

MACFARLANE TRUST

Minutes of a Meeting of the Trustees
Held at Alliance House, 12 Caxton Street, SW1H OQS
On Tuesday 15th September 1998 at 11.00a.m.

Present:

The Reverend Prebendary Alan Tanner, Chairman
C. H. Grinsted, Deputy Chairman
~~Mr K. Bellamy~~
GRO-A
Mr C. Hodgson
Mr T. Hunt
Mrs K. Stubbs

In Attendance

Mrs Ann Hithersay
Mrs Fran Dix
Mrs Jenny Jackson

Apologies

Mr N. Lawson
Dr M. Winter
Miss P. Winterton

98.27 - MINUTES

Minutes of the Meeting held on 3rd June 1998 were approved after the following amendment was made to Minute 98.24: the heading at the top of page 6 was amended to read 'It was Further Resolved'

98.28 - MATTERS ARISING

98.16 The Chairman reported that he had received a response to his letter to Baroness Hayman that had accompanied the Strategic Review Interim Report which had been sent to her as the newly appointed Minister of State for Health at the end of July.

Baroness Hayman had expressed interest in the Trust and its work and had welcomed the Review. However, she had said that the Department had been unable to identify funds available to support the work of the Review in the current year. She therefore suggested that an application be made for Section 64 Project funding for 1999/2000. Baroness Hayman also welcomed the opportunity of a future meeting with Trustees but felt that given the fundamental nature of the Review, a meeting should wait until the Review is complete and it would be possible to discuss the Trust's future, as well as past, work.

98.29 - ADMINISTRATORS REPORT

Staffing Matters

The Administrator reported that staff restructuring was in progress. The Chairman explained that it had been felt necessary to appoint a member of staff with specialist financial and computer skills, and that in order to achieve this it had been necessary to introduce other changes. It was necessary for Trustees to ensure that the Trust's finances were managed properly and to reduce the amount of time spent by the Deputy Chairman in overseeing the financial activities of the Trust.

There had been a good initial response to the advertisement in the Times recruitment section and 6 candidates had been shortlisted for the post of Finance Officer. It was hoped that an appointment could be made in early October.

In being reminded that restructuring required abolition of the role of Office Manager, and the appointment of a full time administrative secretary, the Trustees received an assurance from the Administrator that there would be full compliance with employment law if redundancy was an issue.

98.30 FINANCE

Summaries

The Trustees received and noted summaries as follows:

- a) Summary of grants made as at 31st August 1998
- b) Asset valuation as at 31st August 1998

Review

The Chairman then indicated that notwithstanding the absence of three Trustees the time was opportune to pause and take stock of issues considered to be of importance in contemplating the future management and use of funds entrusted to the Trust and he invited the Deputy Chairman to speak.

The Deputy Chairman began by reminding the Trustees of the decision to produce as at the end of each calendar quarter an Asset valuation using reports from the Investment managers, and from the Trust's bankers, which would remove the uncertainty arising from office calculations required in the past to prepare monthly valuations. He also reminded Trustees that for the first time in its history the Trust had suffered a fall in the value of its investments, due to global trading conditions, and it was right that Trustees should have an interim valuation as at 31st August now tabled. The valuation showed that since the beginning of the financial year asset values had dropped by 8.3%, whereas the FTSE 100 index had fallen in the same period by 11.5% thereby vindicating the decision of the Trust to keep new money provided by the Government at the beginning of the financial year in cash or 'near cash', and there would be no change while markets remained volatile.

The Deputy Chairman then broadened his review by reminding Trustees of (i) the refusal of the Government to make further monies available to those suffering from hepatitis C infection (ii) the extra burden such refusal could place on the funds of the Trust (iii) the reduction in grants already imposed on other charities (iv) the sensitive situation the Trust was about to face in applying for an increase in its Section 64 Grant.

Against this background of financial restraint there were important issues to be faced e.g.

