

## MACFARLANE TRUST

**Minutes of a Meeting held at Alliance House, 12 Caxton Street, SW1  
On Tuesday 19<sup>th</sup> October 1999.**

**PRESENT:** The Reverend Prebendary Alan Tanner OBE, Chairman  
Mr C Hodgson Trustee  
Mr T Hunt Trustee  
Mrs P Latimer Trustee  
Mr N Lawson Trustee  
Mr P Stevens Trustee  
Dr M Winter Trustee  
Miss P Winterton Trustee

**In Attendance:** Mrs A Hithersay Chief Executive  
M/s F Dix Social Worker  
Mrs GRO-A Benefits Adviser  
Mr R Shepherd Finance Officer

**Apologies:** Mr GRO-A Trustee

The Chairman explained that Mr Clifford Grinsted had been invited to attend part of the meeting, as Honorary Consultant to the Trust, in order to present papers he had prepared. However due to a rail accident on the line from Eastbourne, he was unable to attend the meeting today.

### **99.41 Minutes of the Meeting held on 12<sup>th</sup> July 1999**

The Minutes of the Meeting held on 12<sup>th</sup> July 1999 were approved.

### **99.42 Matters Arising from the Minutes**

- (i) Winter Payment Advances.  
The Finance Officer reported that 3 advance payments had been made to date.
- (ii) Management Costs: April to June 1999  
The Chief Executive said that the Report presented to the July meeting of the Board had contained inaccuracies. It had been pointed out to the Board at the previous meeting that some figures shown were too high. The previous Report had been prepared by the Temporary Finance Officer, following modifications to the accounting system made by the previous Finance Officer. It was unreliable, and should be destroyed. The Report presented today, for the half-year to 30<sup>th</sup> September 1999, had been prepared by the new Finance Officer, Rodney Shepherd. Much work had been done to correct previous inaccuracies. It was therefore believed that the Half-year Report represented a true picture of Management Costs to date.

(iii) 99.03 Section 64 Grant Update

The Chief Executive reported that, as yet, no formal confirmation of the Section 64 Core Grant for the three- year period 1999/2000 to 2001/2002, had been received from The Department of Health. In September the Trust had received a payment of £95,000, which was stated to be an 'interim payment' for the first two quarters of 1999/2000, based on the previous year's grant. The Trust had also received the first stage payment of the Project Grant of £23,000. However, no funding had been received for replacement of outdated computer equipment.

The Chairman reported that he and other Trustees had met civil servants the previous week and reminded them that in June 1999, Lady Hayman had assured him that funding would be found to cover the cost of outdated equipment. Civil servants had said that 'as yet no natural source of funds to cover these costs had been identified'. They had then suggested that if the Trust was to receive the next capital top-up payment early, the interest accruing between the receipt of the payment and the beginning of the next financial year, might be off-set against the expenditure on outdated computer equipment.

The Chairman reminded Trustees of the original assurance from Government that all administrative costs of the Trust would be funded separately from the Trust Fund. The suggestion made to use interest from an early top-up of the Trust Fund to set against the overspend on capital equipment, could be regarded as significant 'blurring' of the original distinction between the funds.

In the ensuing discussion, Trustees expressed outrage at the poor responses received from The Department. They were reluctant to accept the proposed 'solution' to meet the cost of replacement of outdated computer equipment. The Honorary Treasurer pointed out that even if the top-up payment was received by 1<sup>st</sup> November 1999, at current interest rates, it was unlikely to be sufficient to meet the full cost of equipment replacement.

The Chief Executive was requested to write to The Department in the strongest possible terms expressing the Trustees' outrage and asking for:

- written confirmation of Section 64 core Grant Funding for the three-year period;
- payment of overdue Section 64 monies;
- payment of, or an indication of the date of likely receipt of , the next capital 'top-up' payment.

(iv) 99.26 Special Payments Trusts

The Chairman said that there were vacancies for new Trustees for the Macfarlane Special Payments Trusts I & II. He hoped that it would be possible to invite the new Department of Health appointed Trustee to fill one of the vacancies, when that person had been identified.

Meanwhile he would discuss the matter with the Honorary Treasurer and the Deputy Chairman.

(v) 99.33 Bereavement Project

Mr Hodgson reported that a Section 64 Project Grant had been applied for, to cover the cost of the Project over a three- year period. A response was expected from the Department early in the New Year. The Project Group, which included Mrs Latimer, the Chief Executive, the Social Worker and a very experienced bereavement counsellor known to Mr Hodgson, had met a number of times. A first letter had been sent to all those who had been bereaved between January 1995 and July 1999. Eleven people had responded. A further letter had gone to those families bereaved between the Trust set up in 1988 and the end of 1994. To date approximately 20 replies had been received. Those responding had identified that they would have liked to:

- a. have received one to one counselling following bereavement
- b. have met others who had been similarly bereaved
- c. have more contact/help from the Trust

The Group had identified two issues:

How to respond to those who had been bereaved in the past, and  
How to respond more effectively to those bereaved in the future.

