THE MACFARLANE TRUST

Minutes of the Meeting of the Board of Trustees held on Monday 25 January 2010 at The New Cavendish Club, 44 Great Cumberland Place, London, W1H 7BS from 10.00am

PRESENT

Mr C FitzGerald

(Chairman)

Mrs E Boyd

(Chairman NSSC)

Mr GRO-A Dr S Chapman Mr P Dolan Mr GRO-A

Dr V Martiew (Medical Trustee)

Mr GRO-A Mr R Mishcon Mr P Spellman

APOLOGIES

Mr R Evans

IN ATTENDANCE Mr M Harvey

Harvey (Chief Executive)

Mr N Fish

(Assistant to the Chief Executive)

Ms L Haigh

(Finance Manager)

Ms R Riley

(Support Services Manager)

BY INVITATION

Mr I Davies

(Messrs Wilsons for 441.10)

Mr A Roberts

(Messrs Wilsons for 441.10)

439.10 Apologies for Absence

Mr R Evans provided his apologies in advance of the meeting.

440.10 Minutes of the Previous Meeting

Mr GRO-A stated that it had not been he who felt that the Trustees of the Eileen Trust would see the issuing of new loans so close to a possible merger as unfavourable. Subject to this alteration, the minutes of the meeting held on 26 October 2009, previously circulated, were approved and signed as a correct record.

It was pointed out that agenda item 445.10, and the equivalent one in future, should have stated that the Board were to "receive the minutes and *ratify the decisions*" of the NSSC; this would be rectified.

441.10 Wilsons Solicitors – Letter of Advice to Trustees of the Macfarlane Trust sent on 8 January 2010.

The Chairman introduced Mr Ian Davies from Messrs Wilsons and advised Trustees that Mrs Moira Protani was unable to be in attendance due to personal family commitments.

The Chairman referred Trustees to the letter of advice from Messrs Wilsons dated 8 January that had been previously circulated. Mr I Davies spoke to the contents of this letter. [Relevant comments are included in minute 443.10]

442.10 Matters Arising

429.09 (406.09) A schedule of the values of the first charges on properties where the Trust had a second charge was tabled. The Board were advised that where the information had not been immediately to hand (for those loans prior to October 2003) further information was being sought. Unsecured loans would be considered at the year end. 430.09 The decision, following the "round robin" dated 30 October 2009, to finance the balance of funding required to provide a bench at the Birchgrove Woodland was confirmed. 431.09 The Chairman and Chief Executive gave an oral report in respect of the implementation of the Government's response to the Archer Inquiry. The Board noted that the disbursement of the non-discretionary payments through the MSPT2 Trust as varied was implemented on 28 January 2010. Mr R Mishcon asked if there had been any problems with obtaining consent from Primary Beneficiaries (PBs) for the Trust to share their data with MSPT2. The Chief Executive responded that there had not been, other than minor issues with two PBs which had now been resolved. He added that there were 3 PBs who had not responded and whose funds were being accrued for them. The Support Services Manager added that she was in touch with the estates of those who had died since 20 May 2009 and that the money would be paid to them in due course. A discussion ensued as to whether more should be done to try and locate those PBs whose whereabouts were unknown. Some suggestions made by the Board were, through the Trust's solicitors, to place a suitable advertisement in a national paper or the HQ magazine; to contact the PBs' old Haemophilia Centres; to check the register of deaths in case they had passed away. The Chief Executive noted the Board's comments and would consider the suggested options that were put forward. Mr P Spellman asked if there was a contingency fund in place for those beneficiaries who run out of money before April. The Chairman responded that PBs had been made fully aware that the payment they received was to cover the period up until the end of March. It was also hoped that, subject to a policy being agreed, the backdated discretionary top up payments would go through in February.

On behalf of the Board, Mr P Spellman thanked Wilsons Solicitors and the office for all their hard work in delivering the non-discretionary payments.

