

MACFARLANE TRUST

Minutes of a meeting held on Tuesday 1st February 2000
At Alliance House, 12 Caxton Street, London SW1 OQS

PRESENT: Mr Peter Stevens	Deputy Chairman (in the Chair)
Mr GRO-A	Trustee
Mr Chris Hodgson	Trustee
Mrs Pat Latimer	Trustee
Mr Nicholas Lawson	Hon. Treasurer
Dr Mark Winter	Trustee
Miss Patricia Winterton	Trustee

In Attendance: Mrs Ann Hithersay	Chief Executive
Mr Rodney Shepherd	Finance Officer

Apologies: The Reverend Prebendary Alan Tanner OBE, Chairman

The Deputy Chairman explained that The Chairman's wife was ill, and he had been asked to Chair the Meeting today. Members expressed their concern and asked that their good wishes be passed to The Chairman and Mrs Tanner.

Trustees agreed that 'something substantial' should be done to acknowledge the great contribution and commitment the Chairman had given to The Trust since it was set up in 1988. However, now was not the right time to approach The Reverend Alan Tanner about the nature of such an event. Trustees recorded their gratitude and appreciation of the Chairman's work and looked forward to an opportunity to mark this in an appropriate manner at some future date.

Miss Winterton reported that as Trustees appointed by The Secretary of State for Health, at the present neither she nor Dr Winter had been re-appointed as Trustees when their Terms of Office had expired. She was concerned about their legal status as Trustees and had asked that the Trust's solicitors comment on the matter. Paisner & Co had indicated that although she and Dr Winter could be regarded as Trustees under Section 97(1) of the Charities Act 1993, because they were still carrying out their duties as Trustees, it was questionable whether they were covered for common law indemnity. Miss Winterton said the present situation was untenable. She had asked the Chief Executive to instruct Paisner & Co to write to The Department of Health, stating that if she and Dr Winter had not been re-appointed as Trustees within two weeks of the Department's receipt of the letter, Miss Winterton and Dr Winter would cease to regard themselves as Trustees, and would offer their resignation to the Secretary of State forthwith.

Trustees agreed with the reported action and also noted that The Secretary of State had failed to fill the two vacancies on the Trustee Board, despite numerous reminders.

MINUTES

00.01 Minutes of the Meeting held on Tuesday 19th October 1999.

Mrs Latimer pointed out that she had abstained when the vote to appoint a new Chairman had been taken at the last Meeting of the Trustee Board. The amendment to the Minutes was noted.

The Minutes of the Meeting were approved.

00.02 Matters Arising from the Minutes

99.42 Section 64 Core Grant - Update

It was noted that a further quarterly payment of the Core Grant had been received from The Department of Health in January to cover the third quarter of 1999. A final quarterly payment for the current financial year was due now.

Trustees expressed continuing outrage at the inefficiency of The Department in meeting its commitments to the Trust, which had been set up to do the work of Government. The Chief Executive was asked to write once more to Department contacts about the many outstanding matters that had been raised at a recent meeting with civil servants in January.

99.33 Partners & Families Bereavement Project

It was reported that the Project was progressing well. A first meeting of the South East Pilot Support Group had been held towards the end of January, and despite a low turnout, the two young widows who had come to the meeting had greatly appreciated the support and counselling provided. A further four meetings of the Group had been arranged, and it was hoped that others would join in.

The proposal to send 'second letters' followed by telephone calls to bereaved families within two months of a death had not yet been implemented due to lack of staff time. However, it was hoped that if the Section 64 Project Grant for the Bereavement Project, applied for last September, was approved by The Department of Health, it would be possible to recruit additional help to assist with the Project.

Responses to recent Project mailings had included five people who had requested visits from Trust Representatives, and two people who had asked for 'bereavement counselling' to be made available to them.

Trustees noted the report and said that bereavement appeared to be a big problem for a few people. It was within the remit of the Trust Deed to provide support to dependants of registrants who had died, and it was hoped that the Project Grant application would be approved by the Department. It was also suggested that it might be possible to set up a satellite organisation able to raise funds to support dependants and families of deceased registrants of the Trust.

00.03 Chief Executives Report

Social Worker

Trustees noted with concern the prolonged absence of the Social Worker and the additional burden this placed on the small staff team. Trustees agreed an appropriate budget to provide additional locum support and confirmed that the Chief Executive should follow up leads to find appropriate additional help.

