

MACFARLANE TRUST

Minutes of a Meeting of Trustees held at Alliance House

12 Caxton Street on Monday 12th July
1999

PRESENT:

The Reverend Prebendary Alan Tanner, Chairman Mr CH Grinsted,
Deputy Chairman Mr [GRO-A] Trustee Mr C
Hodgson, Mr T Hunt Mrs P Latimer Mr P Stevens
Mrs K Stubbs Dr M Winter Miss P Winterton “

In Attendance: Mrs A Hithersay, Chief
Executive

Ms F Dix, Social Worker Mrs [GRO-A]
[GRO-A] Benefits Adviser

Apologies:

Mr N Lawson

The Chairman welcomed back Fran Dix following the [GRO-A] He said she had been much in Trustees' thoughts over recent weeks.

The Chairman then extended a formal welcome to Mrs Latimer and Mr Stevens, who were joining the Trustee Board. Mrs Latimer was a Social Worker at the Haemophilia Centre at Newcastle Royal Infirmary, and would bring very considerable experience gained to the role of Trustee; Mr Stevens had been one of the original Trustees, and was rejoining the Board at a time when his business experience would be of great value to the Trust.

99.24 Minutes of the Meeting held on 28th April 1999

99.18: The Board agreed to insert the word 'now' in the following phrase:

"the granting of long-term loans of the type now proposed... and to insert at the end of the Minute, the following phrase:

'The Chairman has still to arrange a meeting with Paisner and Co.'

following the above amendments, the Minutes were approved as a true record.

99.25 Matters Arising from the Minutes

99.03 Section 64 Grant The Chief Executive reported that despite letters and telephone calls, no Section 64 funding had been received for the Macfarlane Trust since the beginning of the current financial year. This meant that to date all 'management costs' had been borne by the Trust Fund.

The Chairman reported that the issue had been raised at a meeting with Civil Servants that had taken place prior to the meeting with Lady Hayman to discuss the Strategic Review Report in June. Officers had explained that immediately prior to the last Election, the outgoing Conservative Government had introduced staff cuts of 25%, followed by cuts of 22%. The situation had not become easier, and continued short staffing meant that delays were occurring in a number of areas. In the light of this information, the Chairman had felt unable to raise the issue of slow responses from The Department, when he met Lady Hayman shortly afterwards.

Trustees felt that the matter should be vigorously pursued, and the Chairman agreed to write to Lady Hayman in response to her recent letter, and refer to concern at the continuing delay in payments being made to the Trust,

The Minutes were adopted.

99.26 Chief Executives Report and Statistics to 30th June 1999

Finance Officer Actions to recruit a new Finance Officer were noted. The Chairman would be meeting a potential candidate for the post later in the day. It was hoped that the position would be filled by the beginning of August.

(ii)

Special Payments Trusts The Chairman confirmed that Trusteeship of the Special Payments Trusts was completely

independent of being a Trustee of the Macfarlane Trust. He would **review the matter very soon.**

It was also noted that the Department of Health had been a bit slack' **in renewing** and appointing Trustees to Macfarlane and Eileen trust, and to **the** Special Payments Trusts. This matter should also be pursued with vigour.

99.27 Financial Reports April - June 1999

Quarterly Investment Summary and Asset Valuation The Report was noted.

(ii)

Monthly Grant Summary Questions were raised about the early payment of Winter Payments', normally paid to registrants in November each year. The Chief Executive said that **a** few people asked for their payments early, occasionally **as** early as the Summer, so that they could **make**

special purchases of fuel at a reduced rate. **1** Trustees asked that a check be made on this practice, to see how **£** widespread it was. The request was noted.

(iii)

Quarterly Management Summary It was noted that General Costs were significantly higher than **budgeted** for the Quarter. The Chief Executive said that some of the **additional costs** were due to budget **phasing**, but **confirmed** that she would look **into** the **matter** and **report back to Trustees** at the **next meeting**.

