

THE MACFARLANE TRUST

**Minutes of the Meeting of the Board of Trustees held on Monday 27
October 2008 at the Novartis Foundation, 41 Portland Place, London W1
from 10.00am**

PRESENT	Mr C FitzGerald	(Chairman)
	Mrs E Boyd	(Chairman – NSSC)
	Dr S Chapman	(Chairman – EAC)
	Mr R Evans	
	Mr S Fuller	
	Mr C Hodgson	
	Mr R Mishcon	
	Mr P Spellman	
	Dr M Winter	(Medical Trustee)
APOLOGIES	Mr G Clarke	(Hon. Treasurer)
	Mr P Dolan	
	Mr GRO-A	
BY INVITATION	Mr James Smith	(First Actuarial – Item 382.08)
	Ms Vicki Burton	(First Actuarial – Item 382.08)
	Mr GRO-A	(Chairman – Partnership Group – Item 385.08)
	Mr GRO-A	(Past Chairman – Partnership Group – Item 385.08)
IN ATTENDANCE	Mr M Harvey	(Chief Executive)
	Ms R Riley	(Support Services Manager)
	Mr N Fish	(Assistant to Chief Executive)

375.08 Apologies for Absence
These were noted.

376.08 Minutes of the Previous Meeting
The minutes of the meeting held on 14 July 2008, previously circulated, were approved and signed as a correct record.

377.08 Matters Arising
363.08 (346.08)(e) the amended Report & Accounts were tabled. The Chairman reminded the Board that the draft accounts had been circulated for comment on 1 October, that a note of a meeting held with the Auditors on 9 October had been circulated subsequently and that a copy of the final Report & Accounts had been circulated electronically on 24 October. The Chairman thanked those members of the Board who had responded with comments and alluded to several matters in the

Accounts, in particular the removal of MSPT2 payments from the Income and Expenditure statement. There being no further comments or observations the Report and Accounts for the period to 31 March 2008 were approved and signed.

The Chairman noted that, following the Board's approval of the revised investment policy, the Investment Managers had acted quickly to implement the changes and the resultant increased weighting of the reserves portfolio towards bonds had helped to reduce recent losses somewhat.

365.08 The Board noted that this matter would be dealt with under 379.08

366.08 – Mr Mishcon referred to the Board's conclusion that his dissertation should be reviewed with a view to seeing whether there were any sections that could be adapted so as to make it possible for the Board to agree publication in an expurgated form.

The Chairman responded that he had previously asked the Assistant to the Chief Executive to review the dissertation in line with the sentiments expressed in the minutes and that, while many of the points raised were not of concern, some key areas of difficulty remained. He reminded the Board that if the dissertation was to be available on the internet, via the University's website, beneficiaries could and would access it. Mr Mishcon said he would provide a further expurgated version of his dissertation for the Chairman to review. The Chairman undertook to do so and to discuss any issues still arising with Mr Mishcon. If any such issues then remained unresolved, they would be referred back to the Board for review.

371.08 noted.

378.08

Chief Executive's Report

The Chief Executive went through his report page by page and invited comments. Matters raised included the following:-

- The likely costs of sending a delegation to the World Federation of Haemophilia Congress in 2010 would be to the order of £1280.00 per person excluding the Congress registration fee (approximately £400.00) and subsistence. The Chairman felt that if another delegate were to attend then it should be a beneficiary of the Trust. If required, the Board had no objection to a delegate receiving sponsorship provided they knew who the sponsor was.
- The likely outcome for Department of Health funding for 09/10. The Board were informed that a meeting with departmental officials would take place the following day.
- The current position in respect of the introduction of the Employment Support Allowance and action taken by the Trust to try to ameliorate the process of claiming the benefit for the Trust's community of care.
- The arrangements for closing the office over the Christmas

Holiday. It was agreed that the Trustees' Lunch would be rearranged for 19 December.

