

MACFARLANE TRUST

Minutes of a Meeting held on Tuesday 2nd May 2000
At Alliance House, 12 Caxton Street, London SW1.

PRESENT:	Mr Peter Stevens	Chairman
	Mr GRO-A	Trustee
	Mr Chris Hodgson	Trustee
	Mrs Patricia Latimer	Trustee
	Dr Mark Winter	Trustee
	Miss Patricia Winterton	Trustee

In Attendance:	Mrs Ann Hithersay	Chief Executive
	M/s Fran Dix	Social Worker
	Mr Rodney Shepherd	Finance Officer [part of the time]

Apologies: Mr **GRO-A** was unable to attend the meeting due to ill health. Trustees sent their good wishes to Mr **GRO-A** and hoped he would soon be fit enough to return to the Trust.

MINUTES:

00.17 Minutes of the meeting held on 1st February 2000

The Minutes were agreed as a true record.

00.18 Matters Arising from the Minutes

99.33 Bereavement project - Update

Mr Hodgson reported that to date there had been three meetings of the South East support group. Whilst the Group was very small, the work done was most valuable. It was hoped that a second group might be established in the Midlands later in the year.

The application for Section 64 Project funding had not been successful, but the Trust had been invited to re-apply again next year. It was hoped that it would be possible to send a follow-up letter to all those who had responded to the earlier letters, and also to send 'second letters' to those bereaved, as had been planned last year.

00.06 Staff Contracts and Handbook

Following consultation with Trustees and staff, the contents of the Handbook and Statement of Employment Particulars had been agreed. These two documents formed the new staff contracts. Copies of the Handbook and individual Statements of Employment Particulars had now been issued to each member of staff for signature and return.

00.19 Chief Executive's Report

The Chief Executive's Report was noted. The issue of the Ex-gratia payment to **GRO-A** **GRO-A** made in 1998 and the subject of a challenge from the National Audit Office that the payment should not have been made from Section 64 funding, was discussed. It was agreed that the Chairman would seek a meeting with a senior officer of the NAO to discuss the contents of Clifford Grinstead's letter of 16.02.98 to Derek Dudley of the NHS Executive. Charles Lister had agreed to identify an appropriate person within the National Audit Office for the Chairman to approach about the matter. Trustees were not prepared to accept the Department's decision to withhold £4,000 of the Section 64 grant for the current year on the basis of unclear and insufficient information from the Department.

Statistics Report.

It was noted that the number of dependants was increasing. Trustees said that they would like to see dependant numbers recorded more clearly on the statistics form. This was agreed.

00.20 Financial Reports

(i) Monthly Grant Summary - Report to 31.03.00

The Chairman said that he had drawn to the attention of Lord Hunt the increase of expenditure on single grants over recent years and had pointed out that current monthly payments were not keeping pace with identified needs of registrants. This was why there had been such a steep rise in this particular area of expenditure. It was hoped that the proposed payment changes would lead to a fairer and more satisfactory system of payment.

(ii) Quarterly Management Expenditure to 31.03.00

The Management Accounts for the year ended 31st March 2000 showed an excess of expenditure over income on administrative costs of almost £26,000. The main areas of overspending had been on staff costs and consultancy

Staff costs had been in excess of budget due to the need to replace the Finance Officer early in the financial year 1999/2000, and use of agency staff to cover the period between the departure of the first Finance Officer and Rodney Shepherd starting in August. To this could be added the additional cost of assistance during the long period of absence on sick leave of the Social Worker during the final Quarter of the financial year.

There had been an overspend on the consultancy budget due to the use of an external Human Resource consultant to advise Trustees on staff

salary and grading structure and do work to bring the employment contracts into line with European law.

Options to address the Management Fund overspend were discussed. Trustees agreed to transfer the cost of investment management charged by Principal Investment Ltd, from the Management Fund to the Trust Fund in order to treat both investment managers' fees consistently and to comply with recommendations made in the Charities SORP. This would release sufficient funds to reduce the deficit to an amount that could be contained within the Grant for the year 2000/2001.

