

THE MACFARLANE TRUST

Minutes of the Meeting held on Monday 21 August 2006 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 C Hodgson
Mr P Dolan
Dr M Winter (Medical Trustee)
Dr S Chapman
Mr R Mishcon
Mr GRO-A
Mr S Gregg

APOLOGIES Mr GRO-A
Mr G Clarke (Treasurer)

IN ATTENDANCE Martin Harvey (Chief Executive)

BY INVITATION Mr GRO-A (Chairman of the Partnership Group)
Ms Sue Phipps (Eileen Trust Board member)

231.06 Apologies for Absence
The apologies were recorded.

232.06 Mr GRO-A
The Chairman reported that Mr GRO-A had decided to resign as a member of the board of trustees. Mr GRO-A was appointed by the board of trustees.

233.06 Ms Sue Phipps
The Chairman welcomed Ms Sue Phipps, a trustee of the Eileen Trust who was present for the item on the minister's response to the business case for increased funding.

234.06 Trustees determination to consider a response to the Minister's Letter dated 28 July 2006 in respect of the Funding Bid as represented in the business case submitted in November 2005.

The Chairman proposed that this matter be taken now, this was agreed. The formal letter from the minister was tabled. The Chairman referred to his report on the substance of the letter

that had been previously circulated by e-mail; Dr Chapman was furnished with a copy.

The Chairman sought the views of members present.

There followed a wide ranging debate, the following points are salient.

- a) That there had been, as widely reported, unprecedented levels of cut-back in available resources to the NHS. It would be relatively simple for the DH to report that against this climate an increase had been made against all expectations. All negotiations with the DH were "political" in content and that the Trust had no political constituency to offer as a bargaining counter.
- b) That any future negotiations should be in line with traditional practices adopted by the trade union movement using the economic arguments available. That the settlement might be initially welcomed but, at any meeting, the need for realistic levels of funding to address cost increases in basic living should be reinforced.
- c) That the issues need to be addressed in practical terms and that each Trust's funding requirement should be addressed separately.
- d) That the offer was not unexpected and the matter is now with officials. It was unlikely that the minister would deviate from her decision and the only realistic route to take would be with officials.
That the tactic of seeking graduated increases to the levels expounded in the business case over a three year settlement period would be point for debate with officials.
- e) That the letter clearly indicated an offer to talk further, the key was how this "offer" should be addressed.
- f) That any negotiations should distinguish clearly between the capital and revenue submissions in the case.
- g) That the business case, a view shared by all, had not been addressed in any meaningful way and that any future meeting should be demanded with urgency as this was a matter that reflected the needs of registrants now.
- h) In terms of a way forward, the matter of resignations should be reserved; there was need to understand the political situation that now confronted the Trust; use the meeting with officials to seek to develop the funding situation over a period (see d); that

the Trustees had a clear duty and responsibility in their duty of care to the beneficiary community.

i) It was unlikely that the savings in the probable funds budgeted for the Skipton Fund Ltd could be of benefit to both trusts, but this would be explored with officials.

j) In terms of the law, registrants were asked to forego their legal rights. Is there a legal case to go back to the government? The Trust had an obligation therefore it could be held that as a matter of law, the trustees are obliged to review their duty of care to the beneficiary community.

k) The Chairman reported on the comments the had received from two registrants and advised the board of their contents, specifically:-

- That the Chairman should write to all Members of Parliament.
- That the Chairman should make a public statement in respect of the letter from the minister.
- That the trustees should resign en bloc.
- Seek a judicial review.
- That the reserves should be committed to providing support for the beneficiary community.
- The statement by John Hutton when a minister at the department.

The Chairman asked members of the board to adopt the following proposal:-

“that after debating the response to the minister’s letter dated the 28 July replying to the business case for increased funding, the invitation to attend a further meeting with officials should be accepted to re-express the key points in the business case and how they affect the community of care; that the letter from the minister does not address the views of trustees and that they are minded to resign and that there is a will to discuss with officials what sum of money there is that accords with the business case where that might be found and from where”.

An amendment was put seeking to strike out any reference to resignation at this stage and to only accept the invitation to attend a further meeting and to seek at least a three year continuation of funding at the level finally agreed.

The amendment was accepted and carried.

Mrs Sue Phipps was thanked by the board for attending this part of the meeting and then withdrew.

- 235.06 Minutes of the Previous Meeting**
The minutes of the meeting held on 8 May 2006 were signed as a correct record.
- 236.06 Matters Arising from the Minutes.**
216.06 – 189.05 Noted.
219.06(d) – Noted.
220.06 – Noted. The Chief Executive advised that the funds had not yet been received.204.06
221.06 – Noted. The board expressed their congratulations to Mrs Boyd on her successful re-election.
221.06(2) – The Chief Executive reported that a valuation on the property owned by 1063 had been sought. He further reported that 1063 could not agree to any negotiation in the reduction of his debts as this information would be shared with other lenders and his credit rating would be impaired. The board resolved that this was against policy in respect of the treatment of debt and that before any relief could be given it as necessary to approach lenders to see if there was a possibility of gaining a reduction in the registrant's liabilities.
- 237.06 Chief Executive's Report**
The report and annexes of the WFH congress in Vancouver and report on the Men Only 3 event were received.
- 238.06 Financial Reports**
The following reports were noted.
1) The first quarter of grants and regular pay for the period were noted as were the comparisons for expenditure in the previous three years. The cost centres were similarly noted.
The summary of support expenditure for the first quarter only and the total cash outflow of £980,907 was noted (this include the summer payment that would only appear in the first quarter).
The board noted that actual management expenditure was below budget.
2) Investment Report
Noted.
3) Annual Accounts 2005/06
The accounts for the period were formally received. Corrections to the area subscribed to Messrs Dolan and GRO-A were noted.
- 239.06 Honeycombe Legacy**
The grant of £2,000.00 to 1534W was ratified.
- 240.06 IT & Webmasters Report**
The report was noted.
- 241.06 National Support Services Committee**

The Chairman of the NSSC presented the minutes and schedules of support of the meetings held on 3 May 2006, 7 June 2006 and 5 July 2006.

