

THE MACFARLANE TRUST

Minutes of the Meeting of the Board of Trustees held on Monday 19 July 2010 at The New Cavendish Club, 44 Great Cumberland Place, London, W1H 7BS from 10.00am

PRESENT Mr C FitzGerald (Chairman)
Mr A Burgess
Dr S Chapman
Mr P Dolan
Mr R Evans
Mr S Fuller
Dr V Martlew (Medical Trustee)
Mr GRO-A
Mr R Mishcon
Mr P Spellman

APOLOGIES Mrs GRO-A (Chairman NSSC)
Mr GRO-A (Chief Executive)

IN ATTENDANCE Mr N Fish (Assistant to the Chief Executive)
Ms L Haigh (Finance Manager)
Ms R Riley (Support Services Manager)

BY INVITATION Mr Richard Champion (Principal Investment Management)

458.10 Apologies for Absence

Mrs GRO-A provided her apologies for absence in advance of the meeting. The Chairman reported that, following a period of ill health, Mrs GRO-A was making good progress. The Chairman and Dr S Chapman provided an oral update on the condition of the Chief Executive; the Board asked that their best wishes be conveyed to him and his wife.

459.10 Minutes of the Previous Meeting

452.10 Mr R Evans requested it be minuted that he had stated that the Trustee appointment process should be agreed in advance.

453.10 4) The minutes should have made it clear that this was an appeal case.

Subject to these corrections, the minutes of the meeting held on 26 April 2010 were approved and signed as a correct record.

460.10 Matters Arising

450.10(442.09, 429.09, 406.09) Secured Loan, note 2 on schedule - The Chairman asked for an update on the circumstances of this beneficiary. Mr S Fuller responded that he had now moved away from the registered property due to a relationship break-down. The Support Services Manager was

MACFARLANE TRUST
Cash-flow
Period: 01/04/10-31/03/11

	Predicted cash flow 2010-11	Budget 2010-11
Reg Pay		
Non-infected beneficiaries	165,260	900,000
Discretionary "Top Up" Payments	829,509	950,000
		1,850,000
Grants		
Office Guideline grants	44,770	20,000
Exceptional circumstances & Trustee grants	42,998	40,000
Designated fund	89,828	100,000
		140,000
Beneficiaries Groups		
Haem. Soc. Project "Activate"	11,253	11,253
Bereavement Project	2,000	2,000
		13,253
Beneficiaries Events		
Men Only Weekend	13,706	16,000
Women only	3,746	5,800
SFW-4	22,000	22,000
		43,800
Subcontractors		
THT	2,000	5,000
Benefit Advice	8,000	5,000
		10,000
Total	1,235,070	2,077,053

Total allocation from DoH	2,329,000	2,301,312
Net management cost as per budget	-288,428	-288,428
Net allocation	2,040,572	2,012,884
Donations	10,145	0
PIM income generated estimate (minus management fees)	120,000	150,000
Interest estimated	1,500	5,000
Total amount available for charitable purposes	2,172,217	2,167,884
Shortfall/Surplus	937,147	90,831

unsure of the details of the first charge and would wait until an appropriate time to request these. The Chairman was confident that the details would emerge in the course of the separation proceedings. Secured loan, note 4 on schedule – The Support Services Manager informed the Board that this beneficiary had recently found employment and would begin making repayments once she had settled into the role. The Chairman asked that the NSSC revisit the issue of non-performing loans at their next meeting.

454.10 The Chairman referred to the Financial Reports that were not discussed at the previous meeting due to time constraints and that no comments had been received by email. He explained that the reasons for being over budget in 2009/10 (albeit by only £5k) were the bonuses paid to the staff in recognition of their special effort to deliver the changes brought about as a result of the implementation of the Government's response to Lord Archer's Inquiry Report and the unbudgeted Consultancy fees for the work carried out on risk assessment and staff pensions review. In response to a question from Mr P Spellman, the Chairman confirmed that all the legal fees incurred in relation to that implementation had been reimbursed in full by the Department of Health (DH). The Chairman referred to the tabled amendment sheet entitled 'Total Funding 2010-2011' and informed the Board that £70k had been allocated provisionally to MFET for management costs and that the balance after all non-discretionary payments and the Eileen Trust's 4% share had been allocated to the Trust, leaving £2.3m for charitable disbursements and management costs.

