

MACFARLANE TRUST

Minutes of a Meeting held on 23rd October 2001 At Alliance House, 12 Caxton Street, London SW1H 0QS

PRESENT:	Mr Peter Stevens	Chairman
	Mrs Elizabeth Boyd	Trustee
	Mr Chris Hodgson	Trustee
	Mrs Pat Latimer	Trustee
	Dr Mark Winter	Trustee
	Mr Anthony Yeaman	Trustee
In Attendance:	Mrs Ann Hithersay	Chief Executive
	Mr Rodney Shepherd	Finance Officer
	M/s Claudette Allen	Social Worker
APOLOGIES:	Mr Gordon Clarke	Hon. Treasurer
	Mr Ian Hayes	Trustee

01.39 Minutes of the Meeting held on 17th July 2001

The Minutes of the Meeting were agreed as a true record.

Mrs Latimer said she wished to clarify her point made in Minute 00.53 - Prescription Charges. She confirmed that there was no problem with regard to prescription charges related to Factor VIII or Factor IX. It was prescriptions for all other drugs, in particular those related to HIV treatment that presented difficulties.

01.40 Matters Arising from the Minutes

01.31(i) Review of Single Payments

It was agreed that an analysis of Single Payments for the first 6 months of the financial year would be tabled in raw form under Financial Matters.

01.38 Trustees' email addresses.

It was confirmed that email addresses would be circulated to all Trustees.

00.53 Prescription Charges

Dr Winter reported that he had spoken to colleagues at UKHCDO. The problems related to prescription charges were not localised. The Organisation had agreed to approach the Regional Pharmacists Group which has powers to waive prescription charges to certain people in their area. It would be suggested that special codes be allocated to people with haemophilia and HIV so that they could be prescribed

medication under the same conditions as patients with sexually transmitted diseases.

The Chairman agreed that the issue of prescription charges should remain 'on the agenda' for his forthcoming meeting with the Minister of State for Health.

01.41 Chief Executive's Report

The Report was noted.

(i) New Computers

The Report identified a need to replace computer hardware because current computers had been bought in 1997 and had been upgraded to the limit of their capacity. Unfortunately it had not been possible to accrue for replacement of computer hardware within the confines of the present Section 64 Core funding.

After discussion it was agreed in principle to replace computer hardware. However the Hon. Treasurer asked that the Trust get another estimate to compare with the one provided by Symac; the company that supports the Trust's computer systems. It was also recommended that we talk to The Department of Health to see whether further funding could be made available under Section 64 Core funding.

(ii) Secured Loans

The Trust's solicitors: Berwin Leighton Paisner, had provided a draft Loan Agreement that might be used as an alternative to placing a charge on registrants' property in order to secure a loan. It was proposed that the loan agreement be used for amounts up to an agreed amount.

Mr Yeaman said that the proposed loan agreement would give a certain level of protection to the Trust, but he felt that it needed to be sharpened up. He pointed out that it would be possible to find 'out of town' solicitors who would be prepared to place charges on property for considerably less cost than that charged by BPL.

After discussion it was agreed that a loan agreement should be used for secured loans below £10,000. For amounts in excess, it would still be necessary for the Trust to take a charge on property. Mr Yeaman agreed to review the loan agreement and propose how it might be tightened up to provide greater protection for the Trust. Mr Yeaman also agreed to suggest ways to find 'out of town' solicitors able to place charges on property.

It was agreed that Trustees should always consider carefully whether to make grants instead of loans. There was nothing in the Trust Deed to prevent this and getting money back after a death could prove a problem for the Trust in the future.

01.42 Financial Reports

(i) Monthly Grants Summary

It was noted that Single Grants had increased in amount and number over the first 6 months of the year. Some Guideline grants had been increased significantly last September and the number of applications for accommodation related grants had noticeably increased this year.

Regular Payments totals had also been considerably higher this year, due to the monthly increase of £100 introduced in September 2000.

Trustees discussed the implications of the steep increases in grant payments and agreed that it would be necessary to introduce stricter controls. It was agreed that time would be spent at the end of the meeting to review the Office Guidelines and propose ways to reduce expenditure over the remaining months of the financial year.

(ii) Management Costs to 30.09.01

The Finance Officer pointed out that the Trust had not received Section 64 Core Funding for the Macfarlane or Eileen Trusts this financial year. This meant that all management costs had been covered from Trust funds and it appeared as if there was a deficit against the budget for the first half of the year. However, if core grants had been paid by the Department of Health, it would be seen that there was a small surplus of income over expenditure for the first 6 months of the financial year.

