

THE MACFARLANE TRUST

Minutes of the Meeting held on Monday 24 January 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)
	Dr M Winter	
	Mr P Spellman	
	Mr GRO-A	
APOLOGIES	Mr G Clarke	(Treasurer)
	Mr W Payne	
	Mr R Tyrrell	
BY INVITATION	Mr A Beaney	PIM
	Mrs Julia Jukes	PIM
IN ATTENDANCE	Martin Harvey	Chief Executive
	For specific business on the agenda	
	Mr K Foster	Skipton Fund Administrator
	Ms L Hague	MFT Finance Section

Principal Investment Managers (PIM)

The Chairman introduced Mr Alan Beaney and Mrs Julia Jukes from PIM. He reminded members present that it had been agreed that PIM should review investment performance over the previous year and look at likely future investment trends that may affect the Trusts investment portfolio.

A comprehensive report from PIM was circulated. Mr Beaney and Mrs Jukes appraised members of the technical matter contained in the report. The board concluded that the current cautious approach to investment practices should be continued.

After several pertinent questions, the Chairman thanked Mr Beaney and Mrs Jukes for their attendance and giving such a professional presentation.

129.05 **APOLGIES FOR ABSENCE**

The apologies were recorded.

The Chairman appraised members of Mr Yeaman's current status in respect of his former trusteeship. *(Subsequent to the meeting the Trust's lawyer advised that, on the basis of the Trust's information about the Haemophilia Society and Mr Yeaman, that he should be regarded as no longer being a Trustee. The Chairman has, accordingly, written to him expressing his thanks for his services).*

130.05 **Minutes of the Previous Meeting**

The minutes of the meeting held on the 11th October 2004 were agreed as a true record.

131.05 Matters Arising from the Minutes.

120.04 – The trustees “awayday” was yet to be arranged. The Chief Executive’s apology was noted.

121.04 – This matter would be reported on later in the agenda.

124.04 – The matter was noted.

131.05 Chief Executive’s Report

The report, circulated with the agenda, was received. The attachments were noted and, where appropriate, approved. The Chief Executive reported that the Trust might be invited to make a presentation at the 2006 World Federation Congress in Vancouver. Dr M Winter felt that the unique position of the Trust made such a proposition, if it took place, a valuable and informative part of the overall Congress agenda.

132.05 Financial Reports

1) 159.05 (1). The report was approved.

2) 159.05 (2). The formal audited accounts circulated with the agenda to each member were received. The Chairman reported that the overall headcount of beneficiaries was inaccurate and, when available, the correct figures would be circulated to all trustees.

(3) 159.05 (3) Dealt with at the start of business.

4) 159.05 (4) The draft revenue budget was noted. The Chief Executive reported that, in light of anticipated staff changes, the numbers as published may well change during the year.

IT Report

The IT report from the Trust’s webmaster and IT consultant was noted. The board noted the amount of hard work afforded to the Trust by the Webmaster and expressed its appreciation.

The following trustees have already agreed or were prepared to agree to receiving e-mails direct from registrants through the Trust’s domain:

Mr P Stevens (Chairman)

Mr G Clarke (Treasurer)

Mr **GRO-A** (Chairman – Partnership Group)

Mr P Spellman said he would be more than prepared to receive letters from registrants for tabling for debate at future meetings.

133.05 Amendment to the Trust Deed.

The paper 160.05 and the accompanying explanatory letter from Berwin Leighton Paisner was received. The Chairman advised members of the rationale behind this variation to the Deed and the further variation that would be put to members of the board at a later date and the various developmental stages leading to the objectives behind the amendments.

The variation to the Trust Deed was agreed unanimously by those present. The Chief Executive was instructed to ascertain the formal agreement of those trustees (Mr W Payne and Mr R Tyrrell) who were unable to be present.. Mr G Clarke had made his consent to the variation clear beforehand. (*Chief Executive's note: These minutes are self-explanatory; if either Messrs Tyrrell or Payne have any reservations, can the Chief Executive be advised*).

The Trustees resolved, pursuant to Section 82 of the Charities Act 1993, to confer upon any two of their number an authority to execute in their names and on their behalf a deed of amendment in the form attached to these minutes, which will amend Clause 12 of the charity's trust deed.

Mrs Elizabeth Boyd

The chairman then apologised to members present for the introduction of an item of business not on the agenda. He advised members that he felt the need for a Vice-Chairman and that this office had been an appointment in the past. He proposed Mrs E Boyd, currently Chairman of the NSSC as Vice Chairman of the Macfarlane Trust. It was resolved unanimously to accept the Chairman's proposal that Mrs Boyd be appointed Vice Chairman.

134.05

National Support Services Committee

The minutes of meetings of the committee held on the 27 October were received. The Chief Executive reported that the minutes of the NSSC meeting held on the 1 December were missing; they would be circulated with the full board minutes. Mrs E Boyd (Chairman) answered several questions from members.

