

MACFARLANE TRUST

**Minutes of the Meeting held on Monday 11 October 2004
at Alliance House, 12 Caxton Street, London SW1H OQS at
11.00am**

PRESENT	Mr Peter Stevens	(Chairman)
	Mr GRO-A	
	Mr Bill Payne	
	Mr R Tyrrell	
	Ms E Boyd	
	Dr M Winter	
APOLOGIES	Mr A Yeaman	
	Ms T Morgan	
	Mr G Clarke	(Treasurer)
	Mr P Spellman	
IN ATTENDANCE	Martin Harvey	Chief Executive
	Ms J Cohen	HSS

The chairman welcomed Ms Jude Cohen, the recently appointed Head of Support Services, to her first meeting of the Board of Trustees.

- 115.04 Minutes of the Previous Meeting**
The minutes of the meeting held on the 11th August 2004 were agreed as a true record.
- 116.04 Matters Arising from the Minutes.**
108.04 -The meeting with the Department of Health would take place in November at a date to be agreed. The board noted that it had been almost a year since the last regular meeting between the department and the Trust.
- 117.04 Chief Executive's Report**
The Chairman reported on his recent visit to see GRO-A in hospital. The board accepted the recommendation from the Chief Executive that a review of the Trust administration should be undertaken by the REG. This was to ensure that the administrative robustness of the Trust's infra-structure was sufficient in terms of deployment to support the new arrangements for delivering registrant's services. The report was accepted.
- 118.04 Financial Reports**
1) The report at 144.04(1) was received. Members noted the downturn in cash outflow as represented in the office grants schedules.

2) There was no report at 144.04(2). The Chief Executive explained the circumstances as to the absence of management accounts.

3) The report at 144.04 (3) was noted. The Chief Executive advised that Mr Alan Beaney would be invited to the January meeting of the Trust to review investment performance over the year.

4) The draft audited accounts have yet to be finalised. The Chief Executive recommended that authority be given to the Chairman and Treasury to agree the accounts when ready. This was agreed.

IT Report

The IT report from the Trust's webmaster was noted. The board noted the amount of hard work afforded to the Trust by the Webmaster.

119.04 The Bereavement Project

The report by way of minutes was noted. Mrs E Boyd spoke to the report and informed the Board that the recent Bereavement Weekend event had been a great success. There were some issues of an administrative nature to be clarified which would be addressed at the forthcoming meeting of the Group. Mr R Tyrrell spoke of issues that had been put to him, in particular the changes in the way the Trust was proposing to deliver support services.

(Chief Executive's Note: 1) A report from Mrs Boyd, giving areas of concern expressed by the Parent's Group, is attached. 2) It is likely, subject to agreement by the board that this item will be a matter for the NSSC).

120.04 National Support Services Committee

The minutes of the committee were received. Mrs E Boyd (Chairman) answered several questions from members. It was agreed to continue with arrangements for the HepC and Haemophilia seminars. The SFL staff event would be treated as a priority. The possibility of holding an away-day for trustees, addressed by registrants was considered.

The Chief Executive would liaise with Dr. Mark Winter and Ms Elizabeth Boyd as to time-table and agenda.

121.04 Department of Health Report

There was no report from the Department of Health. The board noted that arrangements for a regular meeting, in November, were in hand.

122.04 Haemophilia Society Issues

The letter from Berwin Leighton Paisner, circulated with the agenda, was deferred.

The e-mail from the Society's Chief Executive to the Trust's Chief Executive was noted. It was resolved that the Chief Executive would continue with discussion areas with his opposite number in the Society decided to continue with refer this specific matter to the NSSC.

123.04

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 1 October. The report was received. Mrs E Boyd accepted an invitation to attend the December meeting of the Group.

124.04

Berwin Leighton Paisner

The Chairman referred to the letter from BLP. He reminded members of the Board of the history leading up to the agreement to create a corporate trustee. He further reminded members of the board of past presentations to the Society, where agreement was inconclusive and that there had been no response about the proposed changes in governance from the DoH.

On the 1 October there had been a second presentation. This followed a meeting, on the same day, with the auditor which had centred around the VAT difficulties. The Chairman further reported that the Department intended to appoint new directors to Skipton, possibly from special interest constituencies according to "Nolan Rules".

The Chairman proposed that the earlier decision (94.04) be reversed and that the Trust and the Fund remain separate bodies. This was accordingly resolved.

It was also agreed to review the Trust Deed in respect of governance arrangements.

124.04

Annual Plan 04/05

The annual plan and updates on progress were noted. The Chief Executive reported that there would be first draft annual plan available for the next Board Meeting.

125.04

Working Group Reports

There were no reports from either the Grants or Remuneration & Employment Working Groups. It was noted that the work of the Grants Working Party would be absorbed by the NSSC.

126.04

V-CJD and impacts in respect of MFT.

The Chairman reported on the perceived impacts the recent announcement would have on the MFT registrant community. He also spoke about the potential for reviving the business case that had been set aside pending ex gratia payments received from the Skipton Fund.

Dr M Winter spoke of the wider impacts the V-CJD announcement would have had on haemophilia patients who

had been infected with HIV and now were at risk of being infected with V-CJD.

After a general discussion, it was resolved that an outline business case with no detailed costings be put to ministers. This would comprise a letter from the Chairman embracing both the negative impact of the V-CJD announcement and the longevity that many of the Trust registrants were reasonably entitled to now anticipate.

127.04

GRO-A DoB GRO-A/81

The correspondence circulated with the agenda was noted. It was resolved that Ms GRO-A be confirmed a registrant of the Trust.

128.04

Any Other Business

The diary for 2005 was considered. It was resolved that meetings of the MFT Board should be held on the 24.1.05, 25.4.05, 18.7.05 and 17.10.05. (*Chief Executives Note: Because of the decision by the Alliance House trustees to withdraw the basement from routine hire, the venue for meetings will be the Novartis Foundation, 41 Portland Place, London W1).*

The meeting terminated at 1.00pm