Finance Officer

Trustees noted that the Finance Officer was overcoming system problems and could foresee a time when the accounting system would work as specified. The work in editing changes to payments was very time consuming indeed and it was hoped that in time a swifter and more efficient way of editing would be found. The Hon. Treasurer said that he hoped that it would soon be possible for him to make regular visits to Trust offices to provide support to the Finance Officer.

00.04 Finance Reports

04(i) Quarterly Investment Summary and Asset Valuation

Trustees noted that an additional £2 million 'top-up' payment had been received from The Department of Health in January. In accordance with advice given, this sum had been put on special deposit until the end of the year so that the interest gained could be used to off-set deficits arising on the management fund.

04.(ii) Monthly Grants Summary

The Grants Summary was noted.

04.(iii) Quarterly Management Summary

Trustees noted that figures shown for December 1999 were accruals, so the Third Quarter Management Summary was still at draft stage. The Finance Officer hoped to be able to provide firm figures within the next month. Trustees noted that the main overspend for the year was in the 'Staff Costs' area, and suggested that, though undesirable, it might be possible to charge some of the overspend relating to 'services to registrants' to the Trust Fund, or meet it from interest on the most recent 'top-up' grant from The Department.

04.(iv) Draft Budget - 2000/2001

The Draft budget was approved. It was noted that the Section 64 Budget did not allow for any 'contingencies', thus making it very difficult to cover costs of temporary replacement of staff on prolonged sick leave.

04.(v) To Approve and Sign a Revised Bank Mandate.

The revised Bank mandate was approved, and signed by those present.

04(vi) Forecast of Capital Requirements.

This item was deferred to be discussed with the report from the Payments Review Group later in the meeting.

00.05 To Ratify an Equal Opportunities Policy for the Trust

The Chief Executive explained that it was now necessary for all organisations applying for Section 64 funding from Government to include an Equal Opportunities Policy statement with their applications. In September 1999, the Trust had applied for a Project Grant under Section 64. Staff had prepared the draft Equal Opportunities Policy submitted to the meeting today. This had been drawn up based on the policy used by the Haemophilia Society. It was hoped that Trustees could ratify the Policy.

Trustees considered the Draft Policy and recommended that the Policy be amended to limit provision of Trust services to the 'whole community of people with haemophilia\related bleeding disorders who *contracted HIV as a result of NHS treatment with contaminated blood products....*

Trustees then approved the Equal Opportunities Policy unanimously.

00.06 Revised Staff Contract and Handbook

The Draft Statement of Employment Particulars and Staff Handbook prepared by Tony Miller of Miller Brand Associates, following consultancy work commissioned by Trustees in May 1999, had been submitted to the Meeting for approval. Together these two documents formed the new staff contracts required under European Employment legislation. The Chief Executive confirmed that staff had been consulted about the changes to their contracts of employment and said that it was important that the new contracts of employment were issued to staff as soon as possible.

After discussion, Trustees agreed that final approval of the documents should be given by the Honorary Officers following further scrutiny of The Staff Handbook.

00.07 To Approve an extension to the Lease at Alliance House.

Trustees noted that following negotiations with UKTA, Landlords of Alliance House, it had been agreed that the Trust's lease be extended to 2008. The new rent agreed until 2003 was £22 per square foot, with effect from June 2000. There would be a further rent review in 2003. UKTA had also agreed to find space in the basement of the building for safe storage of Trust archive material.

00.08 A Report on a Meeting with Civil Servants.

The Deputy Chairman reported that Dr McGovern had been ill. Therefore the Trust team had met with Mr Charles Lister. The tone of the meeting had been friendly, and Mr Lister had listened to the points raised by the Trust.

Mr Lister had confirmed that The Department would attempt to find a way to fund costs incurred by the Trust to replace outdated computer equipment, by the end of the current financial year, as had been promised by Lady Hayman last summer.

Mr Lister had acknowledged that delays had arisen in confirming The Trust's Section 64 Core Grant for the current period, and had said that The Department intended to find a means to support The Trust that did not rely on Section 64. He hoped that it would be possible to put a new mechanism in place before April 2002, when the Trust's current three- year approval under Section 64 came to an end.

Mr Lister had noted that The Trust had asked for a meeting with the Minister of State for Health, Lord Hunt, early in 2000. He had said it would be important that civil servants had an opportunity to meet Trust representatives before the meeting, so they were in a position to ensure that Lord Hunt was fully briefed. After discussion, it had been agreed that the meeting with Lord Hunt be arranged to take place before Easter, and that a special meeting with civil servants be booked to take place at least 10 days prior to the meeting with Lord Hunt.