- The Assistant to the Chief Executive apprised the Board of the current position in respect of establishing a policy for conservative dental treatment free at the point of delivery that could curtail the need for costly intrusive dental care in the absence of that provision. To date the responses received had not been overly promising. The Medical Trustee apprised members of the medical and economic benefit of exempting persons with haemophilia should be exempt from charges for conservative dental treatment. He added that the responsibility for dental care resided with Primary Care Trusts and not Comprehensive Care Centres and that he had taken steps to try to move this forward. He said he would follow up his inquiries and report back to the January Board meeting.
- The responses from the six firms of lawyers which were market tested will be considered by as and when they are received. In the interim the Trust continues to utilise the services of BLP if needed.
- The current situation in respect of MSPT2 category (g) claimants and why those that would have qualified for payment were excluded just because they were not party to the original litigation and the moral case that existed for consideration. This will be discussed at the meeting with departmental officials the following day.
- The appointment of a Medical Trustee to succeed Dr Winter. A suitable candidate, Dr Vanessa Martlew (Clinical Director of Haematology at the Royal Liverpool Hospital) had been interviewed but the process of finding a successor is subject to "Nolan Rules" and prior to any confirmation, an advert will be published about the trusteeship to establish if there are any further expressions of interest. *(Note: It is hoped that an appointment can be made before the January 2009 meeting of the Board)*. All other Trustees whose appointments are coming to an end have been notified and will let the Chief Executive know if they wish to be reappointed by the end of November.
- The reports from the conference organiser were noted.
- The IT report was noted. Mr Fuller made a number of technical observations about the report. The Chief Executive said they would be reported to the responsible officer.

379.08

Trustee Strategy & Development Day

The Chairman reported to the Board that he felt the Strategy & Development Day had been useful and he summarised the key strategic issues that those present had addressed. *(Note: All Trustees were furnished with a copy of the Strategy & Development Day agenda).*

The Board were asked to consider two policy issues arising from the Strategy & Development Day, they were:-

1) The Proposed Welfare Policy

The Chairman introduced the paper that had been considered and opined that it was, as previously reported, a further step in the Trust's objective to refine the focus of its financial support so as to provide more for those in greatest need. He went on to say that the proposed welfare policy had been reviewed informally by a lawyer from the Charity Commission in terms of meeting the Trust's objectives and that the lawyer had no doubt that the policy was within the powers of the Trustees to adopt and that their judgement as to what was fair in terms of its application would not be challenged. He concluded by saying that the key issue associated with the proposed welfare policy was the construction of the proposed census form that would be designed to elicit the information the proposed policy required so that the appropriate level of regular payments could be disbursed.

Mrs Boyd reminded the Board of Trustees that it was important to consider as part of the proposed policy the plight of those primary beneficiaries who were on Incapacity Benefit but were denied Income Support and the associated "passport" benefits. She went on to say that recent information reported to the Trust suggested that some 75% of those primary beneficiaries in this situation could not reasonably survive without the Trust's regular payments.

Mr Mishcon referred to the aide memoire he had circulated at the Strategy & Development Day that had illuminated a number of disbursement inconsistencies when comparing and contrasting the social and economic status of primary beneficiaries and opined that while the policy proposal before the Board may well be deemed unobjectionable it might not be judged to be fair, in particular to those primary beneficiaries who could be considered to be most in need of relief. He too referred to the inequalities which could arise from a failure to recognise the disadvantages suffered by some beneficiaries who, even though themselves are on very low incomes, were nonetheless denied Income Support and the advantages that accrued through the acquisition of the associated passport benefits.

Mr Hodgson was concerned that the proposed welfare policy could lead to means testing and felt that he could not support such a tendency.

