

THE MACFARLANE TRUST

Minutes of the Meeting of the Board of Trustees held on Wednesday 1 September 2010 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 GRO-A
Mr R Mishcon
- APOLOGIES** Mrs GRO-A (Chairman NSSC)
Dr V Martlew (Medical Trustee)
Mr P Spellman
- IN ATTENDANCE** Mr N Fish (Assistant to the Chief Executive)
Ms R Riley (Support Services Manager)
- BY INVITATION** Mr Mark Simmons (Senior Social Worker)
(tele-conference) Ms Tracey Dunkley (Clinical Nurse Specialist)

469.10 Apologies for Absence

Apologies had been received from Mrs GRO-A, Dr V Martlew and Mr P Spellman. The Chief Executive was also unable to attend. The Chairman provided a brief update on the health of Mrs GRO-A and the Chief Executive and was pleased to report that both were making progress with their recoveries.

470.10 Minutes of the Previous Meeting

461.10 Mr R Mishcon pointed out that he had exchanged correspondence with the Department of Health (DH) rather than met with them and suggested one or two further amendments to this minute.

It was agreed that the minutes would be considered by the full Board at the October meeting and were not therefore signed off.

471.10 Matters Arising

464.10 Mr R Evans requested a paper with a range of options for consideration and agreement by the Board at the October meeting.

470.10 Mr Mishcon asked what was happening with regards to applying for a cy pres scheme. The Chairman wished to discuss this matter with Mr Mishcon and would do so outside of the meeting.

472.10**Discretionary Disbursements to the Non-Infected Community**

The Support Services Manager provided a detailed oral report on the three visits that she and the Support Services Officer had attended with members of the bereaved community. The circumstances and needs of each were very different and the visits had been useful in determining their needs. The Board thanked the Support Services Manager for the report and also wished to record its thanks to the Support Services Officer.

The Chairman informed the Board that he had invited Mr Mark Simmons, who had extensive knowledge and experience of dealing with the bereaved community, to attend the meeting after it had become apparent at the last Board meeting that some Trustees felt they were without hard information on the circumstances of this group. Due to unforeseen circumstances Mr Simmons and Ms Tracey Dunkley, Clinical Nurse Specialist, instead joined the meeting via tele-conference. The Chairman welcomed Mr Simmons and Ms Dunkley and explained that the Trustees were currently considering whether the best way to support the bereaved community would be through regular payments or grants or a combination of the two and that they would appreciate it if he would answer any questions that they had. A summary of the most relevant questions and answers can be found at the end of the minutes. The Chairman thanked Mr Simmons and Ms Dunkley for their time and for providing a useful overview of the needs of the bereaved community.

In light of the Support Services Manager's report and the information provided by Mr Simmons, the Chairman felt that the best way to support the bereaved community would be to introduce a system of banded regular payments which attempted to bring all widows up to an income of at least £12,000 net per annum. The established policy of paying supplements for dependants would differentiate between the number of people within the household and a system of grants would deal with the specific needs that some individuals had. Once the community knew that support was available and the application system was manageable, more might well come forward. Even if numbers were to double the policy would remain affordable and if too many grant applications were received the Trust could tailor its responses to grant applications accordingly, particularly for higher requests.

Mr Mishcon stated his view that the difference between widows and Primary Beneficiaries (PBs) was that the latter would remain infected with HIV for the rest of their lives and that the aim of the Trust should rather be to help widows move on with theirs and to provide that incentive. He referred to his paper (previously circulated by email) which sought to establish the specific needs

of each widow individually so that the Trust could utilise its resources to relieve those needs. Each widow would have very different circumstances, some would have re-married, been divorced, have dependants etc. Mr GRO-A read aloud an email from Mr P Spellman who also felt that the Trust should be going down this route.

The Chairman responded that the Trust must soon be in a position to say to the DH what it had done with the money that had been allocated to relieve the needs of the bereaved community.

Mr Evans agreed that it was vital the Trust could show that it had done something. He thanked Mr Mishcon for his paper which was immensely helpful and agreed that the detail he was suggesting would be interesting but also that it would be very time consuming, would create a lot of work for the office and would be interpreted by many as means testing. It would therefore be preferable to increase the support for the bereaved community through means other than grants. Whatever the Trust came up with would not be perfect. He added that a population of aging widows would need ever greater support so the Trustees should perhaps consider setting up a fund for this purpose.

