Administrator had heard from Paisners.

FINANCE

96.30 EXPENDITURE

The Summary of Grants made to 31st August had been circulated. The Administrator pointed out that single payments were still ahead of last year, due in part to a large sum which was paid out in May. In general terms, this trend was insignificant. He also drew attention to regular payments which were beginning to increase but this matter would be dealt with under Agenda Item 96.32. The Trustees took note.

96.31 FINANCIAL REPORT TO 31 AUGUST 1996

The Administrator's Financial Report to 31st August together with the Investment Summary at 1st September had been circulated to the Trustees. The Administrator referred to his projection of income for the year and drew attention to the fact that although income from investments would be lower than last year, the drop should be balanced by a higher income from cash deposits since the new Government grant had been mainly held as cash. No recommendations for policy or procedural changes were made and the Trustees accepted the report and agreed that no special action was required.

ASSISTANCE AND GRANTS

96.32 REPORT ON REGULAR PAYMENT REVIEW

a. **Progress of Update.** A report on the Update of Regular Payments had been circulated. The Administrator reported that although progress had been slightly slower than anticipated due partly to postal strikes and partly to the holiday period, nevertheless returns had been reasonable. There were those, however, who needed to be encouraged to reply and the Administrator sought sanctions from the Trustees on which a reminder circulation could be sent.

Following discussion it was agreed by all present that these recommendations should be followed, as amended:

i) replies must be received within 30 days in order to qualify for automatic backdating to April. Later replies would only qualify for the new rate from the date the application was received, and

ii) anyone who had not replied by 7th January would be reassessed at the lower rate (£80) and subsequent corrections would not be backdated.

b. Anomalies. The Administrator brought to the attention of the Trustees a small number of actual and possible anomalies in the regular payments system which appeared unfair to some individuals.

i) After some discussion, it was the consensus of the Trustees that in the case where a widow's last child becomes independent the regular payment should continue at a rate of £55 for a further three months.

ii) The case of a child whose money had been held by Master Turner was discussed. Once this child had turned eighteen, the capital was no longer protected from the benefits' system and was therefore set against unemployment benefit, the person being unable to claim benefit. As there appeared to be little enthusiasm for the case, after discussion it was agreed to leave this.

iii) The Administrator brought to the Trustees' attention a situation where an orphan was brought up by a guardian. He suggested that recognition should be made of the other child within the family unit. After discussion it was agreed that payments could not directly recognise a child who was not legally included as a beneficiary of the Trust, but an increase above the standard rate could be made on a discretionary basis to be determined by the Trustees. A new section on orphans would be drafted for incorporation in the next Handbook.

iv) Payment to widows with children who remarry was discussed. It was agreed that although listed as widows payments this help was actually targeted at the child(ren) and hence whoever had care of the child could receive the payment. This could therefore include mothers who had been divorced and widows who remarried as well as other guardians.

v) The Trustees agreed that the small number of people on Invalidity Benefit who might otherwise receive less total income than those on Income Support should have the deficit made up by giving an appropriate level of payment within the regular payments system.

The overriding principle in all the changes outlined above was for the simplicity of the system.

96.33 WINTER PAYMENTS 1996

The paper on Winter Payments which had previously been circulated was discussed. In the first instance the Trustees agreed the continuity of this payment and following discussion it was unanimously agreed that the Winter Payment should rise to £525 this year and subsequently be reviewed annually.

96.34 APPLICATIONS

a. Requests.

Mr Williams presented 8 applications for financial help. 5 of these were approved totalling £6,150.00. In the case of one of these applications, a loan of £2,500 was agreed as an advance on payment and in the case of another application it was proposed that a loan could be made in order to allow redemption of a secured loan and elimination of arrears of mortgage in return for which the Trust would make a second charge on the property on an equity share basis.

b. **Women's Weekend.** Ms Harrington presented her proposal for a Women's Weekend which was being set up by the Haemophilia Society Task Force. She reported that a letter had been sent out to all living members of the Macfarlane Trust (asking them to hand the letter to their wife, partner, mother, sister, daughter), widows and mothers asking them to complete a simple form to ascertain not only whether or not they would be interested in attending a Women's Weekend, but also what areas of discussion they would be interested in. The response had been very encouraging. Ms Harrington was therefore approaching the Trustees on behalf of the Haemophilia Society Task Force for a financial contribution towards this weekend. After discussion, it was agreed that a contribution of £7,000 would be made to the Haemophilia Society and that the Haemophilia Society would be asked to provide the names of those Macfarlane Trust members who attended, so that the sum could be allocated as direct assistance to eligible individuals.