Arising from the minutes, Mr Dolan asked about the provision of dental treatment and that the Trust should consider providing support for such requests. Dr Winter explained that it was vital for a number of clear medical reasons that all dental treatment for the registrant community should be conducted through the Haemophilia CCC

Mr Dolan asked about the "exceptional circumstances" that needed to be established in respect of applications for respite breaks. The policy was explained and how it correlated with the letter setting out the summer payment.

It was agreed that an analysis of respite requests for support and where they originated, in terms of applicant Centre, would be considered at the October meeting of the NSSC.

The minutes and attached schedules were accepted.

242.06

Partnership Group

The Chairman welcomed Mr [GRO-A] Chairman of the Partnership Group.

Mr [GRO-A] presented the report on substantive issues that were attached to the notes of the meeting held on the 17 July 2006.

The Chairman confirmed to Mr [GRO-A] how support service policy matters were dealt with and that the final arbiter on policy confirmation was the full board of trustees.

Mr [GRO-A] asked if the medical trustee should be a member of the NSSC to properly make a judgement on medical issues. Mr [GRO-A] was advised that all NSSC papers were sent to the medical trustee and the medical trustee confirmed that he was always available for consultation if required. The Chairman advised Mr [GRO-A] that it was always necessary to strike a balance in respect of the support offered by an individual's clinician, the views of trustees in respect of that medical support and the advice, when sought, from the medical trustee. There was a requirement to balance the trustees obligations in respect of their duty of care and financial probity.

The policy on respite as a whole was discussed.

Mr [GRO-A] stressed the fact that any trustees who attended the Partnership Group would be welcomed and that this would enhance the meaning of "partnership".

Dr Winter suggested that there might be a rota of trustee attendees and this could be considered at each meeting of the board. The Chairman said that it was important for PG dates to be published well in advance.

Mr GRO-A in addressing a question from Dr Chapman on perception of the board of trustees by the PG, said that the main difficulty was the perception as to how the Trust makes funding available and that perceived under-funding was a historical problem that has simply carried through.

The report and notes of the meeting of the 17 July were received.

Mr GRO-A was thanked by the board for his attendance and the withdrew.

Mr Dolan expressed the importance of medical reports in respect of those applications for support when medical input was necessary.

243.06

Formal third stage appeals for determination.

1823A – On advice from the medical trustee and a review by the board as a whole, the appeal was upheld; the establishment of costs as set out in the office guidelines was to be ascertained.

1755 – This was declined in that the medical grounds stated were not consistent with current Trust policy.

1425A – This was declined as the Trust had met its full commitment under existing Trust policy.

1174 – This was declined in that medical grounds stated were not consistent with current Trust policy.

1088 – That a grant for the partial repayment of the family loan be approved and be treated in terms of time-frame as an enhanced setting up home grant.

(Chief Executive's Note: Following advice from the medical trustee, the board resolved that all applications for support for medical procedures such as assisted conception, dental treatment, lypodystrophy etc should be referred to the appropriate Primary care Trust to establish if funding might be available. This will be a matter for policy review at the October meeting of the NSSC).

244.06

Tainted Blood Information

At the request of the bereavement group, the matter of circulation of information about the tainted blood campaign to the wider bereaved constituency was considered. It was resolved that the information should not be circulated.

- 245.06 Employment Affairs Committee**
There was no business to consider under this item other than that mentioned in the Chief Executive's report.
- 246.06 Haemophilia Society Issues.**
The board of trustees noted that the Chief Executive had held routine meetings with the Chief Executive of the Society.
- 247.06 Department of Health Report**
This matter had been debated earlier, minute 234.06 refers..
- 248.06 The Annual Plan**
The annual plan and recorded updates for the current and previous quarters were noted. The board were advised that the end of 2006 would see the culmination of the current annual plan in that this document has commenced following the publication of the Long Term Review.
- Mr Mishcon considered that the recommendation to introduce the PQASSO quality assurance benchmark might well be unnecessary.
- 249.06 The Risk Assessment Strategy**
Mr Spellman raised the matter of the possible necessity of an Internal Audit Committee to monitor Trust expenditure. IT was agreed that this should be considered at the forthcoming Trustee Development Day on the 4th November 2006.
- The report was received.
- 250.06 Skipton Fund Ltd**
The Chairman acquainted members of the board with the current situation in respect of the Fund and the retrieval of funds stolen.
- 251.06 Any Other Business**
The Chairman asked members present if they had any further business not itemised on the agenda. There being no further business, the meeting terminated at 4.30pm.
- The date of the next meeting of the board of trustees is scheduled for the 16th October 2006.