443.10 The Future Governance of the Trust post Archer

The Chairman referred Trustees to the paper circulated by e-mail on 19 January 2010 and subsequently sent by post. He thanked the EAC for the paper they had created following a discussion into the governance and structure of the Trust which had been noted.

One of the major factors that the paper sought to address was the fact that the Trustees currently used their discretion to disburse around £500k per annum in the form of one off grants; under the post-Archer arrangements there would be twice that amount available for discretionary disbursement (albeit mainly for the non-infected community). For this reason he felt that, until policy decisions had been reached and bedded in, it would be hard to envisage how the make-up of the Board would need to be altered. He then referred the Trustees to the final page of his paper and the "Matters for early decision".

A wide ranging discussion ensued and it was resolved that each Trustee could, if they so wished, make a written submission expressing their views with respect to the future make-up of the Board to the office by the end of February. These would then be collated and distributed to the full Board for their consideration and discussion with a view to a possible decision being taken at a Trustee away day in the autumn. For ease of reference, the Trustees were asked to address the points contained within the Chairman and Mr Davies' papers in the order that they appeared. It was also agreed that the terms of office be extended to 31 March 2011 for all Trustees whose terms were due to expire prior to that date. This decision would be put to the Department of Health and the Haemophilia Society for their approval. It was also agreed that the level of staffing would remain the same until policy decisions had bedded in, at which time it would be reviewed.

Mr I Davies agreed that retaining the current Trustees whilst changes were afoot was prudent. He reminded the Board that the Charity Commission's guidelines stated that the make-up of a Board of Trustees should include relevant experience and knowledge to enable the charity to get its work done. He added that provided the current Trustees kept in mind what was best for the charity and what would help it to proceed then they couldn't go far wrong.

Mr A Roberts felt that the name of the new non-discretionary vehicle (NDV) would be important as the Trust's beneficiaries had for many years been receiving money from the Macfarlane Trust. It needed to be made clear what would be happening,

why the money would be paid through a different body and that it made no difference to the beneficiaries on a day to day basis since it would be the same people that they would be dealing with. The Chief Executive asked Mr Roberts if consent would need to be obtained again from PBs for their data to be used by the new NDV even though the previous consent form referred to 'payment vehicles'. Mr Roberts felt it would be better to request this again but agreed that provided there was a piece of correspondence from the Trust which stated 'if you do not object to the sharing of your data then there is no need to reply' then that would suffice. The name of MFET Limited was suggested as the name for the new NDV and there were no objections.

The Chairman then directed the discussion towards the Trust's reserves and how these could best be utilised. After receiving the post Archer settlement from the Department the reserves, if they retained their current value, would appear as some £5m in the Final Accounts. Due to the risk that the Department may try and recoup some or all of these funds, thought needed to be given to disbursing in the order of £4m in reasonably short order; £1m would be the level required to cover 6 months forward spend and management costs. Mr I Davies instructed the Board that even though the Trust had a large reserve fund there would be no urgent need to spend it in the eyes of the Charity Commission since future needs could be considered as well. The Chairman invited the Board to discuss the notion of utilising up to £4m to support the bereaved community, bearing in mind the likely numbers who would come forward for support. Mr Mishcon felt that it would be wise to establish how many of the 850 or so deceased PBs were married and how many of those still alive were married to determine future liability. He also felt that dependants, carers and orphans needed to be considered. Mr. GRO-A believed that very few of the widows with whom the Trust had lost contact would come forward for support and that the focus should be on the current widows and dependants whose whereabouts were known. Mrs E Boyd and Mrs V Martlew felt that a good way of trying to locate widows with whom the Trust had lost contact would be through the National Haemophilia Centres. In response to an issue raised by Messrs GRO-A and GRO-A the Chairman responded that unfortunately the past needs of this group could not be addressed since charity law only allowed for past and future need to be considered.

It was resolved that the Chief Executive would draft an open letter establishing who it was that the Trust were seeking to find in order to provide financial support should they require it. This would be sent to the National Haemophilia Centres and the Haemophilia Society for their newsletter.