96.35 REVIEWS

Mr Williams presented 12 applications to be reviewed by the Trustees. Of these, 7 were again rejected by the Trustees. However, they agreed:

- i) continued care costs amounting to £400 a month subject to a review at each Trustees' meeting.
- ii) £1,500 in a case where further evidence had been provided of serious disrepair to windows which was shown to be detrimental to health .

iii) The capital cost only of £1,800 for a quality artificial limb with the suggestion that the member could contact the Trust in twelve months' time when actual maintenance costs would have been ascertained.

iv) £1,000 towards the help of house moving costs to a widow.

v) A request for short term assistance with the interest element of a loan repayment was made. After discussion, it was agreed that Mr Grinsted and Mr Williams should have an exploratory meeting with the applicant and then report back to the Trustees at their November meeting.

96.36 GUIDELINES

The Administrator introduced the paper on Payments Guidelines concerning Risk-reduced Conception and Motability which had been circulated.

a. Risk-reduced Conception. In order to simplify the guidelines minor amendments had been drafted. After discussion the Trustees agreed that in principle, and subject to Dr Winter's approval the new guideline should be adopted. It was also agreed that the guideline should come within the staff mandate. The guideline should therefore be redrafted for decision in November.

The Administrator reported that the Birchgrove Group were planning to hold a meeting on spermwashing at the end of October/beginning of November.

Trustees had various reservations about becoming involved in this event especially on the basis of so little information, or evidence of planning. It was agreed that the Administrator should reply on this basis, requesting more information and costing.

b. Motability. It was agreed by the Trustees that as it was still possible to lease suitable Motability cars within £1,000, the current guideline for Motability should remain unchanged.

POLICY ITEMS

96.37 FEEDBACK

Letters from two members were reviewed. A request for additional help for school uniform was discussed and it was agreed that the Chairman would reply explaining why additional help could not be given.

A letter of complaint regarding a regular payment assessment was considered and noted by the Trustees. It was agreed that no change in policy could be made.

96.38 STRATEGIC REVIEW

A paper on a Strategic Review of the Future of the Trust had been circulated.

The Administrator stressed that he sought a definite time bracket for the review and plan to consider. After discussion it was decided that a working group from with Trustees should be set up to consider the different aspects and a report should be made to the next meeting.

96.39 MEETINGS/VISITS/LIAISON

The Administrator reported that the number of personal visits conducted by the Benefits Adviser continued on a regular basis. Since Mrs **GRO-A** had started with the Trust she had made 22 home visits, 7 hospital visits, 2 visits to Centres in addition to which 4 members had visited the office. Of the 2 appeals and 4 Tribunal appearances, all had been successful.

96.40 NEWSLETTER 33

An outline draft Newsletter was tabled. It was agreed that the Trustees would be sent a final draft in time for them to make any final comment to the office by 20 September, aiming for distribution before the end of the month.

96.41 ANY OTHER BUSINESS

- a. **Future Meetings (1997).** The provisional date of Tuesday, 9th September was confirmed and additionally, Thursday, 20th November was agreed.
- b. **Mini-Alloc dates.** The following mini-alloc dates were agreed starting at 9.30 a.m. (except as shown):

Friday, 27 September:	Ms Harrington
	Miss Winterton
Thursday, 17 October:	Mr Hodgson
	Mr Pudlo
Thursday, 7 November:	Mr Grinsted
	Mrs Stubbs
Friday, 13 December:	Mrs Cowe
	Mr GRO-A
Friday, 31 January 1997: (11.00 a.m.)	Chairman
	Dr Winter (confirmed subsequent to meeting).

The Chairman thanked the everyone for their time and contribution and then asked the members of staff to leave the room so that M96.42 could be discussed.

96.42 STRATEGIC REVIEW (STAFF IMPLICATIONS) - Trustees only

Staff implications of the strategic review were discussed.

GRO-C

21 November 1996

The Rev Prebendary Alan Tanner
Chairman