(iv)

Computer Systems Replacement Costs The Report was noted. It was expected that the full cost of the exercise **would** amount to approximately £64,000 over a three year period.

The Chairman said that Lady Hayman had indicated that these costs would be met from Government funds, but had asked that the trust did not specifically link expenditure incurred with 'Year 2000 Compliance'.

Proposals for Savings. – Management Costs The Chairman

proposed that the paper submitted by the Chief Executive should be studied by a group comprising of The Chairman, the Hon Treasurer, the Chief Executive and Mr Stevens. He suggested that more work was required before the issues raised in the paper could be fully considered by Trustees.

The Chief Executive said she had been asked to look for management cost savings, and as one of the areas proposed would require a Trustee decision by the date of the next meeting in October, she had felt it essential to circulate the paper for the July meeting. The Chairman had been aware of the areas identified in the paper before the meeting.

It was agreed that issues raised in the paper would now be discussed as proposed. A report would be made to Trustees at the next meeting.

99.28 Draft Annual Report and Accounts

The Deputy Chairman, in introducing the draft Annual Report and Accounts for the year ended 31 March 1999, invited Trustees to note items worthy of special attention including, in particular, investment performance, expenditure on computer systems, the accumulating deficit on the Management Fund and the impact on management income and expenditure of the failure of the Government to honour during the financial year, commitments to fund special projects. The Deputy Chairman then invited comments, and having responded he commended the report and accounts for approval. Upon a proposal from the Chair, it was agreed that the Report and audited Accounts for the year ended 31st March 1999 be approved and signed.

The Deputy chairman was thanked for his considerable commitment of time in ensuring their accuracy and appropriate presentation.

99.29 Report of a Meeting with Baroness Hayman, Minister of State for Health

The Chairman reported that the meeting with Lady Hayman had taken place in mid-June. It had been an excellent meeting, with each Trust representative presenting their piece, and Lady Hayman carefully listening to all that was said, showing real interest in each presentation.

The atmosphere had been good, and the team came away well satisfied with what had taken place. A subsequent letter from Lady Hayman had been circulated to all Trustees, and a further meeting with Civil Servants was planned for the Autumn.

99.30 Loan Agreements

The issue of the Trust making loans to registrants was raised with Civil Servants at the meeting prior to the Trust's presentation to Lady Hayman. No objection had been raised. The Chairman would therefore meet with Paisner & Co, as agreed at the April Meeting, to discuss the matter of a **Variation to the Trust Deed**.

99.31 Charity Commission Consultation - User Trusteeship

The Charity Commission was reviewing its Guidance to Charities on the **involvement of users in the management of charities**. A **consultation** document had been circulated to a **wide range of charities and trusts for** comment. A response was due to be made to the Commission by 21% July. Revised Guidance would be published in October. The particular aspect of the proposed guidance that necessitated wide consultation was that of 'User Trustees' which meant '**beneficiaries of a charity**' becoming trustees. **Issues** relating to potential "conflicts of interest" were of particular importance to the Commission..

Lively discussion took place in which the following issues were raised:

"Whilst the Haemophilia society and other similar charities had Trustee Boards where users frequently formed the majority of Trustees, because of the nature of these charities there were no major 'conflicts of interest', as ti was no distribution of funds from which individual Trustees might benefit.'

The main function of Macfarlane Trust was to distribute funds made available by Government to those with haemophilia and HIV. It was felt that with 'user trustees' on the Board, there could be potential 'conflicts of interest on many issue.

Dr Winter thought that it would be difficult not to be inhibited in provision of medical advice to the Board if 'user trustees' were present at meetings.

It was recalled that when the Trust was formed in 1988, user **trustees were** included on the Board. However, following advice from the Charity Commission, they stood down and were replaced. There now appeared to an

'opening up on the part of the Commission. It was important to wait and see what the revised Guidance recommended **for** charities such as ours.

