

THE MACFARLANE TRUST

Minutes of the Meeting of the Board of Trustees held on Monday 24 January 2011 at The New Cavendish Club, 44 Great Cumberland Place, London, W1H 7BS from 10.00am

- PRESENT** Mr C FitzGerald (Chairman)
Mr A Burgess
Mr P Dolan
Mr R Evans
Mr S Fuller
Mr R Mishcon
Mr P Spellman
- APOLOGIES** Mrs E Boyd
Dr V Martlew (Medical Trustee)
Mr GRO-A
- IN ATTENDANCE** Mr M Harvey (Chief Executive)
Mr N Fish (Assistant to the Chief Executive)

- 484.11 Apologies for Absence**
Mrs Boyd, Dr Martlew and Mr GRO-A had provided their apologies in advance of the meeting.
- 485.11 Minutes of the Previous Meeting**
Subject to a minor amendment at 478.10 (2) the minutes of the meeting held on 25 October 2010 were approved and signed as a correct record.
- 486.11 Matters Arising**
477.10 (464.10) – The Board requested that a draft governance paper be produced to confirm the process by which Board appointments and terms of office would be determined in due course.
478.10 – It was noted that the Finance Manager had not yet sent details of the total costs of upgrading the Trust website to the Trustees which needed to be done.
- 487.11 Implications for the Macfarlane Trust of the Statement by the Secretary of State for Health on 10 January 2010.**
The Chairman reported as follows:-
- The indexation of the fixed annual payment of £12,800 to all primary beneficiaries to the Consumer Prices Index (CPI) was the only additional benefit for the mono-infected that had come out of the Coalition Government's review. It was still unclear from what date the index-linking would apply. *(Since confirmed to be with effect from 1 April 2011 by reference to the annual CPI increase announced in October 2010.)*

- It was particularly disappointing that the same was broadly true for those co-infected beneficiaries who had received a Stage 1 Skipton Fund payment but had not progressed to Stage 2 even though their circumstances were often such as to justify significant extra support. The Government recognised that this was so but had decided that the variation in quality of life among infectees, including co-infectees, post Stage 1 and pre Stage 2 was so considerable that to give additional fixed payments to co-infectees risked creating unwarranted and unwanted anomalies between HIV and Hep C infectees. The Government's position was that the additional support that was no doubt justified in many instances could and should be delivered on a case by case basis through the discretionary mechanisms of the existing Trusts and the new Hep C Trust.
- Stage 2 co-infectees will receive both the £12,800 per annum paid (by MFET on a non-discretionary basis) to MFT (and ET) beneficiaries and the new £12,800 per annum to be paid to those who have received (or will receive) Stage 2 Skipton payments, together with an additional £25,000.00.
- Those not qualifying for free prescriptions would now be entitled to have the cost of the annual passport paid for them. It was noted that there were no prescription charges anyway in Wales and from 1 April 2011, there would be no prescription charges in Scotland either.
- Mr Mishcon pointed to the hopes previously expressed that there would be a benefits passport. The Chairman confirmed that the DWP, having seemed initially to be prepared to entertain the idea, had come down firmly against the creation of any "privileged" category of benefit claimants for fear of bringing down an avalanche of other claims for similar privileges and so there would be no such passport.
- Mr Evans asked if, in political terms, the Government saw the matter as now closed. Mr Fuller felt that the matter was now closed and is unlikely to be re-visited.
- Mr Evans asked what the current position was with the devolved administrations. The Chairman reported that there was agreement to use the Skipton Fund as a payment vehicle even if the scheme was "England only". It was hoped that the devolved administrations would "sign up" to the English scheme in due course.
- Mr Dolan informed the Board that the Scottish Government was settling its budget for 11/12 very shortly. He had a meeting scheduled with the Minister for Health on 3 February and said that it could not be ruled out that Scotland would now make its own arrangements.
- The Chairman reported that instructions from the Department of Health have been sent to Messrs Wilsons to amend the Skipton agency agreement to enable the new non-discretionary payments to be made. Payments will be back-

dated to either 21 December 2010, the date when the full Ministerial Statement should have been made or 10 January 2011 when it was actually made. (*Since confirmed as 10 January 2011.*)

- It was reported that the Government's plan was for the new Hep C charity to be registered by 31 March 2011 and to be fully operational by October 2011. The Chairman had urged the Department of Health to take the opportunity presented by drafting a new set of objects for the new Hep C charity which would be fit for purpose in the 21st century to agree, where appropriate, to corresponding changes in MFT's Objects Clause and at the same time to reflect what appeared to be a key provision in the Objects Clause of the Thalidomide Trust enabling their Trustees to make disbursements for the relief of their victims' disabilities or for the relief of their financial needs. He believed that this should provide greater scope for more sums to be disbursed than was the case at present.

Mr Mishcon asked after the MFT objects clause application to the Charity Commission and what progress had been made. The Chairman replied that, in the light of the discussions regarding the objects of the new charity and synchronising MFT's objects with them, this was "on hold". The hope was that we would get what wanted by agreement with the Department through these discussions and, by then being able to present an agreed position, we should be able to make quicker and smoother progress with the Charity Commission.