For those bereaved in the past, the Group proposed that initially two 'pilot support groups' be established in Hampshire and the Midlands. These groups should be small, and supported by an experienced facilitator. If the need for one-to-one counselling became apparent for any individual or family, this should be addressed, using appropriate local facilities where practical.

If Project funding became available in the Spring, this would be used in line with the proposals submitted to the Department, which included setting up support groups where needed.

For those newly bereaved, or who would be bereaved in the future, the Group proposed that the present response from the Trust be expanded to include a second letter to families 3 -4 weeks after the death. The letter would be a friendly follow-up from the Trust, and would offer a visit from someone at the Trust, if required. If no response to this letter was received, a telephone call would be made approximately two weeks after the letter. If requested, the visit could be made to the bereaved family by a Trustee or member of Trust staff. It would be an informal and supportive visit, not a professional assessment of needs.

Trustees took note of Mr Hodgson's Report and asked him to report further to the next meeting of Trustees in January. Meanwhile approval was given to meet costs related to the two pilot support groups proposed.

#### **99.43 Chief Executive's Report and Statistics to 30<sup>th</sup> September 1999**

The Chief Executive's Report was noted. It was agreed that the Treasurer would respond to the issue raised concerning a temporary increase in hours of employment for the Finance Officer.

It was pointed out that the Statistics Report had not included the 'deaths per 1000' for 1998. This figure should be included in the next Report.

#### **99.44 Staff Terms and Conditions of Service**

Mr Tony Miller of Miller Brand & Co presented his second stage Report on Staff Terms and Conditions of Service. He explained that the Staff Handbook, which accompanied the Report, and would become part of the employee's Terms and Conditions of Service was still at draft stage. However, the Handbook would be based on the old NJC Terms and conditions, as shown in the 'purple' and 'green' books produced by the Employers Organisation - previously known as The National Joint Council for Local Authorities.

Two Trust staff had contracts of employment that directly linked their pay and conditions of service to the old NJC. It had been decided that the proposed new scheme would reflect these links, whilst employees would no longer be contractually linked to the system. This was possible because the 'green' book, produced by the Employers Organisation in 1997, made it clear that 'local agreements' would be used in future to determine salary grades and specific terms of employment.

Mr Miller proposed that staff salaries should remain linked to the Employers Organisation spine points, but that a Macfarlane Trust grading system, supported by an evaluation system, should take the place of the old NJC system. Mr Miller's Report had included revised job descriptions for all staff, together with an evaluation scheme and proposed grading structure for staff. He had evaluated all staff using the new system, and had included suggested new grades for staff within the Report. Mr Miller acknowledged that time spent with staff had been short, and said that job evaluation was largely a matter of opinion. He was aware that there might be a need to adjust the proposed grades.

The Chairman welcomed the very positive and objective Report and said that the Trust had sought an independent view in order to settle uncertainties about staffing and remuneration. The Appraisal process would be used to revise any anomalies that might be contained in the Report, which he commended to Trustees for approval.

The Chairman said that he had invited Mr Miller to become involved in the appraisal of the Chief Executive's role, following the somewhat unsatisfactory process entered into at the beginning of the year. Mr Miller would now be assisting in this process with the agreement of the Chief Executive.

Trustees approved the Report and welcomed Mr Miller's involvement in the appraisal of the Chief Executive.

#### **99.45 Financial Reports to 30<sup>th</sup> September 1999**

- (i) Quarterly Investment Summaries and Asset Valuation  
The Reports were noted.
- (ii) Monthly Grant Summary  
The Grant Summary was noted.
- (iii) Grants Analysis - 2<sup>nd</sup> Quarter 1999/2000  
The Grants Analysis was noted.
- (iv) Quarterly Management Costs Summary  
The Management Costs Summary for the Half-year to 30<sup>th</sup> September 1999 was noted.

#### **99.46 Alliance House - To Consider Possible Relocation of the Office**

Papers had been prepared by Mr Grinsted, as Honorary Consultant to the Trust, with the Chief Executive. These were considered by Trustees.

The Trust lease at Alliance House would expire in 2003. There was a review, with a break clause at 24<sup>th</sup> June 2000. If the break clause was to be implemented, it was necessary to give the landlord at least 6 months prior notice. As the rent was likely to be increased in line with that of other tenants in the building, the Chief Executive had identified another possible property suitable to accommodate the Trust's main office.

Apart from possible financial advantages of a move, it would be useful for the Trust to have access to parking suitable for people with disabilities, and to have more space for storage of archives and equipment. These would be available at the alternative property.