The Chairman reminded the Board that in his Inquiry Report Lord Archer had recommended a system of financial support for widows unconditionally and in a subsequent Parliamentary debate had cited an example of a widow who could not afford the train fare to attend. The Chairman suggested that it would be consistent with this approach to provide a minimum level of financial assistance to such a widow. Mr GRO-A added that such a system of support would also recognise what the bereaved community had gone through in the past. The Chairman agreed but added that such recognition could not be across the board since the Trust still had to operate within its charitable objectives of determining need to justify support. In response to questioning the Chairman confirmed that the policy would be reviewed annually, the net income of the *household* would be used and there would be no summer and winter payments.

A number of Trustees referred to the imminent changes to Disability Living Allowance and the impact that this would have on many PBs finances. The Chairman appreciated this but reminded the Board that initially the DH had set aside circa £2m for the relief of the needs of the non-infected community and that the Trust had already persuaded them to allow half of this to be used for the benefit of PBs; it would simply not be right to divert any more of the money that had been designated for the

relief of the needs of the non-infected community, at least until those needs had been ascertained and, so far as possible, relieved.

The Chairman proposed that the Trust proceed with Recommendation 1a) in the paper resubmitted to the meeting at the £12,000 pa level (subject to checking affordability) and that Recommendation 2 (setting out a calibrated system for the availability of grants) remain on hold until a later date. Further visits would be arranged to determine the extraordinary needs of individuals. Mr Evans seconded the proposal at the £12,000 level but was keen to consider the possibility of bringing members of the bereaved community up to a minimum net annual income of £15,000. The remaining members of the Board were in agreement, pending affordability and fine tuning by the NSSC, but reiterated that it must not impact upon the Reserves. The Chairman was confident that it would not but said that the issue of the reserves could be considered again at the Board's meeting in October. The policy would be initiated with effect from 1 September 2010 with the possibility of backdating to 1 April 2010 or 20 May 2009 subject to affordability. A paper with refined bandings and costings would be presented to the NSSC at their next meeting for discussion and comment.

Mr Mishcon asked if the Board thought it would be desirable to write to all PBs and widows to ascertain what their current conditions were to help the Trust apply its reserves. Mr Evans asked what information the Trust already had on beneficiaries' properties from past census data, how relevant this information was in practice and what the levels of debt were. The Support Services Manager would find out and report back. The Chairman was not against Mr Mishcon's suggestion but felt it would be better to wait until the Chancellor had made his expected announcement on 20 October which might have a material impact on the availability of certain State benefits for PBs. This too could be considered at the next Board meeting which was scheduled for 25 October.

A discussion ensued regarding the roll out of the Government's Employment Support Allowance policy and the likely impact on PBs. It was resolved that the NSSC would discuss the matter fully at their next meeting with Mr S Fuller to be invited if necessary.

It was reported that certain PBs would soon be benefitting financially from the resolution of the US group action and that this would impact upon their benefits. The Chairman noted this and felt the Trust should keep a close eye on what was happening. The Trust's Benefits Adviser, Neil Bateman, should be involved where necessary. Due to the fact that it was not

Trust business and that the settlement would not affect the majority of beneficiaries it was felt prudent not to make any specific reference to the issue in the Newsletter.

473.10

Cover for the Chief Executive

As a result of the Chief Executive's extended period of absence due to ill health, the Chairman had asked the Trust's members of staff to hold a meeting to discuss the various day to day roles carried out by the Chief Executive and to make provisions within the office to cover these. The Assistant to the Chief Executive provided an oral report on the outcome of this meeting giving the names of the staff members who would be responsible for particular aspects of the Chief Executive's role.

The Board were satisfied with the provisions that had been made but were in agreement that it might only be possible to provide cover in this way in the relatively short term and that there were aspects of the role that might not be so easy to cover in the longer term. The matter would be kept under regular review.

474.10

Any Other Business

- 1) (a) The Chairman provided an oral report on the meeting he had attended with Departmental officials on 19 July 2010. He informed the Board that the meeting had been led by policy officials and that Mr Stopes-Roe had taken a back seat. The meeting had been an information and data gathering exercise on the part of the DH and they had been furnished with schedules containing a large amount of statistical information following that meeting. Copies of these schedules were tabled. The Assistant to the Chief Executive reported that he had emailed and phoned DH officials on various occasions to offer a follow up meeting in order to explain the schedules but that the offer had been declined because the DH were content that the information was clear. Mr Evans believed it was encouraging that somebody from the Minister's private office, Yemi Fagun, had been in attendance, and felt that she should be copied in on all future correspondence with the DH. Mr GRO-A informed the Board that he had heard from a fellow beneficiary that there were to be two important DH meetings in early September. The Chairman and staff members in attendance had not heard about these and the Assistant to the Chief Executive would contact the Chief Executive of the Haemophilia Society to ask if he had heard anything. The Chairman reminded the Board that the tabled schedules were for the benefit of the Trustees only and were not for wider dissemination.