444.10 Discretionary Support to the Infected Beneficiary Community

The Board received the paper from the Chief Executive with a recommendation and supporting information from the National Support Services Committee. The Chief Executive spoke to the recommendation from the Committee. He reminded the Board that the Committee had worked according to the decision taken by the Board (minute 432.09 refers) whereby the Committee's remit was to develop Option 1 which was to make discretionary payments to those below a certain household income, originally mooted at £50k gross, roughly equivalent to £35k net after tax and NIC for a person with an income earned from employment, based on the additional costs of living with HIV currently estimated at around £4,800 per annum from information contained within the 2005 Business Case entitled Funding Long Term Survival. The Chief Executive went on to say that the genesis of the Committee's deliberations and subsequent recommendation were clear in the paper that had been circulated with the agenda. He added that, rather than assuming those receiving Income Support fell within the £7k-£14k net household income bracket, the Committee had felt that the value of Income Support should be calculated in each case. Census forms had been sent and just under half of the 132 individuals on Income Support had responded. The maximum cost to the Trust if all those yet to respond were found to fall within the lowest income bracket would be £140k per annum. Mr R Mishcon alluded to the article on Pay Disparity that was attached to the papers and directed the attention of Trustees to the perceived additional costs of raising children as well as the comment expressed in the article that in 2004/05 those with annual incomes of more than £35k gross were considered to be in the richest 10% of the population. The Chief Executive suggested that the Board may want to take the cost of raising children into account and directed Trustees to the tabled spreadsheet which gave an illustration of the likely additional costs of making disbursements to primary beneficiaries with, or responsible for, dependent children that was equivalent to what was now remitted to widows with dependent children and guardians that cared for the dependent children of deceased PBs; there was an additional schedule which provided the illustrative costs of paying a flat rate supplement of £100 pcm to PBs with dependent children. He reminded Trustees that when considering the cost of each, the cost of all discretionary supplements currently paid under existing policy were removed. The Chairman pointed out that the cost of the current supplements policy should not be taken into account since existing supplements were no longer payable post Archer. Mrs E Boyd added that the number of dependent children, and

therefore costs, were unlikely to be as high as indicated on the spreadsheet because some of the children were duplicated in cases where both their mother and father were PBs. Mr R Mishcon added that there were further issues for the Committee to discuss regarding dependants and that this was very much a work in progress.

The Chief Executive then formally put forward the following recommendations of the National Support Services Committee:-

- 1) That the discretionary "top up" payments as set out in the schedule "Post Archer policy proposal Further Variation (CF)" be agreed in the current financial year and back-dated to 20 May 2009 payable to all PBs or to the estate of those PBs that had died since 20 may 2009.
- 2) That from April 2010, the "top up" payments to each PB be paid at the same time and frequency as their non-discretionary payment. Legally, the non-discretionary payments were owned by the PB concerned from the moment the NDV received it, the funds could not be retained without the PB's permission and it was the duty of the NDV to disburse the funds within a reasonable time frame according to the wishes of the recipient. It had been confirmed that the Department would remit the funding allocation for the disbursement of non-discretionary and discretionary payments at 1 April and 1 October in each financial year meaning PB's could receive their payments biannually, quarterly or monthly.

After a measured debate, the Board agreed as follows:
1) That the proposed discretionary payments at the amounts indicated on the spreadsheet "Post Archer policy proposal — Further Variation (CF)" be paid and back dated to 20 May 2009. When informing PBs of the discretionary payments it would be made clear that the policy was subject to review annually and to the receipt of sufficient funding from the Department of Health. The Chief Executive would send the draft letter to the Board by round robin before it went out to the beneficiary community

2) It was agreed that the "top up" payments would be paid at the same time and frequency as the non-discretionary payments as indicated by each PB in response to a written request. The Chief Executive added that the new census form would have to be geared towards finding out each PB's income and family circumstances.

NOTE: For practical reasons in the main to do with the repayment of existing and new loans the discretionary "top up" payments will be paid monthly notwithstanding the disbursement frequency of the non-discretionary payments.