The Chief Executive reported that since the papers had been circulated to Trustees, she had had a meeting with representatives of UKTA, the landlords. It had been suggested that a rental of £23 per square foot would be acceptable to UKTA, and that a rental of £22 per square foot might be considered by the Board of UKTA.

Trustees felt that once costs of relocation had been taken into consideration, it was unlikely that a move could be justified purely on grounds of financial advantage. However, if in the interests of efficiency and staff comfort the move would improve working conditions, then within an agreed budget, Trustees would approve a decision to relocate the Trust office.

It was agreed that a surveyor should be asked to prepare a report in line with requirements of Charity Law. The Chief Executive should also gain estimates for the cost of removal to alternative premises, and partitioning in the

proposed new offices. This being done, the decision whether or not to move would be delegated to the Chairman together with the Honorary Treasurer and the Deputy Chairman.

The Chief Executive was requested to arrange for a survey of both offices to be carried out and on the basis of this, to seek a further meeting with representatives or UKTA to negotiate a firm rental for the remainder of the lease. This would enable Honorary officers to take an informed decision on the best option for the Trust.

#### **99.47 Investment Policy**

A paper had been prepared by Mr Grinsted which concluded that, for the present time, the Trust should continue to use Principal Investment Management and COIF to manage Trust funds.

The Honorary Treasurer said that he had sought independent advice on the paper from his accountants, who had agreed with the recommendations contained in the Paper. He commended the Paper to Trustees for approval.

Trustees received the Paper and expressed appreciation to Mr Grinsted for the very considerable work undertaken to produce the Report.

Trustees agreed that the accounting treatment of management fees paid to Principal should be dealt with by the Honorary Treasurer and the Deputy Chairman at a future date.

#### **99.48 Appointment of a new Chairman and Honorary Treasurer**

The Chairman said that he would be standing down at the end of March 2000. He proposed that Mr Peter Stevens be elected to succeed him. If the proposal was approved, the Chairman suggested that Mr Stevens be appointed Deputy Chairman with immediate effect, and that he start sharing full duties as Chairman from the beginning of January 2000.

There being no other nominations for the role of Chairman, Mr Peter Stevens was elected unanimously. Mr Stevens accepted the role of Deputy Chairman with immediate effect.

The Chairman then proposed that Mr Nick Lawson be formerly elected to the post of Honorary Treasurer, with immediate effect. Mr Lawson agreed to accept the nomination, and there being no other candidates for the role, he was elected unanimously.

#### **99.49 To Approve a Variation to the Trust Deed to enable Loans to be made.**

The Chairman said that the proposed Variation to the Trust Deed to enable the Trust to make loans to registrants had initially been raised at the April meeting of the Board. At that time it had been agreed that he would raise the matter

with representatives of Government, and if there were no objections, he would discuss the proposed wording of the Deed again with Paisner & Co.

The Chairman had referred to the proposed Variation to the Deed at a meeting with civil servants in June, and again in October 1999. No objections had been raised. The Chairman had met with Paisner & Co, and was now confident the Deed would provide powers to enable the Trust to make loans to registrants of the Trust if it were so minded. He commended the Deed of Variation to the Board for approval. Approval of the Variation was proposed by Mr Nick Lawson and seconded by Mr Peter Stevens. Mrs Latimer abstained because she did not feel she had been a Trustee long enough to understand the full implications of the proposed Variation. The Variation was approved by a majority of Trustees present.

#### **99.50 Strategic Review Follow-up**

- (i) **Partnership Group Report**  
Mrs Latimer reported that the meeting of the Partnership Group, held on 23<sup>rd</sup> September, had been exceptionally difficult to Chair. She was unfamiliar with her role as a Trustee, and those registrants present had been very angry.

The Group had discussed issues related to user involvement in the Trust's decision-making process, and confirmed that eventually they would like to see 'user Trustees', if this became possible as a result of changed guidance from the Charity Commission.

The Group had also asked about Macfarlane Trust representation on the Haemophilia Alliance, and membership of the World Federation. It was clear that those registrants present at the Partnership Group meeting did not feel that the Haemophilia Society adequately represented their very special needs to either of these organisations.

A copy of a letter from a Trust registrant to the Haemophilia Society Board, seeking greater registrant involvement in selection of Haemophilia Society nominated Macfarlane Trustees, had also been circulated at the meeting.

Mrs Latimer said that she felt there was a lot of frustration amongst users who felt powerless in the system. She believed it would be useful to involve registrants in familiarisation and training for Macfarlane Trustees. It would be possible for a small group of registrants to develop a presentation to enable people to become more informed about 'what it was like living with HIV'.