- 2) The Chairman spoke to the tabled figures relating to the management fee charged by the Trust to MFET Limited for the disbursement of the non-discretionary payments through the office. Mr S Fuller expressed his concerns that the fee did not accurately reflect the cost to the office of administering these payments. Mr Mishcon reminded Mr Fuller that the auditors were content with the value being used and hoped that this would provide some comfort. In response to questioning by the Chairman, the other Trustees present did not express any concerns with the value of the fee being charged. In light of this, while not agreeing with the amount being used, Mr Fuller accepted that the matter was closed.
- 3) 2001, Appeal against the NSSC's decision not to agree a grant to provide a temporary buffer while the beneficiary underwent hepatitis C treatment. The NSSC members present felt that the new information provided by Ms Tracey Dunkley did now indicate that there were exceptional circumstances and agreed to discuss the matter again at their meeting immediately following the Board meeting.

Mr P Dolan informed the Board that the Penrose Inquiry in Scotland would soon be publishing its preliminary report and that the document would be available online.

The next Trust event, Something for the Weekend, would be taking place between 29-31 October and the Chairman would be attending the dinner on the Friday evening. The matter of events coordination would be discussed at the Board meeting in October. The inauguration of the Birchgrove bench would be taking place on 25 September. The Chairman indicated that he would be attending and encouraged other Trustees to do so if they wished. The Support Services Manager would be the point of contact for any Trustee who wished to attend.

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 13:35

Q&A session with Mr Mark Simmons and Ms Tracey Dunkley

Chairman – What are the numbers you deal with in your centre and what support are they looking for?

Mr Simmons – The centre is in contact with 9 widows who still require support but the network spreads wider. The most equitable and easiest way to provide support would be to copy the current model of discretionary “top-up” support for PBs. Some widows have been left with debts by their husbands which they are still paying off and this should be factored in when calculating net income.

Chairman – Did focus groups indicate whether regular payments or grants would be preferable?

Mr Simmons – It would be preferable for them not to have to apply for grants regularly unless there are exceptional circumstances. There is historical resentment towards the Trust due to the cap in hand nature of applying for grants and having to do so would bring back a lot of painful memories for them.

Chairman – What is the age range of the widows you deal with?

Mr Simmons – The age range is vast, from ladies in their 30s to those in their 80s.

Chairman – Not as many completed census forms have been returned as was hoped and expected. If there was a clear program of support do you think more widows would come forward?

Mr Simmons – There are some widows who are financially well off and have no interest in approaching the Trust at all for financial support. That is not to say the family does not experience other problems, particularly with children who suffer from psychological problems associated with the tragic loss of their father. Of the 9 widows who are in contact with the centre, 5 experience financial difficulties and only 2 of those 5 have returned a completed census form. If the Trust had a system in place it is likely the uptake would increase nationally.

Mr Mishcon – You say the best way to support this group would be through regular payments but we know there are widows in very different financial situations. Should the Trust distinguish between incomes and situations and how should it deal with those with new partners?

Mr Simmons – The discretionary policy for the PBs takes into account household incomes and that should apply for widows too. Equity with that policy for the time being would be beneficial with annual reviews.

Mr Mishcon – Even if their financial needs differ?

Mr Simmons – Yes.

Mr Evans – What are the financial needs of the bereaved community likely to be in 10 years?

Mr Simmons – The next few years will be difficult for those on low incomes. More widows will be added on a regular basis, in the last few weeks a PB died and another one is seriously ill. The newly bereaved sees a huge drop in her

income as the money her husband was receiving in State benefits and from the Trust tails off.

Mr Evans – Given your comment on the psychological damage caused to children, to what extent should the Trust be providing support for this problem?

Mr Simmons – In the short term, affected children should be referred for support through their GP. This process can take a long time so the Trust should consider providing provision for 12 or so counselling sessions by which time the GP referral should have kicked in.

Mr Mishcon – You said you want resources to be aimed at those most in need but a system of regular payments with the availability of grants contradicts the earlier statement regarding the differing needs of a young widow and an elderly widow.

Mr Simmons – A system of regular payments should not differentiate between those in the prime or twilight of their life. The design of the policy and the household income banding could take into account financial needs as well as the increased needs of supporting dependants.

Mr Dolan – You mentioned that people have difficulties with means testing. Could you elaborate on this?

Mr Simmons – The main concern that widows have is the notion of having to sit before a panel to discuss their situation. PBs used to be concerned with completing census forms but less so now that they know their purpose.