After a vigorous discussion, the Chairman summarised the basis on which it appeared that, while the Welfare Policy proposals were broadly accepted by the Board, they should again be referred back to the Committee for further consideration. He remarked that the Board had accepted that it was right when seeking to set a Welfare Policy to have regard to the fact that the additional or "passport" benefits available to those households which did qualify for Income Support were not

available to those which did not, even though those might themselves be on very low incomes and might well therefore be deserving of extra support from the Trust. It was clear that the Board's preferred approach was to have regard, when setting benchmarks for differential levels of financial support for beneficiaries, not to gross average household incomes but to net figures which would include the full value of all benefits received (other than from the Trust) on the one hand as well as all income (including tax credits) on the other but after appropriate deductions for income tax and National Insurance. While this did not mean individual means testing (which had been broadly recognised to be overly intrusive and in any event impracticable for the Trust to attempt), the Board also recognised that it was entirely right in seeking to relieve the needs of beneficiaries to focus most on those whose needs, both financial and health related, were the greatest. The Board agreed that the matter be referred back to the NSSC for further consideration and that a further report be available for the January 2009 meeting.

2) Rich Picture Ltd.

The Chairman reported that a presentation had been given by Rich Picture Ltd. at the Strategy & Development Day and that there was agreement that the Board should approve the proposal that a trial programme should proceed, even though some concerns had been expressed about the "management style" construction of the programme content. The Chief Executive reported that the Trust had obtained external funding for this trial programme from a Primary Care Trust in Kent and the trial would be offered, in the first instance, to the beneficiary cohort in that county. The Board approved the recommendation arising from the Strategy & Development Day. The Chief Executive will ensure that the Directorate of Public Health of the PCT is aware of what the funding will be used for.

Other matters from the Strategy & Development Day:-

3) The Charity Commission

The Chairman reported that there had been an interesting presentation from Mr David Boyd, a lawyer with the Charity Commission but attending in a personal capacity, who apprised members present of various aspects of the 2006 Charities Act, the current strategic thinking of the Commission and interesting areas that might contravene the "Public Benefit" test. He advised the Board that Mr Boyd had said he thought that the proposed policy on disbursements and welfare support would satisfy the Commission's criteria in terms of meeting "need" and that if the Board wanted confirmation they should formally ask the Charity Commission for advice.

- Mr Mishcon's Dissertation

The Chairman reviewed the difficulties that he felt the Board had expressed at their meeting in July which were summarised in the relevant minute of that meeting that had been included in the

Strategy & Development programme. Mr Mishcon advised the Board that it had never been his intention to bring the work of the Trust into disrepute and that he was simply advancing a proposition that, in his view as a lawyer, there was a risk that a breach of fiduciary duty might have taken place over a considerable period of time. He was more than prepared to expurgate the dissertation and remove any reference to the Macfarlane Trust, the possible breach of fiduciary duty and to fully cooperate with the Board to meet any reasonable conditions they might wish to see. After a discussion about the current situation, the Chairman suggested that he meet with Mr Mishcon to talk through any remaining areas of difficulty once he had familiarised himself with the further expurgated version of the dissertation.

- 3) Strategy & Way Forward

The Chairman reported on the debate in respect of the discussion points that the Trust should consider in terms of developing its forward strategy. He reminded the Board that all members had been furnished with a copy of the paper. He advised the Board that Dr Chapman and the Chief Executive would review the initial findings expressed at the Strategy & Development Day and that a "first stage" paper would be prepared for consideration by the Board at the January 09 meeting.

380.08

Partnership Group (PG) Report

The Chairman welcomed Mr [GRO-A] (Immediate Past Chairman of the PG) and Mr [GRO-A] (Chairman of the PG). He expressed, on behalf of the Board, his thanks for all of the work that Mr [GRO-A] had done and welcomed Mr [GRO-A] as the new PG Chairman.

Mr [GRO-A] and Mr [GRO-A] circulated a note of matters arising from the last meeting of the PG held on 18 August 2008. Mr [GRO-A] reported the following: -

- Due to rumours originating from the Men Only 4 weekend about the activities of the Long Term Funding Working Party, the start of the meeting was spent reassuring those present that the Trust was not about to shut down. Mr R Evans, as Chair of the Long Term Funding Working Party, will consult Messrs [GRO-A] and [GRO-A] about how best to engage the beneficiary community as and when the time comes to raise the issue of the long term with them.
- The PG would like to thank the Trust for the work that has been done with regards to ESA and category g) claimants.
- The idea of creating a democratically elected "mini-PG" has been scrapped as the PG feel they have a sufficiently strong working relationship with the Board already.