00.09 A Position Statement related to The Birchgrove Campaign .

The draft Statement of the Trust's position with regard to the Birchgrove Campaign for recompense was amended to replace the phrase '*living with the effects of contamination with HIV*' by '*who had been infected with HIV as a result of treatment with contaminated blood products*'.

Trustees noted that the Statement would only be used if the Trust was asked to comment on the Birchgrove Group's campaign.

00.10 Strategic Review Follow-up

10.(i) Partnership Group Report

Mrs Latimer reported on her second meeting as Chairman of The Partnership Group. The meeting has started off with further anger and frustration being expressed by some members of the Group. However after discussion it had been agreed that the Partnership Group was not the right forum to campaign about perceived lack of representation by The Trust or The Haemophilia Society on hepatitis C issues. The Birchgrove Group representatives present had reported that they would be campaigning independently for recompense from Government for their infection with hepatitis C in addition to HIV.

Birchgrove representatives had also reported to the meeting that they had hoped to obtain free computers from Apple PLC, so that those registered with the Trust could access treatment information from the internet.

A pilot scheme with 'Body Positive' in the London area would take place in the New Year. The purpose of the Project was to demonstrate that people with haemophilia and HIV could make use facilities offered by 'Body Positive', and recognise the value of therapies and other opportunities for support offered through this organisation which had branches all over the country.

Other issues that had been raised at the last meeting of the Partnership Group in November 1999 had included:

Membership of the Group: there had been a request that more Trustees participate. The Deputy Chairman had agreed to attend the next meeting of the Group in February;

The cut-off date for the Macfarlane (Special Payments) (No.2) Trust and concern that this should be extended. A Deed of Variation has now been approved by the Secretary of State for Health and Trustees of the Trust;

How the Partnership Group could become more involved in identifying the additional costs of living with haemophilia and HIV. A small Group had been formed to work with staff and Trustees on this issue;

The Partnership Group had also proposed that an Update Day be held to inform Trustees about what it was like living with the effects of haemophilia and HIV. Mrs Latimer felt that this proposal could be of great benefit to all Trustees, and hoped that Dr Winter would be able to provide medical information to Trustees about treatments and side effects. She had identified a small group who would be prepared to work with her to prepare a range of presentations for the Update Day.

Trustees welcomed the proposal to hold an Update Day, and identified Tuesday 13th June, from 11.00am to 4.00pm as being a suitable date and time.

10.(ii) Payments Review Group

It was reported that, as agreed last October, all Regular Payments had been increased by 11% in January 2000.

The Review Group had recommended that further research be done to identify the additional costs of living with HIV. A small group which including staff, Trustees and registrants, had worked on this issue, referring to the model used in determining Regular Payments in 1990 and 1993. The Group had also identified new areas of need that related to long-term survival and the effects of combination therapies. The Group had identified revised costs of living with HIV and had made recommendations to the Payments Review Group based on substantial increases to Regular Payments and reductions and restrictions to one off Single Grants. In order to confirm that a move to higher

monthly payments and more restricted single grants would be the preferred choice of the majority of surviving registrants, a brief Questionnaire had been circulated with the Christmas Newsletter. Responses received had demonstrated overwhelming support for such a change of policy.

The Forecast of Capital Requirements presented to Trustees had identified the effects on a projected movement of capital of increasing monthly payments by £75 a month; £100 a month and £125 a month. These projections had not included making adjustments to address anomalies related to differing payment rates to those receiving DLA at Middle and High rates, and increasing payments to those people on the Basic payment rate to the Standard rate, as proposed by the Payments Review Group in October.

Trustees considered the options presented in the light of continuing uncertainty about further 'capital top-up' payments from Government.

Mr Stevens proposed that the anomalies referred to be addressed, Regular Payments increased by £50 a month and a budget for Single Grants set at £50,000 a year.

Dr Winter said that Government had required the Trust to carry out a 10 year Strategic Review which had identified new and increasing needs. He believed that The Trust was at a critical point: hepatitis C co-infection was a significant new issue in the lives of those surviving registrants, and at this stage it was not known how this might affect life expectancy of the registrant group as a whole. There was growing anger and frustration amongst survivors and the Trust must demonstrate that it was reacting to the findings of the Strategic Review. To do fail to do so would result in a most damaging loss of credibility. Dr Winter proposed that Regular Payments be increased by £100 a month, and Single Grants be restricted to health related needs only.