(iii) Investment Summary to 30.09.01

The Asset Valuation showed that there had been potential losses in the value of investments of around 11% on the year to date. Much of this fall in value had been caused by continuing problems in the world stock markets. The longer term outlook had been greatly affected by the events of September 11th in USA, but it was too soon to take action as a result of this. It was agreed that the Hon. Treasurer would address investments as a high priority for action. It was felt that the UK market had performed better than the US stock market and some stocks had performed well where as others had been a disaster. The Hon Treasurer agreed to address the merits of maintaining two portfolios and in particular to assess the benefits of a specifically managed portfolio. He would report to the next meeting of the Trustee Board in the New year.

01.43 Regular Payment Structure - Possible Changes

The Chairman said that he had been working on reviewing Census forms that had been returned to the Trust. As a result he had come to realise the 'fiendishly complex system' that was used to assess individual Regular Payments. The criteria used went back to the founding of the Trust. At that time it had been decided that payments should be based on 'need' but should not be 'means tested' as such. It had been agreed to use the Welfare Benefits System as a 'proxy' means test without independently assessing financial need

in each case. The payment bands used by the Trust had remained unchanged for many years. Two of the bands were affected by the status of the individual; the basic rate was not. The Trust does not always know of changes in status and the Chairman had found that many of the monthly payments were being made at the wrong rate due to lack of information.

The current system of assessing Regular Payments was too complicated. The Chairman hoped that it would be possible to propose a simpler and fairer way of assessing payment rates. A small working party to include the Social Worker, the Benefits Adviser and himself would prepare a paper for the next Trustee Board in the New Year. Simplification was the main aim.

01.44 Department of Health Report

The Chairman reported that there had been no significant action since the last Trustee Board meeting. There had been no further information from The Department on Trustee Board appointments and no date had yet been arranged for a meeting with the new Minister with responsibility for blood safety issues. The Chairman hoped for an early meeting with civil servants.

01.45 Implementation of the Corporate Management Review

The Corporate Management Review had included recommendations that had resulted in the Trust asking The Department for help with long term forecasting and business planning. It had been agreed that a Finance Trainee would be seconded to the Trust for a 6 month period to assist with this work. It was hoped that Kathleen McFarlane would be able to start work in December 2001 and complete the project by the middle of 2002. The Finance Trainee would report to the Chief Executive and seek guidance on aspects of her work from members of the Strategy Group.

The Corporate Management Review had helped to reveal the need for additional staff support to the Finance Officer. A new post of Finance Assistant had been included in the Section 64 Core funding application.

01.46 Bereavement Project Report

Trustees received a detailed report of the residential meeting that had taken place in September. The Chairman thanked those involved and said that he regarded the weekend as a 'seminal event' in the history of the Trust. The Reports helped give a clear picture of the needs uncovered by the meeting and it would be necessary to consider carefully how we went forward from here. It was hoped that it would be possible to hold a similar weekend next year. An application for Section 64 Project funding had been applied for; it was hoped that this time it would be successful.

Mrs Boyd said she had been amazed by the level of stigma still attached to HIV, particularly outside London. The weekend had provided an opportunity for many of those present to speak freely about what had happened to them.

Dr Winter said that the Project had a well-defined purpose and needed to continue. The Project could be used to highlight specific issues such as the need for specialised bereavement counselling and stigma related to HIV. Trustees felt that there was a need for the Social Worker to carry out Social Assessment type visits approximately 3 months after a death and make recommendations for specific ongoing help from the Trust. There should also be telephone calls to bereaved families and something might also be done by the Trust to mark the anniversary of a death.

It was estimated that if no Section 64 funding was available for the work, the Trustees would need to earmark approximately £10,000 a year to allow the work to continue at its present level, to include a residential meeting once a year and support to 2 or 3 local groups. The funding agreed by Trustees last April would allow the setting up of a further support group in the North West region based in Manchester.

Confidential Report

Trustees discussed a confidential Report of a closed meeting that had taken place over the Residential Weekend.