The Chief Executive **confirmed** that she **would** be attending a Consultation Meeting at the Charity Commission later in the week. She would ask specific questions related to grant making charities and potential conflicts of interest, and hoped that this issue **would** be referred to **more** directly in the guidance to be published in the Autumn.

99.32 Strategic Review

Follow-Up

(i)

Partnership Sub-group Report Mr Tim Hunt reported on the initial meeting of the Group and said that its remit was to carry out a 'multi-agency response to **those areas** of the Strategic Review that called for action by more than one agency.

The make up of the group at the first meeting **included** representatives of The Trust, The Haemophilia Society and Birchgrove Group.

Actions arising from the **meeting** included **plans for** the Manchester Feedback meeting, which had taken place **in** June, and a project to develop more **information on Treatment and Care Choices**, that was being carried by the Haemophilia Society.

The Manchester Feedback Meeting had resulted in two **interested volunteers** wishing to join the Partnership Group who were not members of Birchgrove Group. At the next meeting of the Partnership Group September, it would be important to decide on the **number of user representatives** and how they **might** become members of the Group. Fair **representation was** essential.

Mr Hunt had prepared a budget for the Group of £1,400 a

year, to cover travel costs, hire of a room and refreshments.

Trustees felt that the Partnership Group represented a very important development for the Trust. It presented an ideal forum to feed to Trustees what registrants wanted and what they feel about the Trust. The Group could be regarded as a formal interface between the Trust and the registrants.

It was felt that the Partnership Group should contain at least 2 Macfarlane Trustees. Mr Hunt had agreed to Chair the first two meetings, but due to the necessity for him to stand down as a Trustee at the October Board Meeting, it was important for a successor to be appointed. It was hoped that Mrs Pat Latimer might be prepared to take on Chairing this important Group.

A Budget of £1,400 was approved. Funding should come from the Management Budget.

Payments Review Group

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The Chairman reported that the Payments Review Group had met twice since April. A number of specific proposals had been discussed relating to Regular and Single Payments to registrants. The Chairman regarded the Payments Review as a major area of decision-making for the Trust, which could not be adequately dealt with in the confines of a routine Trustee Board Meeting.

After discussion, it was agreed that the Payments Review should take the place of Cases at the October Board Meeting. Papers would be circulated prior to the meeting. It would be important that everyone attended the meeting, if at all possible.

Conferences Working Group

It was pointed out that since almost all members of this Group were also members of the Partnership Group, it would be more efficient to combine the two Groups.

The Conferences Working Group had not met since the last Board Meeting. However, the Brighton Young People's Weekend had taken place in June, and been a great success.

Plans for a Conference for Positive Haemophiliacs were well advanced. The Conference would take place in early September

The Partners Weekend would take place in Spring 2000.

99.33 Proposed Research into needs of Bereaved Partners and Families

Mr Chris Hodgson reported that recent events had suggested that there was a great deal of unresolved grief, bitterness and anger amongst those who had been bereaved over the years since the Trust was set up.

It was necessary to conduct research to determine the needs of bereaved families, and see how best they could be helped. Mr Hodgson had met with the Director of a Hospice Team, and the Trust Chief Executive and Social Worker to consider how best to carry forward such research. The Group had used a paper on bereavement prepared by Mrs Pat Latimer as part of her Masters Degree, and had drafted a letter to be sent to families that had been bereaved since the Trust had been set up.

Mrs Latimer said that the Centre in Newcastle had continued to support families for about two years after a death. However she was conscious that many families needed ongoing support to help them come to terms with what had happened.

In the discussion that followed it was noted that HIV bereavement was a very complex issue; it was important to enable people to talk to someone who had been in their position.

Bereavement services were very patchy round the country. Where Centres no

longer employed a Haemophilia HIV social worker, needs may not be met adequately at all.

It was agreed that a letter must make it clear to those who had been bereaved that, at this stage, the Trust was simply carrying out research arising out of the Strategic Review.