461.10

The Objects Clause of the Macfarlane Trust

Mr R Mishcon was invited to update the Board on progress made with the amendments to the Objects Clause. He referred the Board to the email from Mrs M Protani, the Trust's solicitor, which contained the wording agreed by the NSSC. The Chairman mentioned that he had accepted that the Objects Clause would continue to use the word "Primary" rather than "Infected" as had been suggested in the Minutes for the previous meeting. Mr Mishcon informed the Board that correspondence had taken place with the DH and that it had been made clear to them that the changes were not substantial and merely sought to tidy up the wording and to ensure that carers were not excluded. If agreed, the next step would be to apply for a cy pres scheme from the Charity Commission at which time a public consultation would occur. Mr Mishcon finished by requesting that:

- i) the Board agreed the wording of the Objects Clause;
- ii) that both he and Mrs Protani attend any further meeting with the DH.

With reference to other emails attached to the papers, the Chairman added that Mrs Protani had thought it might be said that the reason the Trust wished to amend its Objects Clause was because it had too much money and was looking for ways to spend it. He had assured her that this was most definitely not the case; rather that the Board wished to take the opportunity presented by the need in the light of the Government's response to Lord Archer's Inquiry Report to provide for carers who currently fell outside the strictest interpretation of the Objects Clause to make explicit those categories of beneficiary whom the Board (and the Department) had long considered to be covered implicitly by the existing wording. If the DH continued to oppose the changes then the Trust would simply have to continue with its current policies and could not provide support for all carers.

In response to a query from Mr P Dolan the Chairman confirmed that the public consultation would be carried out by the Charity Commission and would involve something along the lines of an advert in the national press. The Trust would notify its members prior to this appearing and would assure them that this was simply a formal process. Dr V Martlew asked if the Clause shouldn't specify *inherited* bleeding disorder. Following a brief discussion the Board felt it would be better to leave *inherited* out unless the DH picked up on it.

It was resolved that the new wording of the Objects Clause be approved and that the process of applying for a cy pres scheme should proceed. Mr Evans suggested that the matter be referred to the DH and Haemophilia Society but agreed that there was no need to await their approval. He also requested an update at the next Board meeting.

462.10

The National Support Services Committee

- 1) The minutes of the meetings held on 7 April, 5 May and 30 June 2010 were noted by the Board.
- 2) There was nothing to report on the Honeycombe Legacy.
- 3) The Chairman spoke to the attached paper and expressed his hope that the policy recommendations would be agreed by the Board since the non-infected community had known since May 2009 that they would be due to receive further support from the Trust and the Trust had actually been in receipt of the funds allocated for this purpose for six months already. He summarised the recommendations and expressed the view that, even if twice as many widows came forward as had so far, the policy would be easily affordable within the annual sum now set aside for non-infected beneficiaries.

A number of Trustees expressed their concerns with recommendation 1a), with the following reasons being cited:

Providing regular payments to widows then removing them because they were not affordable could prove more damaging than not paying them in the first place; would it be right to quadruple the income of those on very low incomes and do they really need it; different areas of the country require different incomes to live; staff visits to assess individual need would be better; the recommendation was not supported by all the members of the NSSC; the funds may be required for Primary Beneficiaries; widows should be consulted if possible; are grants to widows covered by the DWP waivers; a day should be set aside for the Board to discuss the issue in depth.

The Chairman replied that the DH had already agreed that of the roughly £2m originally allocated for the support of the non-infected community roughly half could be used for additional discretionary support for the infected community; the chances of having to withdraw the regular payments were virtually non-existent since the funds came annually from the DH and the policy was well within budget; individual grants could take into account where the beneficiary lived; grants to widows were covered by the DWP waivers but the office would double check; individual means testing might be logical but was not always viewed as favourable or practical.