Trustees agreed that the nature of the Report was such that it had to be referred to another organisation for formal investigation. Its contents could not be ignored. It was important that each person present at the closed meeting should review the Report and confirm to the Trust that what was said was accurate. Those present at the meeting should be advised of the extremely serious nature of what had been said and should be warned that they must be prepared to confirm their concerns at a full public investigation, if necessary; they should also say whether or not they had used the Hospital Complaints Procedure, and if not, why not. In addition they should be asked to agree that the Report be shared with The Haemophilia Society, who would work with the Trust to decide how the Report be passed forward for full investigation.

01.47 Partnership Group Report

(i) A Trust Website

The Chairman reported that there had been only 6 registrants present at the last meeting of the Partnership Group. He had reported on a range of issues but there had been little discussion. It had been possible to update those present on the proposal to develop a Website for the Trust. Three registrants had shown an interest in helping to develop a dedicated Website. It had been decided not to attempt to create a level of the site that would connect with the Members Database. This was because to do so was technically very complex and could involve a change of database; it was also felt by some registrants to risk compromising their confidentiality.

The Chairman asked Trustees to approve expenses of up to £1,000 to develop the Website. This was agreed.

(ii) Haemophilia Society./Birchgrove/ Macfarlane Trust Conferences.

A proposal for the Trust to part fund a conference for HIV positive people and their families had been put forward by The HIV Worker at The Haemophilia Society. The Macfarlane Trust had been asked to make a contribution of £10,640 towards the cost of the Conference. Two years ago the Trust had co-funded a similar Conference for positive men only which had proved very beneficial to those who had attended. Two years before that there had been a very successful conference in Bath for registrants and their families; again the costs had been shared by The Trust, The Society and Birchgrove. Unfortunately it was understood that Birchgrove was no longer in a position to raise funds which meant that costs would have to be shared between The Society and The Trust.

After discussion Trustees agreed that it would not be possible to confirm any financial help for the Conference until it was clearer what level of future funding the Trust could expect from The Department of Health. It was hoped that by the end of the financial year the picture would be clearer and it would be possible to reconsider the application.

01.48 Assisted Conception

Trustees considered papers provided by Chelsea & Westminster Hospital and Luton Primary Health Care Trust together with a supporting paper from the Social Worker.

Dr Winter said that this was a very important issue for many registrants who would like to start a family but were concerned about the risk of passing on HIV infection to their partner. Sperm washing was a technique to reduce the risk of infection. It was now being carried out by a number of centres in the UK. However it was costly and success rates were not high. This meant that 60 - 70% of funding was likely to be wasted. He questioned whether this a prudent use of Trust funds?

It was reported that Mr Ian Hayes had called the Trust to support a proposal that the Trust should fund a limited amount of treatment related to assisted conception.

The Trust's solicitors, Berwin Leighton Paisner, had advised that the funding of such treatment was within the remit of the Trust Deed and the Trust would not be liable if mother or child were subsequently infected with HIV.

After much discussion it was agreed that Dr Winter would write to Chelsea & Westminster Hospital to discover more about treatment success rates and whether or not infection had ever been passed on as a result of the treatment. Dr Winter would also try to find out how many Health Authorities did fund sperm washing as a treatment for couples where one party was HIV positive. The issue would be deferred to the next meeting of the Trustee Board for decision.

01.49 Applications and Cases

Trustees considered nine cases and awarded grants to the value of £6,933 to five registrants /dependants.

01.50 Applications for Secured Loans

Two applications were made for secured loans:

(i) Case 1980

Trustees agreed to increase the charge on the property by a further £12,000 to enable the registrant to have heating installed and a new water main laid to the house that was in an isolated position.

(ii) Case 1930

Trustees agreed to take a charge of £10,000 on the property to enable the positive widow to get out of debt. Trustees made the proviso that Susan Daniels handled all negotiations with her creditors and that no funds were made directly available to the beneficiary.

01.51 Social Worker's Report

The Social Worker's Report was noted.

01.52 Benefits Adviser's Report

There was no Benefits Adviser's Report

01.53 Any Other Business

(i) Meetings Schedule for 2002

The following dates were agreed:

Tuesday 12th February 2002

Tuesday 28th May 2002*

Tuesday 30th July 2002

Tuesday 29th October 2002

*Note Change

(ii) Revised Grant Guidelines

Trustees reviewed the Office Guidelines in the light on the need for financial constraints to be introduced for the remainder of the financial year. A fuller Review would take place as part of the Review of Payments Structure, to be undertaken by the Chairman and others in time for the next Trustees' Meeting.

Revised Guidelines are attached.

There being no further business, the meeting ended at 5.00pm