Miss Winterton reminded Trustees that they did not need to 'ask permission of Ministers' about expenditure of the Trust Fund. Decisions about expenditure were the responsibility of Trustees. However Trustees did need to demonstrate wise spending. To give too much money away could result in 'the brakes being put on the Trust', but to advise the Minister of increased spending in response to identified needs reported as part of the Review was part of their role. It was a question of balance.

Trustees agreed that costings be prepared on the basis of addressing anomalies related to Medium Rate DLA and those receiving only the Basic rate of payment from the Trust, and introducing a £100 monthly increase in Regular Payments for all those infected with HIV. Payments to disabled widows and widows with dependent children should also be reviewed. Since notice of change would be required, the increases could be phased in over the next financial year, with increases to those on Medium rate DLA and those receiving the Basic rate of payment made at the beginning of the year. Further increases to monthly payments could be made later in the year.

Costings based on the proposed should be used at the meeting with Lord Hunt, scheduled to take place in April.

Costings should be presented as 'what the Trust proposes to do' and provided on the basis of informing Lord Hunt of the implications of this change of Trust payment policy on capital top-up requirements from Government. Those attending the meeting with Lord Hunt should seek assurances from the Minister that Government would continue to support the Trust, to enable it to maintain the level of service to those registered.

Trustees agreed that whatever changes were made to the payments system, it was vital that the changes were communicated to registrants clearly and accurately, and that no change was made to the system until this had been done. It was suggested that the Journalist who writes copy for The Haemophilia Society Journal be asked to prepare a special Newsletter for all Trust registrants to explain the policy changes.

00.11 Cases Update

The Cases Update was noted. It was agreed that Mr Hodgson would write to the Grants Director at Motability regarding Case 1406. Mr Hodgson would also prepare a report for the Trust Newsletter and the Haemophilia Society Journal advising members of problems associated with the Motability Lease Scheme, which could leave the family without a car very shortly after the death of the Motability Lease Scheme member.

00.12 Applications and Cases

A total of nine applications were considered by Trustees.

Case 1380 referred to a request for full back-dating of Regular Payments, not made due to Trust error at the time. Trustees approved full backdating and agreed that a payment of £10,360 be made.

Grants amounting to £8,625 were made to 8 other registrants.

00.13 Reports on visits Made - Benefits Adviser

The Benefits Adviser's Report was noted.

00.14 World Federation of Haemophilia - Congress 2000

Dr Winter reported that he had submitted an Abstract to Conference Organisers on the work of the Trust's Strategic Review. Dr Winter felt that the Review had gathered unique information from people with haemophilia and HIV and their families, and this should be shared with the wider international Haemophilia Community. Dr Winter hoped to have the opportunity to make an oral presentation to Congress on the Review.

Mrs Latimer reported that she had submitted an Abstract for a poster presentation to Congress on the Trust's Weekend for Positive Women held in

Liverpool last October. Mrs Latimer hoped that the poster would be chosen for presentation at Congress in July.

Trustees proposed that the Chief Executive should also attend the Congress in Montreal in July 2000. Congress was a two yearly meeting at which all aspects of haemophilia care was discussed. It would provide AH with a global perspective and new understanding of the international situation. If funds could not be raised from external sources to pay for Ann's attendance, they should be found from the Trust's budget.

00.15 Trustee Appointments and Re-appointments

15.(i) The Macfarlane Trust

Trustees noted the response from Paisner & Co related to the position of Dr Winter and Miss Winterton, and formerly endorsed Miss Winterton's proposal that Paisner & Co be asked to write to the Department of Health about the two re-appoints that were so long overdue.

15 (ii) The Special Payments Trusts

It had been drawn to the attention of Trustees that, following the retirement of The Reverend Alan Tanner and Mr Clifford Grinsted, and indications received from Mr John Cashman and Mr Alan Palmer that they wished to stand down as Trustees, Mr Stevens would be the only remaining Trustee of both Macfarlane Special Payments Trusts. It was anticipated that one of the new Secretary of State Appointed Trustees would replace Mr Cashman or Mr Palmer. However, it was necessary for Trustees to nominate two further Macfarlane Trustees to take the places of The Reverend Tanner and Mr Grinsted.

Mr Chris Hodgson and Mr GRO-A were nominated as Trustees to the Macfarlane (Special Payments) Trusts One and Two. Trustees approved the two nominations unanimously.

00.16 Meeting Dates for 2000.

The following Meeting Dates for the Trustee Board in 2000 were agreed:

Tuesday 2nd May

Tuesday 4th July

Tuesday 3rd October

There being no further business, the meeting ended at 4.20pm