(iii) Forecast of Capital Expenditure

The forecast movement of capital presented to Trustees was based on proposals to increase payments to registrants from September 2000, as would be discussed later in the meeting. The forecast indicated that it would be necessary to seek additional capital funds from Government at least one year earlier than had been previously indicated, and also showed that larger amounts of capital would be needed at more frequent intervals in future, if the proposals were to be adopted.

The forecast was noted and it was agreed that detailed discussion on payment proposals would be discussed later in the meeting.

(iv) Quarterly Investment Summary.

The Investment summary for the year ended 31st March 2000 was noted. Reports from Investment managers had not arrived. However it was noted that there had been a fall in value of equities during the latter half of the year, and this was reflected in the year end performance. Assets of the Trust stood at just over £8 million at 31st March 2000.

(v) Draft Audited Accounts for the year ended 31st March 2000.

Draft audited accounts for the year ended 31st March 2000 were tabled at the meeting. It was agreed that Trustees would send in comments by the end of May, and that the Chairman and Chief Executive would liaise with the Auditors to bring the Accounts to Final Draft stage in time for approval at the next meeting of the Trustee Board on 4th July 2000.

00.21 Approval and Signing of the Fourth Deed of Variation to the Trust Deed.

Following advice from the Charity Commission that the Trust was in breach of the Trust Deed by paying for Indemnity Insurance for Trustees, Paisner & Co had advised that it would be necessary to vary the Trust Deed to provide powers for Trustees to purchase insurance cover of this type. The Fourth Deed of Variation gave these powers.

Trustees approved and signed the Fourth Deed of Variation at the meeting.

00.22 Report on a Meeting with Lord Hunt, Under Secretary of State for Health.

The Chairman reported that he and The Hon Treasurer, accompanied by Dr Winter and the Chief Executive, had visited Lord Hunt on 18th April. The Chairman said that the meeting had been 'positive but inconclusive'; it had been curtailed due to our late arrival and a subsequent lunch engagement of Lord Hunt. The Chairman had stressed that the situation in which the Trust found itself today was very different to that which had prevailed in the early days. Twelve years after its foundation the Trust was now meeting the needs of a group of long term survivors of living with haemophilia, HIV and in most cases hepatitis C as well. There was also a growing number of dependants of registrants who had died. Many of these needed continuing support.

Dr Winter had reported that patients were 'worn out' by the effects of living with haemophilia and HIV, and that the effects of co-infection were an added burden that many were finding difficult to bear.

It was pointed out to Lord Hunt that there were considerable inconsistencies in the provision of services and resources across the country, which led to Trust funds being used to underpin inadequate responses from other areas of the statutory sector. The Chairman said that Lord Hunt had expressed considerable interest in this and immediately suggested that someone be appointed to work alongside the Trust to identify cases where other statutory bodies could have allocated funds.

The Chairman had advised Lord Hunt of the need to increase payments to registrants from September. The reaction to this information had been neither positive nor negative. However Lord Hunt had indicated that he expected to have a further meeting with Trust representatives later in the year. The Chairman commented that Lord Hunt knew much about Health Services across the board; he was not a 'touchy feely' man, but was taking a business-like and logical look at the Trust.

00.23 New Trustee Appointments

It was reported that there were currently three Trustee vacancies; from September the number would be increased to four with the resignation of

GRO-A

All Trustees present had received letters of re-appointment from the Secretary of State for Health. Despite many reminders, there was still no further movement on the appointment of new Trustees to fill vacancies left by retirement and resignation of Department appointed Trustees during last year.

The Haemophilia Society acknowledged the need to fill the vacancy left by the retirement of The Reverend Alan Tanner at the end of March, and the further vacancy arising in September. The Chairman and Chief Executive of the

Haemophilia Society were due to meet Peter Stevens and Ann Hithersay to discuss skills required in the two new Trustees to be appointed by The Society. Proposals would then be made to The Society's Trustee board at the end of June.

It was hoped that all four new appointments would be made in time for the October Trustee Board Meeting.