1. The number of applications for single grants was on the increase
2. The value of such grants was increasing.
3. The Strategic Review, although in progress, remained unfunded despite applications to the Department.
4. The Trust already faced a deficit in the Management fund of some £23,000.
5. Average current monthly spend to date remained higher than last year.
6. At the present rate of spend without further funding the Trust fund would be exhausted within five years.
7. If the fund was wholly distributed now, and equally amongst all registrants, each registrant would receive circa £12,000.
8. Some registrants had already received sums approaching that amount by way of advance of regular payments.
9. The increasing tendency for registrants to ask for, and expect, regular payments in advance is diverting the system from its real purpose

In concluding his presentation the Deputy Chairman proposed that some restraint be exercised and that in particular:

- A. There should be a curb on spending whilst the result of the Strategic Review was awaited.
- B. Trustees should revisit the concept and purpose of regular payments.
- C. Meantime the current policy of no advance of regular payments beyond 6 months should be enforced.
- D. Trustees should be more specific about the needs to be met, particularly related to health.
- E. In the consideration of future applications Trustees should be informed on and take into account past benefits received from the Trust.

The Deputy Chairman undertook to commit his presentation to writing for circulation to all trustees, and it was agreed that these important issues must remain open for further discussion.

As a final comment the Chairman reminded the Trustees that Regular Payments had been introduced originally as a fairer way of giving all Registrants similar access to Trust funds. In particular the payments had been raised shortly after the Special Payments had been made so that people could have freedom to use funds according to their own priorities; at that time it had been decided to discontinue a number of types of Single Grants for items such as whitegoods and holidays, at the same time recognising that there might be exceptional circumstances when such payments would be made.

Trustees hoped that the Strategic Review would be followed by a review of Grant Guidelines, and that it would be possible to identify potential new areas for Single Grant funding whilst at the same being clear on areas that would not be supported through this type of grant.

98.31 - ANNUAL REPORT AND ACCOUNTS

The Deputy Chairman introduced the Accounts for the year ended 31st March 1998, pointing out that the Management Fund had been separated from the General Fund and that this treatment highlighted the deficiency of expenditure over income on the Management Fund due to an unavoidable overspend in the year.

Trustees were invited to comment on the Annual Report and Accounts. It was noted that there were two errors in the entry for Trustees: Mrs Stubbs' Christian name had been mis-spelt as had the town shown beside her name. Corrections were noted. It was also pointed out that Miss Winterton should have the letters CBE after her name.

Upon a proposal from the Chair it was agreed that the Report and audited Accounts for the year ended 31st March 1998 be approved and signed.

98.32 - EQUITY SHARE REVIEW

The Equity Share Report was noted. It was pointed out that one equity share was for 58% and it was suggested that Trustees might wish to receive further information on this case. The Administrator said that the case in question was an infected widow living alone and unable to work due to her health. It was unlikely that she would be able to move house as the value of the property after the Trust share had been repaid would be too small to allow her to buy a suitable property.

It was agreed that 98.33 - Applications and Cases would be deferred to the afternoon.

98.34 - VISITS REPORT

The report of visits and contacts made by the Social worker and the Benefits Adviser was noted.

98.35 - JTA FINANCIAL SERVICES LTD – TERMS OF REFERENCE

The Administrator reminded the meeting that JTA financial Services Ltd, (Proprietor – Susan Daniels) was the preferred provider of financial advice to registrants seeking help in financial affairs, and assistance in mortgage applications. It has been customary for the Trust to pay JTA's fees for approved cases of referral, but in recent times it had become clear that JTAs services were being sought and fees being incurred without the knowledge of the Trust. The position had to be regularised and, at the same time, it had to be established beyond doubt that the Trust was not responsible for advice given by JTA Services as an independent company and that no agency or partnership existed between the parties. The Deputy Chairman undertook to prepare documentation for exchange between the parties.

98.36 - RISK REDUCED CONCEPTION

A letter from Dr Winter had been circulated to Trustees pointing out changes in treatment of couples where one partner was HIV positive. A number of Centres in UK were now providing treatment that made it possible to use the infected partner's sperm with significantly reduced risk of the infection being passed on to the mother or child. Dr Winter's letter suggested that it might be necessary for Trustees to review current policy with regard to grant giving for risk reduced conception.