- The PG would like to request that another one off payment be made to combat the rising costs of fuel and food. This will be addressed and communicated to the PG in due course.
- The next meeting will take place on 15 December instead of in January. Mr FitzGerald asked that PG meeting dates be agreed a year in advance to enable a different Trustee to be present at each meeting.

381.08

National Support Services Committee

Mrs Boyd, Chairman of the Committee, presented the minutes and schedules of support payments from the meetings held on 2 July, 6 August and 3 September. The minutes and schedules were noted.

Mr Fuller sought further information in respect of minute 268.08 and the Committee's decision not to allow case papers to be made available to Trustees that were not members of that Committee. He stated that the reason he would like to receive these is so that he can be confident in the process of how grants are considered and that the committee had sufficient information on which to base a decision. Mr Mishcon felt it was important from an appeal point of view that there were sufficient Trustees who had not seen the papers. The Board agreed that the detailed memorandum produced by the office which accompanies each case could be made available to any Trustee who requests it. If, after seeing this, a Trustee still expresses a genuine concern, then the issue should be raised at the next meeting.

The members of the Committee expressed their satisfaction with the amount of information they currently receive for each case.

382.08

Long Term Funding Working Party

The Chairman invited Mr Roger Evans, Chairman of the Long Term Funding Working Party to present this agenda item. Mr GRO-A introduced Mr James Smith and Ms Vicki Burton from First Actuarial Actuaries and reminded the Board of the process by which they had come to be appointed. Prior to tabling the report Mr Smith advised that there was further work to be done, in particular in respect of the bereaved community, and this presentation should be regarded as work in progress. He was also very aware of the need to share the various findings with the Partnership Group in due course.

Mr Smith tabled a report entitled "Provision of Disbursements" and referred to the main findings of the Working Party. They were:-

- The background and specifically the number of infected primary beneficiaries and their age profiles.
- The projection of support and payments for beneficiaries through to 2063, the year when it could be reasonably

- expected that all infected beneficiaries would have ceased to live.
- The objectives of the Trust in seeking to maximise payments to infected beneficiaries in the first instance, the requirement to minimise costs, a solution that was firm and robust and was acceptable to all concerned parties.
 - The various options considered were to:
 - i) continue as at present;
 - ii) reach a final cash settlement;
 - iii) remove the discretionary element of disbursements;
 - iv) buy annuities with an insurance company.
 - The key factors to bear in mind were the:
 - i) cost implications;
 - ii) data requirements in order to evaluate costs;
 - iii) impact on beneficiaries;
 - iv) impact on the Trust;
 - v) the impact on the DH.
 - The short-listed options:
 - i) A final cash settlement with an estimated costing of £102m excluding the costs of running/winding up the Trust
 - ii) To buy annuities with an insurance company with an estimated costing of £130m excluding the costs of running/winding up the Trust.
 - The various assumptions:
 - i) All costs are based accordingly
 - ii) A future investment return of 4.7% pa
 - iii) Life expectancy is in line with ELT 15
 - iv) An inflation rate of 4.1% pa

After a series of questions in respect of the report, the Board congratulated Mr Smith on an excellent report and presentation. It was agreed that there was further work to be done and that the Long Term Funding Working Party should proceed to the second stage. It was also agreed that there should be an "overview" presentation of the report's findings at the forthcoming meeting of the Partnership Group to be held on 15 December.

It was noted that the Trust do not receive their allocation from the Department in advance and discussions are held annually, not tri-annually.

The Chairman thanked Mr Smith and Ms Burton for their contribution.