The issue of 'Users as Trustees' was discussed. It was felt the Charity Commission 'Guidance' issued in the pamphlet 'Users on Board' was unclear on the subject of users who were also beneficiaries becoming Trustees. The Society had no objection to appointing a registrant of the Macfarlane Trust to one of the Trustee vacancies. However, it was felt that specific guidance should first be sought from the Charity Commission about the Trust's position.

00.24 Strategic Response Group Report

(i) Trustees' Update Day

Trustees agreed that if it were not possible to recruit three of the four new Trustees within the next 3 to 4 weeks, the Trustee Update Day should be postponed until the autumn. It was also agreed to invite Charles Lister to the Update Day.

(ii) Amalgamation of the Partnership Group and the Strategic Response Group

The Chairman reported that at last meeting of the Strategic Response Group he had pointed out that the overlap between this Group and the Partnership Group was so obvious that it would be more effective to combine the two groups, thus creating a forum at which issues of common interest to The Trust, The Society, Birchgrove Group and Trust registrants could be addressed. The Strategic Response Group had supported this proposal but agreed that the Board should decide on an appropriate way forward.

Trustees discussed the proposal to amalgamate the two Groups, and agreed in principle. It would be necessary to raise the matter at the next meeting of the Partnership Group later in the month and report back to Trustees in July. The first meeting of the joint group would probably take place in the autumn.

(iii) Campaign Reports: Haemophilia Society and Birchgrove Group

Chris Hodgson as Chairman of the Haemophilia Society reported that the Hepatitis C Campaign was still continuing in Scotland. Susan Deaon, the Minister of State for Health was still considering the Society's request for a Public Enquiry into all contamination of blood products.

There had been continuing confusion about whether the Society's campaign was for co-infected people and mono-infected people, or just those who were mono-infected. Anger had been expressed by a number of Trust registrants about the Society's campaign.

In a House of Commons Debate at the beginning of March, Michael Mates, MP for East Hampshire, had made an impassioned plea for financial support for people with haemophilia who had contracted hepatitis C through NHS treatment with contaminated blood products.

Later in March, Lord Morris had made another impassioned speech on behalf of the campaign in a Dinner Debate in the House of Lords. He had spoken about the moral issue and said that since people with haemophilia had been infected with hepatitis C through the same of contaminated blood products as those with HIV infection, there was no doubt that they also should receive support from Government. Lord Morris had asked that the remit of the Macfarlane Trust be extended to cover those with haemophilia who had been infected with hepatitis C.

There had been no response to the appeal for support made to Tony Blair earlier in the year.

The Chairman and Trustees felt that the Macfarlane Trust should continue to maintain a neutral position with regard to both the Haemophilia Society and Birchgrove campaigns for recompense related to hepatitis C. The Trust can report to Ministers on additional problems caused by hepatitis C co-infection but could not, whilst funded by Government, become involved in campaigning against Government policy.

The Birchgrove Group appeared to understand the Macfarlane Trust position; however the recently formed 'Two Two Group', the campaigning arm of the Birchgrove Group, was not so clear. It was agreed that the Trust's response to the two letters asking for capital payments from the Macfarlane Trust for hepatitis C infection should be to remind the writers that the Trust has never made capital payments. These have been made through the Special Payments Trusts on behalf of Government. Letters should therefore be written direct to the Secretary of State for Health. Copies of letter to the two registrants should be sent to all Trustees for information.

(vi) Haemophilia 2000 - Montreal July 2000.

It was reported that Dr Winter and Mrs Patricia Latimer had both been invited to make oral presentations to the Conference. Presentations will be about the effects of living with 'long term survival' and about the specific issues raised by women registrants.

00.25 Review of Payments - Backdating of Payments to two Groups.

(i) **'Live, No Regular Payments'**

Following the earlier identification of a registrant who had been unaware that he was eligible for Trust support and had therefore never received any Regular Payments from the Trust, staff had searched files and had identified a further twelve files of registrants in a similar situation. These people's files had been reviewed and letters sent to their last known addresses and to Haemophilia Centres where they were treated. As a result of this work six of these registrants have confirmed that they would like to receive monthly payments from the Trust and one person has stated that he does not want help from the Trust. None of those who have responded had realised that they were eligible for support from the Trust. Trustees were asked to approve full backdating of payments to all six registrants.