It was important to limit expectations, and cost any possible outcomes. It might be possible to bring together a group of widows/partners as Strategic Review follow-up action.

The proposed letter should be reviewed in the light of comments made today, **Mrs Latimer expressed an interest** in assisting development of the project. **It was agreed** that a further meeting should be held to **advance the research**.

99.34 Applications and Cases

Ten Cases were considered. Trustees awarded a total of £9,683 to 8 people. A further case was referred to the next Allocations Committee Meeting at the end of the month.

99.35 Reports on visits Made

The Report from the Benefits Adviser was noted.

99.36 Cases Update

The Chief Executive said that this **was a new Report, commissioned** at the request of Trustees. The Report would only include **significant or complex** cases, where the Trust would benefit from further **information on decisions taken**.

This first Report included cases heard earlier in the year, where further action **could be required on the part of the Trust**.

99.37 To Consider an Appeal related to an Equity Share Loan.

This item was withdrawn due to lack of information.
It will be referred to the Chairman, and then on to a subsequent Trustees Meeting

99.38 To Consider a 1st Stage Report on Staff Terms and Conditions of Service

It was reported that, following the last meeting of the Trustee Board in April, it had been agreed that the Appraisal Group would commission an independent Consultant to review current Staff Terms and Conditions of Service. Recommendations would include how these might be updated and brought into line with current employment legislation, and would also include proposals related to salary scales, relativities and evaluation procedures.

Mr Tony Miller, of Miller, Brand Associates, had been referred to the Trust by the Institute of Personnel Development.

Before commencing the assignment, Mr Miller had met the Chairman and Deputy Chairman to confirm his brief with them. He had also met some of the staff team, and had submitted a draft Report to the Appraisal Group. The First Stage Report had been circulated to Trustees for information. The **Chairman had approved continuation** of the Project to Stage Two. It was **anticipated that the assignment would be complete by early September, and recommendations** would be ready for endorsement by Trustees at the October Board meeting, or earlier, if required.

The First Stage Report was noted.

The Chairman pointed out that the Appraisal Group had lost two of its members, and that these spaces needed to be filled so that the **important work of** the Group could continue.

99.39 Trustee Succession

The Chairman wished to place on record appreciation of the sterling service given by Mrs Stubbs in her role as Trustee. In particular, he noted her diligence in response to cases, calling upon her specialist Social Work expertise to guide others in complex matters. Kathy had also been invaluable in assisting in the selection of Fran Dix, the Trust's Social Worker, and had provided the added benefit to the Trust of having two Social Work Trustees to call upon since the appointment of Mr Hunt in 1997.

Trustees wished Mrs Stubbs the best of luck in her new role in GRO-C

The Chairman also paid special tribute to Mr Clifford Grinsted, a Founder Trustee and Deputy Chairman. Mr Grinsted was among the first to be appointed when the Trust was established and he brought a wealth of experience as Company Secretary of a major international company as well as familiarity with the ways of the City and its financial institutions. His wise counsel in our financial affairs had been invaluable. The Chairman had also
mired his integrity, his industry and his enthusiasm in working for the Trust.

The Chairman hoped that Clifford Grinsted, as Deputy Chairman, had found as much satisfaction in the role as he had in the great support given him by Clifford over the years. He would be a hard act to follow.

The Chairman drew attention to the fact that the appointment of Mr Grinsted came to an end today. However, as Mr Lawson, the Treasurer, would be preoccupied with his business commitments until the end of the year, it was proposed that Mr Grinsted's services should be retained as a Consultant. The Chairman would write to Mr Grinsted to set down the terms of his continuing relationship with the Trustees, a copy of this letter to be inserted in the Minute Book.

99.40 Date and place of next
Meeting

The next meeting of the Trustee Board would take place at Alliance House, 12 Caxton Street, on Tuesday 19th October 1999.

There being no further business, the meeting concluded at 4.15pm.