The Chairman reported that he had had a conversation with Dr Christine Lee, Centre Director at the Royal Free Hospital, and understood that the Centre Directors Group were proposing to prepare a discussion paper on the matter.

Trustees discussed issues raised and felt that legal advice would be necessary on whether or not Trust funds should continue to be used 'to create more Trust dependants'. It was suggested that there was a fundamental right to have a family and that it was therefore a choice that the Trust could enable Registrants to make.

It was agreed that the Chairman would report Trustees discussion to Dr Lee; it was his understanding that the Centre Directors Group was to set up a Working Party to consider the matter of new treatments. The Chairman would also raise the issue with the Trust's Solicitors at a meeting to take place shortly. He would report back to Trustees in November.

98.37 - STRATEGIC REVIEW - UPDATE REPORT

The Strategic Review Update Report was noted.

A request for funding for the forthcoming Women's Weekend in October was discussed. It was pointed out that the weekend would provide useful information from 'positive women' that could be used in the Review Report. The initial costing was based on a group of 25 people including staff and facilitators; however it was likely that the group would be smaller than this. After discussion it was agreed that a grant of up to £400 per person be made, not to exceed £8000.

It was proposed that a Conferences Budget should be put forward for next year. Mr Tim Hunt and Dr Mark Winter, assisted by staff, should prepare such a budget and bring it to the November Trustees Meeting.

A letter from the Chief Executive of the Haemophilia Society requesting 'recognition' for the considerable time commitment of the Society's HIV Worker to the Review was considered. Trustees felt strongly that the Worker's involvement in the review had given him a unique opportunity to find out more about his client group through the Review process. There should be recognition of The Haemophilia Society's contribution to the Review, but this should not be financial; rather an emphasis of partnership in pursuance of our common goal.

98.38 - ANY OTHER BUSINESS

1. ALLOCATIONS COMMITTEE

The Chairman said that there were concerns that the present practice of telephone 'Miniallocs' were not working as well now. He had observed that decisions of precedent and large advances of Regpay were creeping in. It was acknowledged that there were a greater number of more complex cases coming before Trustees now and it was necessary to re-introduce consistency to grant giving. The Chairman proposed the introduction of 'round table' Allocations Committee Meetings to be chaired by himself. The proposal was discussed by Trustees present, who agreed in principal that 'round table' meetings were a good idea. A number of different formats for the proposed meetings were discussed. It was agreed that for a trial period of three months the Chairman would be the only 'consistent person' with a rotating group of 3 other Trustees also participating. It was agreed that meetings should take place on 2nd October; 16th October; 6th November and at the Trustees Meeting on 24th November.

2. DRAFT NEWSLETTER

Trustees considered the Draft Newsletter and suggested that Jenny's column might include a note about 'benefit abatement'.

Concern was expressed about the proposed Readers Column; it was felt that by acting as an agent to enable communication between people whose background was unknown to us, there could be risks to vulnerable Registrants, particularly those who were still children and subject to the guidance of the Children Act 1989. It was agreed that an Agenda item be included for the next meeting about assisting Registrants to communicate with each other without incurring risk.

98.33 - APPLICATIONS AND CASES

A total of 11 cases were considered by Trustees. Grants amounting to £ 3,685 were awarded.

Two issues were noted for a future review of grant giving Guidelines:

- (i) 'therapeutic use of time' was an increasingly frequent reason for grant applications and needed further consideration when results of the Strategic Review were known.
- (ii) The case of a 'transport grant' for those unable or unwilling to use a car might be considered when guidelines were reviewed.

There was also a need to look again at information provided to Registrants over the years on what types of expenditure were intended to be covered by Regular Payments and when the issue of Regular Payments had last been reviewed by the Trust. The Administrator was asked to report on communications to Registrants on this subject at the next Trustees Meeting.

There being no further business, the Meeting closed at 4.35pm.

Ann Hithersay
Administrator

4th November 1998