(ii) **The 'Birmingham Ladies' - Barnardo's Cases**

Barnardo's staff working on an HIV project in the Birmingham area had identified three ladies who had contracted HIV through relations with Trust registrants. Barnardo's had approached the Trust about ongoing financial support for these ladies.

After considerable research it was revealed that two of the ladies had received Macfarlane (Special Payments) (No: 2) Trust payments as 'infected intimates' and had, at the time applied for some support from the Trust but had been turned down. After writing to the Department of Health for guidance, it was established that if an individual was recognised by the Secretary of State as being eligible for a 'Special Payment' they were also eligible for continuing financial support through the Macfarlane Trust as an Infected Intimate, not as a dependent of the original registrant. On this basis it was clear that two of the cases identified should have been receiving support from the Trust since the Special Payments were made.

The third case was also of an 'infected intimate', but one who had contracted HIV after the cut off date in December 1990. It had been established that this woman and her son were dependants of the deceased registrant, but not eligible for a capital payment from Government. Trustees were asked to recognise the status of the mother as an 'infected intimate' and the son as a dependent of the deceased registrant and make back payments to the date of the HIV diagnosis of the mother and subsequent birth of the registrant's child.

After considerable discussion about all the above cases, Trustees agreed that each adult person in both categories should receive the same amount of 'ex-gratia payment' in lieu of support that had not been made to them over the years since registration/diagnosis. It was agreed that each person in each category should receive the same ex-gratia payment of £13,080, based on standard rates paid between 1990 and 2000 and including Winter Payments for the period. Each should

continue to receive monthly payments at the level they were eligible for under current rules.

00.26 Payments Review Update

(i) Proposals to increase Regular Payments in September 2000

The Payments Review Group had recommended that Regular Payments to all those people infected with HIV be increased by £100 a month with effect from September 2000. This would cost an additional £575,000 in a full year, but would be partly offset by a reduction in expenditure on Single Grants.

Trustees approved the proposal.

(ii) Proposals to Restrict Single Grants from September 2000

The Payments Review Group had also recommended that Single Grant areas be reduced to cover mainly those areas that directly related to the health needs of applicants. A number of health-related grants would be increased, but the changes should reduce the amount spent through Single Grants by around £200,000 a year.

The issue of Motability Deposits was discussed. It was reported that it had been announced in the Easter Newsletter that deposits would only be available for Motability vehicles where there was no suitable car in the Nil deposit range. This news had created considerable concern amongst registrants. Chris Hodgson said that changes to the nature of the Motor Industry, currently the subject of Government discussions, might mean that the favourable terms that were granted to Motability as purchasers of a very large number of new cars each year, might go if legislative changes reduced the cost of all cars. If this were to happen, those registered with the Trust might be able to get a better deal without going through Motability. Trustees agreed to leave the matter of Motability deposits on hold for the present. The Trust would continue to pay these where there was clear medical evidence that no suitable car was available in the Nil deposit range.

00.27 Applications and Cases

Five cases were considered by Trustees. Grants totalling £5179 were approved by Trustees.

Trustees also approved an immediate increase of the Bereavement Grant from £1,000 to £2,000 in recognition of increased funeral costs.

00.28 Reports on Visits Made

Reports on visits made by the Benefits Adviser and the Social Worker since February 2000 were noted.

00.29 Any Other Business

(i) A Farewell Event for The Reverend Alan Tanner and Mr Clifford Grinsted.

The Chairman reported the he had visited headquarters of the Royal Pharmaceutical Society overlooking the River. He felt this would make a very fitting venue for a formal dinner to say goodbye to Alan Tanner and Clifford Grinsted. He believed it would be possible to negotiate very favourable rates and felt that if possible the event should take place some time in June or July. The Trust should invite all past Trustees as well as present and former staff. The date should be agreed with The Reverend Alan Tanner and should take place as soon as was convenient.

(ii) Use of e-mail for Trust communication Purposes.

The Chairman said that it should now be possible to communicate with all Trustees through e-mail. He invited everyone to advise the Trust of their E-mail addresses as soon as possible.

There being no further business, the meeting ended at 4.35pm.