The Support Services Manager notified the Board that a widow had recently expressed numerous concerns when the suggestion of a home visit had been made and that this was likely to be a recurring theme. It was suggested that the NSSC should consider a menu of questions that she and the Support Service Officer should ask and this case should be used as a tester. Prior to the September meeting of the NSSC, as many visits as possible should be arranged with a report to be provided by the Support Services Manager at that meeting.

The Chairman concluded that, even though the matter of relieving the needs of the non-infected community had already been discussed for over six months at Board meetings as well as at NSSC meetings, a further meeting dedicated to this issue would be arranged.

Recommendation 1b) was formally adopted by the Board.

463.10

Investment Report from Principal Investment Management (PIM)

The Board welcomed Mr R Champion from PIM who distributed a printed handout and provided an oral report on the Trust's investments.

Following the oral report, Mr Mishcon asked why PIM had not reached the benchmark targets set. Mr Champion responded that Gilts had performed badly in 2008 and that historically they

had considered Corporate Bonds to be worth the extra risk but this proved not to be the case in 2008. They held too much equity in the banking sector in 2008 and risk was reduced too early in 2009. More recently the portfolio had been slightly overweight in British Petroleum [during the time of the crisis in the Gulf of Mexico]. He added that PIM now employed 9 analysts specifically for equities, they had a more complex way of dealing with risk and that there was a new CEO in place to improve performance.

The Board thanked Mr Champion for his report.

The Chairman reminded the Board that under the new arrangement, the Trust would only require reserves equivalent to 6 months forward spend, which amounted to some £1m. This meant that there would be £3m to utilise in the near future. Once the reserves had been reduced to £1m the Board could then market test to find the most suitable Fund Manager for that size investment and risk tolerance. The Finance Manager would check the management agreement with PIM and see how long it would take to terminate the contract with them if it came to that.

464.10

The Future Governance of the Trust

The Chairman spoke to his attached paper entitled 'Future size and composition of the Board – a Proposal' and informed the Board that all Trustees other than Mrs GRO-A and Dr Chapman had expressed a desire to continue in their roles.

The Haemophilia Society Board met at the start of July and had noted the paper. Mr Dolan, a Trustee of the HS, added that the HS Board had expressed a desire to have the right to nominate 1/3 of Macfarlane Trust Trustees but 3 if the Trust decided that they wanted a Board of 8, and that one of those 3 should be an HS Trustee. The Chairman said he had not been given that impression by the HS Chief Executive and would seek clarification from him and the HS Chair; he had hoped that the stakeholders would accept that the Trust Board had a duty to appoint the right number of Trustees with the right balance of expertise and experience. Mr Mishcon felt that if the Trust would now be focussing its activities mainly on beneficiaries without haemophilia, it would not require so many HS nominated Trustees. The Chairman suggested that if the HS insisted on nominating 3 Trustees then one of these could be from the bereaved community. He stressed that *all* Trustees represented the beneficiaries of the Trust and *not* their nominating bodies.

Mr Evans requested a proposal of how the Trustees would be appointed; he suggested that if 8 was the optimum number and 9 wanted to remain then could the Board not consider retaining 9 for a further year; and he suggested that the Chairman could

remain in post for a further 6 months, beyond 31 March 2011, at which time the new Board could vote for the Chair.

The Chairman reported that he and Mr P Stevens (Chairman of the Eileen Trust) had met with Anne Milton, the Parliamentary Under Secretary of State for Public Health, following a letter he had sent to her and other relevant ministers. During the meeting the Minister asked for a bid of what the Trust hoped to achieve for its beneficiaries, the Chairman responded that this was a question for the campaigners and beneficiary community.