Mr Mishcon asked about making provision for "carers". The Chairman replied that this was one of the areas of current discussion with the Department but that they did have a material concern that any perception that the beneficiary constituency was being widened beyond dependants would make it necessary to go back to Ministers.

Mr Mishcon opined that the Macfarlane Trust objects clause should not just mention HIV and that help should be available in any medical circumstances.

The Chairman asked if any member of the Board had any further questions or points that they might wish to raise; there were none. The Chairman said that the Board would be kept apprised of any relevant further developments.

488.11

Staffing Issues

The Assistant to the Chief Executive, in his capacity as Secretary of the Skipton Fund, reported that the Fund would like to make more use of Shane Bakers' IT skills and general familiarity with the modus operandi of the Fund. This request was driven by the anticipated workload that would fall upon the Skipton Fund. There would also be a need for some temporary staff in the short-term. It was suggested by Mr

Evans that there may be some experienced staff within the Department of Health who may want a secondment. (Chief Executive's Note: *There may be some beneficiary resistance to taking Department of Health staff on secondment in that those applying for payment might not welcome, as they would see it, those responsible for their condition being part of the payment process. It was also important to be able to offer existing staff development opportunities when they arose.*).

Current developments in respect of the new Hep C charity, which might well have a considerable workload, could mean a substantial increase in staff numbers if, as was planned, the organisation was to be serviced by MFT and housed in its office. (Chief Executive's Note: *The EAC have been asked by the Chief Executive to consider such issues at an early meeting*).

Arrangements to accommodate Linda Haig's absence on maternity leave were functioning well. The Chief Executive would keep a watching brief on cover for Linda Haigh and manage her return to office based work on a phased basis. The Chairman reported that Ms Keisha Baker Benjamin was to start an out-placement for part of her degree course. The Chief Executive and Support Services Manager would discuss the level of cover needed in her absence for four days a week. (Chief Executive's Note: *Temporary cover is now in hand for four days each week until Ms Baker Benjamin returns full time in August*).

489.11

Finance

1) In reviewing the financial reports generally and the investment report in particular, the Board noted that the level of the Trust's investment reserves was now approaching £4.3m.

2) The Chief Executive informed the Board that Messrs Wilsons had made a donation to the Trust amounting to £10,000. The funds were for the academic and/or professional empowerment of the beneficiary community by way of support to undertake an Open University degree. The Board accepted the view of the Chief Executive that a degree in law would be a suitable purpose but felt that a degree in a related professional subject should also qualify. (Chief Executive's Note: *The Chief Executive has consulted Messrs Wilsons and there was no resistance as to the course a qualifying beneficiary might wish to undertake*).

3) Mr Evans noted that in excess of £100,000 was invested in companies associated with the tobacco industry. The Board agreed that such investments were inappropriate for a health related charity. (Chief Executive's Note: *The investment managers are now divesting the Trust's holding in these securities and have put a block on any further*

investment in Tobacco and Tobacco Products).

It was agreed that PIM would be invited to attend the July Board meeting to review investment performance and Strategy. The Assistant to the Chief Executive was asked to find out when investment management services were most recently market tested.

There being no further observations, the financial reports were accepted.

490.11

National Support Services Committee

In the absence of the Chair of the NSSC, Mr Dolan presented the minutes of the meetings held on the 3 November 2010, 1 December 2010 and 3 January 2011 on page by page basis. Subject to two minor points of clarification the minutes of the meetings and the decisions recorded therein were ratified.

491.11

Support Services

The Chairman alluded to the paper from the Support Services Manager circulated with the agenda but not specifically referred to in it. The Chairman thought the paper was well thought through and said that it was clear that a considerable amount of careful consideration had been given to its content. The following observations were made:-

- Mr Spellman reported that requests for single grant support were now less in volume but, such requests being mainly from widows and dependants, they were considerably more complex.
- Mr Mishcon opined that in the knowledge that the non-discretionary payments were not going to increase (at least not beyond the CPI indexation), further consideration should be given to where the Trust's support should be best directed and where financial need might be deemed most necessary. In this context the possible withdrawal of Disability Living Allowance for a number of beneficiaries might well be an issue.
- Mr Evans was concerned about the potential increase in workload, following the announcement, and asked that the Chief Executive consider an operational timescale for this eventuality.
- The Chairman referred to debts passed to widows following the death of the primary beneficiary and again expressed the view that consideration should be given, wherever appropriate, to clearing these by means of one-off payments. Mr Mishcon reported that the NSSC favoured such an approach, particularly in conjunction with approach to the lenders to try to obtain a write off of at least part of the debts.
- The Chairman indicated a preference, subject to affordability, for an annual increase in the discretionary "top up" payments along the same lines as the annual increase in the

Government's non-discretionary payments. Mr Mishcon counselled against making any public statement of index linking as such; he saw no reason why increases might not be given in future years but felt that there should be no firm commitments in this respect.

