

200.05.

THE MACFARLANE TRUST

Minutes of the Meeting held on Monday 18 July 2005 at the Novartis Foundation, 41 Portland Place, London W1 from 11.00am

PRESENT Mr P Stevens (Chairman)
Mrs E Boyd (Vice Chairman & Chairman NSSC)
Mr P Spellman
Mr B Payne
Mr C Hodgson
Mr GRO-A
Mr GRO-A

APOLOGIES Mr G Clarke (Treasurer)
Dr M Winter
Mr S Gregg

IN ATTENDANCE Martin Harvey Chief Executive
For certain business items
Keith Foster Skipton Fund Administrator
Ms Linda Haigh Finance Manager.

159.05 Certificate of Incorporation of the Trustee Body
As indicated on the agenda, the certificate for incorporation was completed by those trustees present. Arrangements will be made to enable those trustees not present to complete the certificate.

160.05 Apologies for Absence
The apologies were recorded.

161.05 Introductions
The Chairman welcomed Mr GRO-A to his first meeting as a nominated representative of the Haemophilia Society and invited all trustees and staff present to introduce themselves.

The Chairman formally advised the board of Mr Roger Tyrrell's resignation for family reasons. The board of trustees unanimously agreed that their best wishes to Mr Tyrrell and their gratitude for his dedicated service should be officially recorded. The Chairman informed the board of trustees that he and the Chief Executive had written to My Tyrrell in line with the sentiments expressed by the board of trustees.

162.05 Minutes of the Previous Meeting
The minutes of the meeting held on 25 April 2005 were agreed as a true record.

163.05 Matters Arising from the Minutes.
The board noted the following:-

131.05 – that an unconditional offer of support to attend the 2006 WFH congress had been obtained. The value of the support was £1000.00 from Principal Investment Managers Ltd, for whose generosity the Board expressed their thanks.

131.05 (124.04) – that arrangements to let the ground floor premises were now in the hands of solicitors.

146.05 – that the amendment to the Trust Deed agreed on 25 April had been submitted to the Charity Commission. The Chairman, as stated in the agenda, advised the board that a technical correction to the amendment had to be agreed by those present. It was to remove the name of Mr T Yeaman from the schedule of trustees that appeared on the amendment agreed in January 2005 as, at that time, he was not a trustee amendment. The board agreed to the correction and instructed the Chief Executive to liaise with the Trust's lawyers to implement the necessary action.

148.05 – that the hacking episode remains under investigation by the Metropolitan Police SCU. The Chairman reported that it was unlikely to proceed much further. The board will be kept informed.

149.05 – that the outcome of the "legacy" meeting appeared under item 188.05 (5) and would be dealt with at that time.

149.05 - that there had been little progress on implementing the Kingston Smith benchmark recommendations in respect of managing the distribution of support service funds to the community of care.

164.05 Amendment to the Trust Deed

The Chairman drew members attention to the papers laid around the table and proposed that this item, not featured on the agenda, might now be taken. The Chairman advised the board that this was a tidying-up measure to confirm the authority of the main board of trustees to delegate functions as it deemed fit.

After a short debate and a number of technical questions being answered satisfactorily, the board agreed that the amendment be adopted. The board resolved that the terms of reference of the National Support Services Committee and the Employment Affairs Committee be reviewed for report back at a later stage.

A reference to the possibility of establishing whether or not the e-mail "hacking" situation was still an issue was discussed in light of this matter as there had been an exchange of information surrounding the need for this technical amendment.

165.05 Chief Executive's Report

The report, circulated with the agenda, was received.

166.05 Financial Reports

- 1) The first quarter of grants and regular pay for the period to 30 June 2005 were noted. Mr P Spellman suggested that there should be some extensive analysis of the trends in grant support to support the business case. This was agreed and will be referred to the NSSC. Mr GRO-A questioned the outturn of grants expenditure in relation to establishing the perceived resource needs that would form the basis of the business case. The recent meeting with a number of trustees to begin the debate for the business case was referred to and a number of salient points and likely patterns of expenditure were discussed.
- 2) The investment report, circulated on the 11 July, was noted. The board resolved that future reports should contain the letter overview and only salient performance indices.
- 3) The management accounts for the first quarter were noted. The board noted that the cash account revealed a small budget surplus. The expenditure on all legal fees was expected to fall markedly in the second and remaining two quarters.
- 4) The board received the 2004/05 accounts. After some minor textual amendments, it was agreed that members of the board be given until Friday 22nd July to notify and amendments. Those trustees not present would be sent copies of the accounts.
- 5) The paper from Mr GRO-A and the Chief Executive, circulated with the agenda, was considered. After careful consideration embracing (1) the specific constituency that might access the fund (2) the purposes for which funding might be given (3) whether or not capital and income or just income should be utilised it was resolved that:-
 - the fund should be available to widows and bereaved partners without dependent children - a bursary or bursaries should be made available to those who apply with particular emphasis being applied to those seeking education or particular training (of whatever sort) that would lead to improvements in their quality of life through financial or social independence.
 - the board would consider all applications.
 - a letter to the specific constituency should be sent.
 - arrangements should be made to transfer the funds to Principal Investment Management Ltd in line with the recommendations contained in the paper.
 - the fund should be called "The Honeycombe Memorial Fund".