The Chairman reported that he, Mr Stevens and the Assistant to the Chief Executive were due to meet the relevant DH Policy Civil Servants following the Board meeting to provide information to help them brief the minister. He stressed that the meeting would not be a negotiation; rather it would be an opportunity to ensure that everybody concerned with policy making had all of the information and numbers that they would need in order to make an informed decision.

465.10

Employment Affairs Committee (EAC)

Due to the retirement from the Board of Dr Chapman, the EAC had elected Mr Fuller as the interim Chair until the end of the year pending approval by the Board. The Board formally approved this appointment and asked Mr Fuller to decide whether or not the vacancy on the EAC would need to be filled; he would share his views with the Chairman in due course. Mr Fuller agreed and stated that it was unlikely that the EAC would need to meet before March 2011.

466.10

Financial Reports

- 1) The 2010/11 first quarter annual discretionary disbursement summary was received and noted by the Board. It was noted that grants for the period were low because only the non-infected community could now apply, save for exceptional circumstances. The Chairman asked the NSSC minute taker to ensure that when a grant for a PB was agreed that the exceptional circumstance was noted.
- 2) The 2010/11 first quarter management accounts were received and noted.
- 3) The 2010/11 first quarter investment report was received and noted.
- 4) Following a discussion by the Board it was agreed that it would be better not to transfer funds to the Allied Irish Bank, where a slightly higher return could be achieved, at the present time but that the matter would be discussed again at the Board meeting in October.

Due to the unfortunate ill health of the Chief Executive, the Finance Manager asked the Board to consider allowing payments over £10k to be approved by the Chairman and

another Trustee (instead of the Chief Executive). This was agreed by the Board.

Finance matters would be moved up the agenda for the Board meeting in October.

467.10

Chief Executive's Report

In response to a question, the Support Services Manager notified the Board that no responses had been received from any widows to the adverts that had been placed in the national press.

The Support Services Manager provided a brief oral report on the World Federation of Haemophilia (WFH) Congress and informed the Board that all of the Trust's delegates found it useful. From the information learned at the Congress the implications for the Trust in the future were a possible increase in requests for psycho-social support from spouses and partners; the need to alleviate the needs of PBs with haemophilia in their 40s and 50s whose bodies were likely to be in a similar condition to people in their 70s and 80s; an increase in support for parents; and a possible increase in requests for help with problems regarding DLA entitlement.

The Board thanked the Support Services Manager for her report and the Chairman requested that she send round a memorandum and reports from each of the Primary Beneficiaries who attended. Mr A Burgess suggested that Mr GRO-A's report should be published on the Trust's website since he was the Chair of the Partnership Group. The Chairman agreed and felt that all of the reports from the other delegates should be posted there as well. He informed the Board that neither the Chair of the NSSC nor the Chief Executive were able to attend due to ill health and that it had been too late to send replacements.

Mr R Evans asked if the Trust had written to Mr G Clarke to congratulate him on receiving an MBE. The Chairman confirmed that he had communicated his congratulations personally to Mr Clarke.

468.10

Any Other Business

The Chairman reported that the final accounts were ready and would be circulated to Trustees for comment; the Chairman's statement would be completed at a later date. He stressed to Trustees that he would be extremely pleased if he were able to comment on the Trust's plans for the reserves by October when it was hoped that the accounts could be published.

Mr Burgess asked if there would be a new Treasurer appointed in the light of Mr Clarke's retirement from the Board. The Chairman responded that at the present time there would not be a replacement but that the matter would be discussed at a later date if necessary.

On behalf of the Board, the Chairman thanked Dr Chapman for the valuable contribution he had made to the Trust over the last four and bit years and paid tribute to the professionalism that he had brought to the conduct of the Trust's affairs.

Unless a special meeting could be arranged before then to continue the discussion referred to at 462.10, the next meeting of the Board of Trustees will be held on Monday 25 October at the New Cavendish Club, 44 Great Cumberland Place, London W1H 7BS from 10.00am.

There being no other business, the meeting terminated at 13:40