

THE MACFARLANE TRUST**404.09**

**Minutes of the Meeting of the Board of Trustees held on Monday 26
January 2009 at Alliance House, 12 Caxton Street, London SW1H OQS
from 10.00am**

PRESENT

Mr C FitzGerald (Chairman)
Mrs E Boyd (Chairman – NSSC)
Dr S Chapman (Chairman – EAC)
Mr P Dolan
Mr S Fuller
Mr C Hodgson
Mr GRO-A
Mr R Mishcon
Dr M Winter (Medical Trustee)

APOLOGIES

Mr G Clarke (Hon. Treasurer)
Mr R Evans
Mr P Spellman

BY INVITATION

Mr Alan Beaney (PIM – Item 393.09)
Mr GRO-A (Representative from the Partnership
Group – 400.09)

IN ATTENDANCE

Mr M Harvey (Chief Executive)
Ms R Riley (Support Services Manager)
Mr N Fish (Assistant to Chief Executive).

388.09 Apologies for Absence
These were noted.

389.08 Minutes of the Previous Meeting
The minutes of the meeting held on 27 October 2008, previously
circulated, were approved and signed as a correct record.

390.09 Matters Arising
377.08 363.08 346.08(e) The Chairman informed the Board that
the Report & Accounts have been submitted to the Charity
Commission.
377.08 366.08 The Chairman reported orally on his various
discussions with Mr Mishcon. He informed the Board that Mr
Mishcon had spent a considerable amount of time expurgating
his dissertation and that its publication on the University website
could now proceed. On behalf of the Board, the Chairman
thanked Mr Mishcon for all the work he had done to resolve this
matter and for the work he had done in writing his dissertation in
the first place. He added that Mr Mishcon and the Chief
Executive would now be approaching consultants for quotations
to review and extract information from the dissertation which
could be of use to the Trust.

378.08 The first meeting arising from the legal market testing exercise took place on 21 January. It was reported that interviews for the two firms selected were to take place on 5 March.

378.08 The Chief Executive reported orally that the Department of Health (DH) should be in a position to confirm the appointment of the new Medical Trustee at the end of January.

378.08 The correspondence between the Medical Trustee and Mr Adrian Pollitt was noted. Mr Dolan referred to the position in Scotland.

383.08 – Noted.

391.09

Chief Executive's Report

The Chief Executive went through his report page by page and invited comments. He referred specifically to the following:-

- That Counsel's opinion in respect of viral infections allowing the Trust's beneficiaries to receive a 'passport' through the ESA assessment was expected in mid-February. Mr Mishcon asked if the barrister was a junior or an eminent figure in the field. The Chief Executive confirmed that the individual was an expert in public health law. Mr Dolan asked if 'viral hepatitis' encompassed all types of hepatitis because in Scotland hepatitis C was a relevant notifiable disease but other types were not. The Chairman asked the Chief Executive to find out and to report back. [The Chief Executive subsequently consulted the Medical Trustee and was informed that 'viral hepatitis' includes hepatitis B & C].

- The Chief Executive reported that he and Mr R Evans had had an informal meeting with Mr B Bradley from the DH with respect to Long Term Funding as well as a follow up telephone call on 21 January. The DH had not rejected the report and were in the process of considering its content.

- Arrangements were in hand for the Chairmen of the Trust and the Eileen Trust to meet in March to discuss the possibility of a merger between the two organisations. The Chairman welcomed any comments from the Trustees regarding this issue. He stated his view that a merger would be difficult to resist provided the DH bear all associated costs and address the financial discrepancies between the two Trusts, principally the £20k difference in capital payments made to infected females. Dr S Chapman asked that if the two Trusts were to merge, presumably to reduce costs, would members of the Eileen Trust benefit from MFT campaigning. Both the Chairman and Chief Executive confirmed that they would. Mr Dolan pointed out that if the two Trusts were to merge ET members would receive less contact with the case worker. The Chairman pointed out that this was a matter for consideration by the ET Board.

- Notes of the meeting held on 28 October between the Chairman, Chief Executive, Assistant to the Chief Executive and DH officials are attached to the report.