445.10 The National Support Services Committee

1) Mrs Boyd, Chairman of the Committee, presented the minutes and schedules of support payments from the meetings held on 7 October, 4 November, 2 &17 December 2009.

The minutes and schedules of grants were noted and ratified by the Board with the following amendments to be made:

- 2 Dec 2009, minute 369.09, p 5 under the heading "Payments". The third sentence should read "Mr Dolan agreed with this and said that the Trust should not, for various reasons, limit the payments to certain individuals and that a lump sum of money should be paid as a matter of course to all newly bereaved or the next of kin".
- 17 Dec 2009, minute 372.09. The last sentence should be removed.
- 2) Discretionary Support to the Non-Infected Community Mrs Boyd gave an oral report on work in progress in respect of the preparation of a set of recommendations representing policy proposals for discretionary support to the non-infected beneficiary community. The main points raised were that the objects of the Trust may need to be adjusted to ensure that payments could be made to carers of beneficiaries who were not related; these would need to be verified by the Charity Commission. Mr R Mishcon added that the objects already needed to be adjusted to replace the term "spouses" with a form of words to include partners; this would provide a good opportunity to make both adjustments.

The Chairman proposed that NSSC minutes and papers should be sent to the Board following each meeting rather than with the quarterly board papers. All agreed and this would be the case in future.

445.10 Financial Reports

The Financial Reports were tabled.

- 1) The schedule of grants and regular payments for the third quarter of the 09/10 financial year were reviewed and noted.
- 2) The third quarter management accounts for the 09/10 financial year were reviewed and noted. The Board noted that legal fees were £5k over budget.
- 3) The third quarter beneficiaries' expenditure budget was reviewed and noted.
- 4) The third quarter investment report was reviewed and noted.

The Chief Executive reported that he and the Finance Manager had met with the Trust's Fund Managers and had informed them that the Trust may need to utilise a portion of its reserves for discretionary disbursement.

446.10 Chief Executive's Report

The Board received the Chief Executive's Report which he went through page by page.

The Chief Executive informed the Board that representatives of the Activate Project would be attending the NSSC meeting in

February. Mr GRO-A had reported to him that an away day organised by the Activate team had been a great success.

Dr S Chapman asked why the Trust would be outsourcing the work on the analysis of the bereaved community. The Chief Executive responded that, within the office, the Trust's staff were too close to the issue and objectivity may be prejudiced. The office frequently received lobbying calls from this community asking what would be done to support them. To avoid allowing the outcome to be swayed by these calls it would be more professional to use an independent expert to undertake the work.

The Chief Executive reported that the Trust continued to have difficulties receiving invoices for the work undertaken by the THT on its behalf. The Support Services Manager would be meeting with them in the near future in an attempt to resolve this issue. She would also be discussing one or two reports from PBs that members of THT staff had left whilst dealing with cases and without informing the Trust. Mr GRO-A reported that the larger THT offices had better facilities to deal with certain areas of support, such as debt assistance, than the smaller ones. He felt that approaching the National Debt Council register would be more beneficial and the Chairman was keen to explore this issue. Mrs E Boyd felt it would be prudent to make a note of the number of beneficiaries applying for assistance in this area.

The Board were informed that the next meeting of the Partnership Group would be on 15 Feb at the Haemophilia Society's office. Mr GRO-A and Mr GRO-A would be attending.

447.10 Any Other Business

Mr GRO-A asked the Board if he could attend the opening of the Birchgrove bench in April as a Trustee of the Macfarlane Trust to which all agreed he could.

The Chairman asked that when sending in their submissions, Trustees state their intentions as to how long they would like to continue being a Trustee.

The next meeting of the Board of Trustees will be held on 26 April at the New Cavendish Club, 44 Great Cumberland Place, London W1H 7BS from 10.30am. The Board Meeting in July will take place on **Monday 19 July** and not 12 July as previously stated; the Chief Executive would inform Mr R Evans.

The meeting terminated at 13:30