

MACFARLANE TRUST

Minutes of the Meeting held on Wednesday 11 August 2004 at Alliance House, 12 Caxton Street, London SW1H OQS

PRESENT	Mr Peter Stevens	(Chairman)
	Mr G Clarke	(Treasurer)
	Mr [GRO-A]	
	Mr [GRO-A]	
	Mr R Tyrrell	
	Ms E Boyd	
APOLOGIES	Mr A Yeaman	
	Dr M Winter	
	Mr P Spellman	
	Ms T Morgan	
IN ATTENDANCE	Martin Harvey	Chief Executive
	Ms S Daniels	IFA

- 99.04 Minutes of the Previous Meeting**
The minutes of the meeting held on the 19th April 2004 were agreed as a true record.
- 100.04 Matters Arising from the Minutes.**
89.04 The Chairman reported relevant matters to do with the Hep C ex gratia payment scheme. He informed trustees present that there would be a meeting of the board of directors of the Skipton Fund Ltd after this trustees meeting.
- 94.04 The Chairman updated trustees present on the proposals in respect of the changes to the way the Trust was governed. Mr [GRO-A] reported to the board that the Haemophilia Society were keen to maintain the good working relationship with the Trust; the Chief Executive reported to members that he had recently met with the new Chief Executive of the Society and that they had agreed to hold regular meetings on matters that were of mutual interest to both the Society and the Trust.
- 101.04 Chief Executive's Report**
The report was noted. The Chief Executive advised members present that [GRO-A] was in hospital and that he had visited her recently. The trustees asked the Chief Executive to pass on to [GRO-A] their best wishes for her speedy recovery.
- 102.04 Financial Reports**
The Treasurer spoke to the reports.
The report at 127.04 (1) was laid around the table. Members were invited to take the report home to digest its contents. A copy of the report is attached to these minutes.

There was no report at 127.04 (2).
The report at 127.04 (3) was only partially complete.
There was no IT report. The Trust's IT consultant was on holiday.

103.04 Financial Adviser's Report

Mrs Susan Daniels presented her report. The report was accepted.

104.04 Social Worker's Report

There was no Social Workers Report.

105.04 Benefit Advisers Report

The report asked the board to consider the matter of fares to and from hospital. If a claimant received income support, assistance was available from the hospital, through the NHS, and it was felt that this need not be a burden on the Trust's limited resources.

It was resolved that **all** claimants on the Trust for assistance in the payment of **all** fares to and from hospital would be reimbursed at the same level as that available from the NHS.

The remainder of the report was accepted.

(Chief Executives Note: Mrs Elizabeth Boyd to ascertain for the Trust the level of reimbursement available from the Royal Free Hospital. The information would be posted on the website and would be implemented from the 1st September).

106.04 The Bereavement Project

The report of the meeting held on the 30 June was noted. Mrs E Boyd advised members of developments in respect of the September bereavement weekend.

(Chief Executives Note: The Chief Executive said he would make available a copy of the "business case for widows" in the form of a briefing document He would also contact the Long Term Review consultant in respect of the report that would be made available to widows)..

107.04 National Support Services Committee (NSSC)

The following were nominated to serve on the NSSC for the ensuing year. Mrs E Boyd, Mr P Stevens (ex officio) Mr R Tyrrell, Mr GRO-A and Mr GRO-A

Arrangements will be put in place for the NSSC to meet to consider the election of officers, the policy and operational remit as agreed by the board of trustees and other relevant matters.

- 108.04 Department of Health Report**
There was no report from the Department of Health.
The Board urged the Chairman and Chief Executive to arrange a business meeting with the DoH as soon as reasonably possible to discuss, inter alia, SF and MFT matters.
- 109.04 Haemophilia Society Issues**
The Chairman reported on matters to do with governance.
The Chief Executive reported on his attendance at the recent annual conference organised by the Society in Loughborough and his recent meeting with the Society's new Chief Executive.
- 110.04 Partnership Group Report**
Mr GRO-A, Chairman of the Partnership Group, presented the minutes (in the form of a report) of the meeting held on the 18 June. The report was accepted.
- The Chairman of the Group agreed that it would be appropriate for him to invite trustees to future meetings of the Group. Mrs E Boyd, MR R Tyrrell and Mr G Clarke immediately expressed interest in attending future meetings.
- 111.04 Annual Plan 04/05**
The annual plan and updates on progress were noted. The Chief Executive was congratulated for having implemented so much of the plan while simultaneously overseeing the establishment of Skipton. The trustees concurred with these sentiments. The Chief Executive drew the trustees attention to the full and explicit cooperation of the staff.
- 112.04 Working Group Reports**
1) Grants Working Party
The minutes of the meeting held on the 14 June were adopted. The attachments to the minutes were noted.
- 2) The Remuneration & Employment Working Party
The minutes of the meeting held on the 14 June were adopted. The attachments to the minutes were noted.
- The Board adjourned at 12.30pm for lunch and to consider a number of case papers.**
- 113.04 Applications & Cases**
1283W – resolved that financial assistance to be maintained pending a review by the Trust's IFA.
1600W – resolved that financial assistance to be maintained pending a review by the Trust's IFA.

1297, 1448 and 1975 (*Chief Executive's Note: these applications comprised representations to the Board of Trustees to consider current policy matters in respect of providing financial assistance for assisted conception and sperm washing. Currently, only ancillary costs such as travel were paid for by the Trust.*)

The Board noted that any change in policy would be a major shift in the nature of support given to the registrant community. There were a number of issues to be considered, such as the background to the current policy adopted by the National Institute for Clinical Excellence (NICE) and the cost factors at the various stages of attempted conception.

Resolved to defer this matter for considered debate by the National Support Services Committee and that a detailed paper embracing all the issues of assisted conception and how that would interface with the registrant community should be taken into account.

It was further resolved to invite Dr Mary Winter to consider a cooption to the NSSC in respect of this issue.

1063 – resolved that as trustees felt that the requirement could be reasonably satisfied by the statutory sector, assistance should only be made available if the level of care available was found not to be available or that the level of care was not satisfactory for the claimant's purposes.

1438 – resolved not to assist the partner of a registrant with education fees as there was no existing precedent and it was felt inappropriate to establish a new policy at this stage.

2012 – resolved that help should be continued.

1758D – resolved that in the event of no other progress on purchasing the interest by the TIB, the Trust's IFSA should seek resolution with the TIB and agree a purchase. The Trust would retain a second charge on the property and that any express agreement with the beneficiary should include a provision to commence loan repayments at a figure that could be reasonably supported by her projected income following graduation.

114.04

Any Other Business

The next meeting of the Board will be on the 11 October. The venue will be Alliance House, 12 Caxton Street, London SW1H 0QS.

The meeting terminated at 2.27pm.