Trustees considered points raised and made the following observations:

As the Co-Chairmen of the Haemophilia Alliance were both Macfarlane Trustees, it would be possible for them to look into whether or not it would be appropriate to include the Macfarlane Trust

in membership of the Haemophilia Alliance. The Alliance had been set up as a 'partnership between providers of care...' It was agreed that Dr Winter would liaise with the Chief Executive on this matter.

As Chairman of the Haemophilia Society, Mr Hodgson reported that the Haemophilia Society Board would be considering Trustee representation at their next Board Meeting. Trustees of the Haemophilia Society were sympathetic to the issues raised and hope to identify ways to respond to them effectively.

Mrs Latimer reported that the Partnership Group had also recommended that two further 'Feedback Meetings' along the lines of those held in Manchester and London, be held in Cardiff and Glasgow. Mrs Latimer understood that funding was still available from the Project Grant.

The Trustee Board approved funding for a further two Feedback meetings from the Project Grant made available to the Trust by the Department of Health for the Strategic Review.

#### **99.51 Payments Review Group Recommendations.**

Trustees considered recommendations proposed by the Payments Review Group.

After considerable discussion, it was agreed that an 11% increase to Regular Payments accurately reflected the inflationary increase in cost of living that had taken place since 1996. It was agreed that, as a first step, an 11% increase to all Regular Payments should be made with effect from January 2000.

A number of Trustees felt strongly that the Strategic Review had identified new needs to be met by additional funding. A cost of living increase would not meet these new needs. One Trustee felt that if the Trust failed to respond to the needs identified in the Review, it would lead to a 'calamitous decomposition of relationships between the Trust and the registrants'.

A provisional 'capital flow' projection that had been prepared identified the serious depletion in capital that would take place if all of the recommendations included in the paper prepared by the Payments Review Group were to be implemented. The Chairman and Trustees were concerned that if Government failed to deliver further 'top-up' payments to the Trust after this year, the remaining capital would be quickly reduced below the 'safety net' level of £4 million established in 1997.

After further discussion, it was agreed that needs identified by the Strategic Review should be more precisely identified. The Payments Review Group should meet again to see what changes might be made to the Payments System to reflect a tangible response to these needs. The Group would need to review the range and level of Single Grants, as well as looking again at Regular and



Winter Payments. Revised cash flow forecasts should be prepared, showing the effects of differing levels of payment increases.

The Trust would prepare financial projections based on increases arising from the next meeting of the Payments Review Group. A meeting with the new Minister of State for Health would be sought early in the New Year. Meanwhile registrants should be advised of the proposed cost of living increase as soon as possible. There would be no increase to the Winter Payment at the present time.

#### **99.52 Reports on Visits Made: Social Worker and Benefits Adviser**

The Report was noted.

#### **99.53 Case 1823 - Equity Share Appeal**

Case 1823 related to an Equity Share agreement entered into between the Trust and Mr and Mrs [GRO-A] in 1990. Mr [GRO-A] had subsequently died, and after remaining in the house for almost 7 years, Mrs [GRO-A] who was herself infected with HIV, wished to move from the isolated rural location to take up an offer of employment in London. It would not be possible for Mrs [GRO-A] to afford an appropriate home in London unless Trustees agreed to re-invest capital arising from the Trust's Equity Share in the property, in her new property in addition to her own share arising from the sale of her home. There were also issues related to the basis of the original valuation of the couple's property in 1990 and the Trust's proportion of the investment, as well as improvements made to the house, over and above normal maintenance, that had been paid for by Mrs [GRO-A] since the Agreement was entered into.

In the ensuing discussion, it was revealed that Mrs [GRO-A] had tried to move house on a number of occasions since her husband had died, but due to subsequent difficulties, the move had never taken place. Trustees agreed that Mrs [GRO-A] should be enabled to move to London and that an allowance should be made for her capital investment in the property over the years.

It was agreed that Mrs [GRO-A] be advised that:

- (i) The Trust was willing to allow Mrs [GRO-A] to sell the house, and use the proceeds to purchase a home in London
- (ii) The original Equity Share arrangement would be terminated in accordance with the Agreement made.
- (iii) The sale price realised would be discounted by £20,000 to allow for improvements made to the property at Mrs [GRO-A]'s expense.
- (iv) The Trust's share of 58% of the remaining equity, would be transferred under a fresh Equity Share Agreement on the new property.

#### **99.54 Meeting Dates for 2000**

Trustees considered proposed dates for the year.

After discussion it was agreed that the next meeting of the Trust would take place on Monday 17<sup>th</sup> January 2000. A revised Meetings Schedule would be submitted and further meetings for the year would be confirmed on that date.

There being no further Business, the meeting closed at 4.20pm

NB: the Date for the first meeting in 2000 was subsequently changed to 1<sup>st</sup> February 2000. Further dates will be agreed at that meeting.