IT Report

The report from the Trust's IT consultant and webmaster was received.

167.05

National Support Services Committee

The Chairman of the NSSC introduced the minutes of the meetings held on 4 May 2005 and 10 June 2005. The minutes were duly received.

The Chairman of the NSSC apologised for the fact that there were no attendees mentioned on the minutes of the meeting held on 4 May 2005. She recalled that all members and the Chief Executive were present.

The policy at 03.05 was confirmed. That was for hospital fares, 13p per mile could be claimed for car usage, 2nd class rail fares could be claimed and that taxis, if used, should be for a specific medical reason.

Summer Payments

The board considered the policy proposal for a summer payment. The Chairman of the NSSC proposed an amendment that the payment as specified should apply to both registrant and infected intimates. This was agreed and the substantive proposal, that a summer payment of £750.00, at an approximate annual cost of (approximately) £316,500 be awarded, was discussed.

Mr Spellman questioned why such an "across the board" payment should be made and wondered if this would lead to further "across the board" payments. Mr GRO-A felt that a lump sum payment as proposed would be of sufficient visible value where it would not be in nor form part of any registrant's day to day expenditure outlays.

Mr Spellman and Mr GRO-A thought that such a payment should be annualised and applied to the current level of regular payments.

The Chief Executive strongly felt that the proposal as tabled would meet the prevailing policy of the board of trustees and complement the objectives defined in the Long Term Review to empower registrants to make financial decisions for themselves. He agreed that if the value of the summer payment was applied to the monthly regular payments, it would be absorbed in the manner Mr GRO-A described.

There was a further discussion, led by the Chairman, on the difficulties in interpreting respite breaks and the problem areas that were associated with such requests. The purpose of this summer payment was to enable registrants and infected intimates to decide for themselves how the summer payment might be utilised. Respite breaks would then not appear on the office guidelines but would still be available subject to the criteria detailed in the policy proposal.

Due to the feelings expressed around the table, it was resolved to put to a vote the proposal that a summer payment of £750.00 be made to registrants and infected partners for any purpose

they deemed appropriate, all qualifying individuals to be notified by letter from the Chief Executive and the letter to be carefully phrased to inform them of the revised policy now applied to respite breaks.

The proposal was carried by a majority of 5 with Mr Spellman and one other trustee voting against.

The NSSC minutes of 4 May were then approved.

The minutes of 10 June were approved and the policy recommendations contained therein were agreed.

168.05

1059 – Appeal

The Chairman gave an extensive background to the appeal contained in the papers circulated with the agenda.

Any decision in respect of the appeal was deferred pending a visit to see the registrant by the Trust's IFA to establish what the registrant might realistically be able to afford. The reason for such a visit was that there appeared to be a degree of confusion as to the resources that were reasonably available to the registrant for loan servicing.

169.05

Employment Affairs Committee

The Chairman introduced the minutes of the EAC held on the 14 June 2005. After a short discussion about the status of the PHI and DIS proposals for staff to confirm them as part of each individual's terms and conditions of employment, the minutes were approved.

170.05

Haemophilia Society

The letter from the Society's outgoing Chief Executive to the Chief Executive was noted. The board were advised that an appointment of a new Society Chief Executive would be made this week (beginning 18 July).

There were several questions about the Skipton Fund raised by Mr Payne which were answered by Mr Keith Foster (Fund Administrator).

171.05

Department of Health

There was no formal report on this occasion. The chairman advised the Board that he and the Chief Executive would be meeting the designated civil servant at the Department of Health, Mr William Connon, shortly.

172.05

Partnership Group

In the absence of the Chairman of the Partnership Group, the Chairman spoke to the notes of the meeting held on 13 June

2005 in Manchester. He opined that the difficulties mentioned therein were of a procedural nature rather than personal.

After a short discussion, the notes were accepted.

173.05

The Annual Plan

Objective D was referred to. It was resolved that the publication of the "office guidelines" now be produced without any reference to respite breaks as a matter of course; that all applications for respite breaks would be a matter for the NSSC. Publication of the guidelines be considered at the forthcoming trustees away-weekend.

There was some concern about the achievement of objectives contained in the annual plan which itself was a by-product of the Long Term Review. The Chief Executive advised the board that there would be a session dedicated to this subject at the weekend.

The annual plan was received.

174.04

Skipton Fund Report

The board noted the significant contribution made by the Fund Administrator and the Finance Manager. The report was received.

175.05

Any Other Business

Mr Spellman raised the question of trustees' liability. The Chief Executive replied that there was significant risk cover for trustees and that confirmation of such cover was mentioned in the annual report and accounts.

The board agreed that the possibility of limited liability, similar to that that would arise through the mechanism of the corporate trustee arrangement should be reviewed. It was agreed that this matter be deferred to the Employment Affairs Committee.

The next meeting will be held on 17 October 2005 at the same venue.