383.08

Employment Affairs Committee

The Chairman of the Employment Affairs Committee presented the conclusions and recommendations of the Committee in relation to the review of the Chief Executive's salary and other terms and conditions of his employment, the key points of which were as follows:-

- his salary which had been increased to {GRO-C} per annum with effect from 1 April 2008 should be increased again with backdated effect from that date to £{GRO-C} per annum and further increased with effect from 1 October 2008 to £{GRO-C} per annum on the basis that his salary would continue to be fully pensionable.
- he would continue to be responsible for his own private health insurance.
- the Trust would continue to maintain a permanent health insurance policy for the maximum amount available taking into account his medical circumstances up to two thirds of his salary less statutory sick pay or the sick pay entitlement under the scheme contained within the Trust Handbook for employees.
- as from 1 April 2008 the Skipton Fund should be invoiced by the Trust for all time spent by him on the Fund's affairs at the request of the Trust and his salary from the Trust should be inclusive of any and all reward for the time so spent, which was not expected to exceed an average of 10 hours per calendar month.
- the review of his salary for each of the years commencing 1 April 2009 and 1 April 2010 should be limited to the NJC award for that year.
- a Contract of Employment and related Job Description had been amended to reflect these new arrangements and generally updated. The Chairman having indicated that he had discussed these recommendations with the Chairman of the Employment Affairs Committee as well as the Chief Executive and was happy to endorse them, the Board agreed that they should be approved and implemented.

384.08

Risk Strategy & Assessment 08/09

The Chairman advised the Board that he felt this matter was of such importance that any review of the strategy should not be carried out in haste. He suggested that up to 3 items from the strategy should be considered at successive meetings of the Board starting in January. This was agreed.

He felt that, in general, the Risk & Assessment Strategy was appropriate for the needs of the Trust but that the full range of identified risks and actions to mitigate those risks should be carefully considered.

The Chairman would like "non-closure or reactivation of a deceased beneficiary's account" to be added to the financial risks. "Creation of a fake beneficiary" may be added to the next Board Meeting agenda for discussion.

385.08

ACEVO Circular (17958)

1) The circular referred to the possibility of payments being made to those who might otherwise be deterred from considering becoming a charity trustee on the grounds of loss of earnings. The Board noted that this would only be likely to apply in the case of a "User Trustee" and that should the question arise that a User Trustee might be financially disadvantaged, the matter would be considered then to decide what action might be necessary to ensure that any loss of earnings was made good.

2) The Board noted the provision of free legal advice available under the ACEVO arrangement.

386.08

Financial Reports

The reports circulated with the agenda were noted.

1) The schedule of grants and regular payments for the second quarter of the 08/09 financial year was noted as being within budget parameters. The schedule of disbursements for the second quarter of the 08/09 financial year was also noted. It was agreed that a revised statement of the indicative costs and income which would include estimated income on the reserves should be distributed with the minutes.

2) The investment report for the second quarter of the 08/09 financial year was noted. It was agreed that the Investment Managers should be invited to the next Board in January to apprise Trustees of developments in the investment markets and their impact on the Trust's reserve portfolio.

3) The second quarter management accounts for the 08/09 financial year were noted.

4) (a) The revised Investment Guidelines were noted and approved.

4) (b) The revised Investment Management Agreement with PIM was noted and approved.

5) The briefing note from the Hon. Treasurer in respect of investment performance was noted.

Mr GRO-A asked if matters relating to financial performance could in future be taken earlier in the agenda. This was agreed. Dr Chapman suggested that one of the two upcoming Trustee vacancies be filled with somebody with expertise in financial matters. Mr R Evans stated that the Haemophilia Society may be able to provide the name of one such candidate.

At a previous meeting the NSSC considered a range of additional supplementary fuel payments that could be made to primary beneficiaries depending on their household income (the list was tabled). Discussion ensued and the Board agreed that primary beneficiaries with a household income below £30,000 should receive £150 and those with a household income over £30,000 should receive £100. The payments will be processed in January.

387.08

Any Other Business

The first meeting of the Board of Trustees in 2009 will be held on 26 January at Alliance House.

The meeting terminated at 3.00pm.