Assisted Conception

The Chairman of the NSSC drew members' attention to the draft minute outlining a draft policy in respect of how the Trust might approach the provision of support for Assisted Conception. She went on to say that this particular matter had been under discussion within the Trust for many years and that the NSSC felt that there was now an opportunity to enhance the established policy.

Dr M Winter said that he was fully supportive of the proposal but was concerned that the chances of success of conception treatments were limited. He went on to say that the purpose of the Trust was to alleviate suffering within the community of care and it was questionable whether or not the Trust should adopt this as a policy.

A lengthy debate ensued. It was resolved in the first instance to ask the Department of Health what their attitude was to the difficulties caused by the apparent post-code lottery that seemed to exist within current NHS provision and to seek confirmation or the Department that the Trust was proposing to support registrants in their attempts to advance conception by assisted means.

Office Guidelines

The general and specific guidelines paper prepared by the Chairman was received. It was resolved to re-affirm as follows:-

- a) That the office should have guidelines of this nature.
- b) That they should be expected to exercise discretion and not regard the maximum sum permitted to be given in any case as an automatic entitlement.
- c) That the Trustees retain the power in all cases to make grants in excess of the guideline amounts if they deem fit, and require the staff to bring to their attention any case where the maximum delegated sum does not appear to be sufficient.

The Chief Executive advised members present that pertinent to the specific case (1701) mentioned in paragraphs 9 and 10, letters of relevance to the case from the registrant and his clinician were laid around the table.

Having considered all the circumstances of the case, and noting that the situation as presented (i.e. the apparent lack of regular reviews) was not the fault of the registrant, it was resolved that the level of current support could not continue. It was further resolved that there should be no immediate cessation of financial support and that:-

- a) The current level of support should continue for a further three months.
- b) In three months it should be reduced by 50%.
- c) In six months support should cease, subject to d) below
- d) The review of policy in respect of complementary therapy should continue to be reviewed.

135.05

Department of Health Report

The Chairman gave a verbal report of a meeting he and the Chief Executive attended with Mr William Connon on the 10 January 2005. Mr Connon is the successor to Mr R Gutowski. The Chairman gave a brief synopsis of the broad range of matters discussed including the business case and implications for the business case in particular and the Trust in general in relation to the forthcoming election, amendments to the Trust Deed, the conflation of section 64 funds and those provided from within the block grant settlement. The Skipton Fund was also discussed in some detail.

136.05 Haemophilia Society Issues

The resignations of Ms T Morgan and the position of Mr A Yeaman had already been noted. There was no matter of any major significance to report.

137.05 Partnership Group Report

Mr GRO-A Chairman of the Partnership Group, presented the notes of the meeting held on the 13 December 2004. The Chief Executive reminded members present about the request from the Group outlined in point 4.

The situation in respect of registrants' communication by e-mail with trustees had been resolved earlier.

The notes were received.

The Chairman of the Partnership Group then updated members on the bulletin board and the challenges arising for the Trust from this mode of communication among registrants and the difficult tone and nature of recent meetings of the Group.

Mr Pat Spellman said he would be delighted to attend any future meetings of the Group.

The Chairman of the Group introduced a copy of a petition letter that was being circulated. The board noted its contents and accepted the advice from the Chairman that he would attempt to deal with the matters raised therein.

A copy of the letter is attached to these minutes.

138.05 Annual Plan Update

The board of trustees noted the final annual plan reflecting achievements and work in progress during 2004.

139.05 Draft Annual Plan 2005

The board noted the draft annual plan for 2005. Mr Spellman felt that more weight should be given to "breaking out" by reference to the original Long term Review. The Chief Executive accepted this point and invited members of the board to comment on the proposals and add to them if they felt it necessary.

140.05 Working Group Reports

The report at 166.05 (1) was accepted in full.

The board congratulated, in absentia, Ms J Cohen on completing her probationary period.

141.05 Skipton Fund Report

Mr Keith Foster, Fund Administrator, spoke to the report circulated with the agenda. After several questions, the report was received.

Members noted that there would be a meeting of the Skipton Fund board of directors immediately following the meeting of the board of trustees.

142.05

Bank Mandates

Mrs L Hague took the opportunity to acquaint members of the board with a number of revised bank mandate arrangements and the various authorities for the Trust and Skipton Fund were agreed and signed.

143.05

Any Other Business

The Chairman reported on the proposal he had received from a small number of registrants about capitalising future revenue receipts from the Macfarlane Trust.

He reported on how it might work, the possible legal ramifications for the Trust and that it was a matter of report for the time being and that views of trustees would be welcome. He took note of a number of reservations expressed around the table.

The next meeting will be held on the 25.4.05. The venue will remain the same.

The meeting terminated at 4.00pm