- The Chairman believed that the new non-discretionary payment of £12,800 per annum for Skipton Stage 2 recipients will have to be taken into account when considering their qualification for any MFT "top up" discretionary payments. However he hoped that the proposed change to the objects clause to permit the medical consequences of beneficiaries' conditions to be addressed separately from their financial circumstances might provide scope for some additional relief to be provided in appropriate cases.
- Mr Mishcon asked that the cost of providing supplementary payments to primary beneficiaries in respect of children should be revisited.
- The Board agreed that the cost should also be assessed of adjusting the policy on financial support for widows to bring net incomes up from the current £15,000 per annum to (1) £20,000 and (2) £25,000 and of backdating any such increases to (i) 20 May 2009 (the date of the Government's Response to the Archer Report) and (ii) 1 April 2010.
- The Board agreed that the current policy for widows of making up to 9 months discretionary support to the value of the £12,800 per annum non-discretionary payment to the deceased primary beneficiary should be extended to the parent carer of such a beneficiary if it was shown that the carer had relied upon the income of the primary beneficiary to support their household. The NSSC should also consider what scope there might be for extending the policies for widows to such carers more generally.
- Mr Evans asked if there were any likely alternatives for the services supplied by the Terrence Higgins Trust. The Chief Executive opined that the beneficiary community were familiar with THT and that to introduce a new service provider might not be well received even though there were some shortcomings, mainly of an administrative nature, in the services provided by THT.
- Mr Mishcon referred to the role of Ms Joanna Fenning – Bereavement Counsellor. He felt it would be helpful if Ms Fenning made recommendations to the NSSC for the provision of bereavement counselling services. It was agreed that both she and Mark Simmons should be invited to the March meeting of the NSSC.
- The Chief Executive reported that provisional information in respect of the numbers of surviving primary beneficiaries (MFT & ET) in respect of non-discretionary payments via MFET Ltd had been given to the Department of Health as

well as information of the numbers and levels of support to other beneficiaries. The exact figures to enable payments to be made in 2011/12 will be reported to the Department of Health at the end of February 2011.

There being no further observations on the paper from the Support Services Manager, the Chairman brought the matter to a close.

492.11

Events Management

The Chairman reported that he had had a satisfactory discussion with Mr GRO-A after the last Board meeting and, as then agreed, had advised him that, if the review decided upon at the meeting recommended continued outsourcing of any part of the organisation and co-ordination of MFT events, that would be put out to tender and he would be invited to make his own proposal. In the meantime, and in recognition of the Board's agreement to continue his Empowerment grant until the end of the (calendar) year, Mr GRO-A had undertaken to provide a paper to assist the review process setting out his own reflections on MFT events and their format and content and some thoughts for the future. His paper was then tabled.

Mr Burgess advised the Board that he had met with Trust staff about the future of events and that there was a reasonable belief that it was now practicable for events to be organised "in house" and without any need to call on any external co-ordination. Mr Burgess said he would be quite happy to help in the coordination of events as and when necessary. This offer was welcomed warmly by the Board. The Chief Executive believed that the problem was not in the organisation of events but in the programme content. The Chairman said that what was essential was that events should continue without interruption from their customary calendar cycle. It was noted that the next event should be Men Only (8) and that, as yet, no arrangements had been made. It was agreed that on his return to the office from sick leave on 1 February the Chief Executive would review the position with the rest of the staff, particularly in light of the additional demands on their time likely to arise over the following six months or so from the implementation of the new arrangements flowing from the Ministerial Statement. If he was then satisfied that, with Mr Burgess' assistance, a wholly in-house solution was now practicable and that there was no continuing need for (or to pay for) any external assistance, he should proceed on that basis. (Chief Executive's Note: *The event will be held on the 3/4/5 June 2011 at the Hilton Hotel, Reading. The event will be organised with the help of Mr Burgess and arrangements are well in hand*).

Mr GRO-A should also be advised of the outcome and, whatever that outcome, the review of the events in relation to format, content and target audiences should continue.

493.11

Any Other Business

It was agreed that the date of the next meeting will be the 4 April, all other arrangements will remain the same.

There being no further business, the meeting terminated at 1.35pm.

GRO-C: Fitzgerald

**THE MACFARLANE TRUST - MEETING OF THE BOARD OF TRUSTEES
24 JANUARY 2011
ATTENDANCE SHEET**

Mr C FitzGerald - Chairman
Name Signature GRO-C

Mrs E Boyd
Name Signature GRO-C

Mr Alan Burgess
Name Signature GRO-C

Mr P Dolan
Name Signature .. GRO-C

Mr R Evans
Name Signature .. GRO-C

Mr S Fuller
Name Signature .. GRO-C

Dr Vanessa Martlew
Name Signature **Apologies Received**

GRO-A
Name Signature **Apologies Received**

Mr R Mishcon
Name Signature ... GRO-C

Mr P Spellman
Name Signature .. GRO-C

In Attendance

Chief Executive
Name Signature .. GRO-C

Assistant to Chief Executive
Name Signature .. GRO-C

Support Services Manager
Name Signature **Apologies Received**

Finance Manager
Name Signature **Apologies Received**