- That the Chairman and Chief Executive would be meeting with the Shadow Minister of Health on 28 January because he was unable to attend the last meeting that had been arranged.
- The Chief Executive and Support Services Manager participated in a briefing held in Canterbury in respect of the externally funded Personal Development Programme on 23 January. The Director of Finance from the PCT that had provided the financial support, Mr David Meikle, had been in attendance. The Support Services Manager reported that the meeting went well and that proposals had been put forward to encourage people to sign up. A letter had already been sent to all Kent based primary beneficiaries and a second one would be going out shortly. There had been one respondent thus far who was willing to market the pilot scheme to others. Mr Meikle was satisfied that the scheme could carry over into the new financial year. The Chief Executive added that the scheme could be extended to other beneficiary classes if need be.
- The Chief Executive clarified that the loans policy had been altered to enable the Trust to charge interest at 1% above the Bank of England base rate from time to time with a maximum cap of 5%.
- The Chief Executive undertook a market testing exercise for the provision of insurance broker services not funded through any commission arrangement and selected WRS Insurance Brokers Ltd who are responsible for a number of the Trust's insurance arrangements.
- That the health & safety audit had been carried out and that the Trust came through it well. It was pointed out that the report only referred to the Trust's beneficiaries as having haemophilia and not to their being infected with HIV. The Chief Executive confirmed that this point had been made to the company who produced the report and that it would be amended accordingly.
- That external funding of around £9k had been sourced to support a Trust delegation to the 2010 World Federation of Haemophilia Congress from the same PCT who are funding the Personal Development Program. A paper will be put before the Employment Affairs Committee (EAC) to consider how best to utilise the funds which will in turn be put before the Board. The Chairman said that he would have concerns if the delegation were increased from one representative to a large group. He added that everybody who attended should contribute either in terms of making a presentation or networking. In line with standing instructions, the external funding support had been reported to the Chairman and Hon. Treasurer.
- There had been no further developments in respect of the female who was recklessly infected by a Primary Beneficiary. The Terrence Higgins Trust's special unit which dealt with such instances had apprised the individual's lawyer.

- Mr [GRO-A] would present the Partnership Group (PG) report of the meeting held on 15 December because the Chair, Mr [GRO-A] was undergoing hospital treatment.
- An IT report, prepared by Mr Baker and the Trust's webmaster, was attached.

392.09

Financial Reports

The reports circulated with the agenda were noted.

- 1) The schedule of grants and regular payments for the third quarter of the 08/09 financial year was accepted. It was noted that Trustee and Office grants were higher than expected. The schedule of disbursements for the third quarter of the 08/09 financial year was also noted. The Chairman asked if the £200k which had been drawn down from the reserve fund at the end of September to aid cash flow problems had been returned to the reserves and, if it had not, whether it should not be included in the figures. The Chief Executive will clarify the situation with the Finance Manager.
- 2) The third quarter management accounts for the 08/09 financial year were noted. The Chief Executive reported that the staff salaries element of the budget for 09/10 was currently being reviewed by the EAC. The full revenue and disbursement budget for 09/10 would be available at the April meeting of the Board. The Chairman asked that the presentation at the April meeting should include a paper explaining any material variances between budget and actual figures once a full year's comparison could be made.
- 3) The investment report for the third quarter of the 08/09 financial year was noted.

393.09

Principal Investment Management Ltd (PIM)

The Chairman welcomed Mr Alan Beaney from PIM. Mr Beaney tabled a report and referred to the following:-

- That during the year lots of discussion had occurred with the Trust about its investment policy. PIM had been made aware of the Trust's need to draw down investment income as well as a portion of the capital and a more conservative approach had been adopted accordingly.
- That around £200k per annum was a realistic and sustainable level of income that could be achieved from the reserves at their current level.
- That redistributing funds from equities to corporate bonds had been a mixed blessing. Losses in the equities market had been minimised but Corporate Bonds had fared less well than safer options such as Gilts.
- That around £500k was held in cash so that, as and when the Trust wished to draw down a portion of the capital, investments would not need to be sold.

- That the current economic crisis was global, that the UK was no worse off than anywhere else and that world governments had reacted with substantial measures to help alleviate the situation. It would, however, take time for these measures to take effect before the global economy begins to recover.

The Chairman added that provided Corporate Bonds were well selected their price should recover, while the disadvantage of shifting toward Gilts now was that income would be halved. He reassured the Board that the Trust's investment strategy was to minimise risk as far as possible by spreading investments over asset classes and within asset classes.

Mr Fuller raised the question of adopting a "stop loss policy" whereby stocks are sold if they reach a predetermined minimum price. Mr Beaney cited various reasons why a stop loss policy is not a good long term strategy; mainly that it eliminates the potential for recovery and realises market losses. The Chairman added that the Trust has (or must be presumed to have) a long term horizon and that a long term strategy is therefore the best route to go down.

394.09

National Support Services Committee (NSSC)

Mrs Boyd, Chairman of the Committee, presented the minutes and schedules of support payments from the meetings held on 1 October, 7 November and 3 & 19 December 2008. The minutes and schedules were noted.

The Chairman reported that the text regarding secured loans would need to be adjusted as it was not quite in line with what had been agreed. He requested that a schedule of all the Trust's unsecured loans should be presented to the next Board meeting with a summary of what the NSSC has concluded on each case it has discussed. Mr Fuller asked how many unsecured loans were yet to be discussed; the Support Services Manager responded that there were none outstanding.

395.09

Revised Disbursement Policy

The Chairman referred the Board to the paper circulated with the agenda and invited the Chairman of the NSSC to address the Board.

The Chairman of the NSSC apprised the Board that the paper was being put forward by the NSSC after they were asked to consider how the Trust could best utilise its reserves. The paper focused first on increasing the assistance given to those receiving Incapacity Benefit but not on Income Support. The Chairman of the NSSC then passed over to the Chief Executive to provide further information on how the paper was put together since it was he had who carried out most of the work. The Chief

Executive referred to the paper and specifically the rationale behind the changes that were being proposed to the regular payment income bands and values. He then invited further comment from the Chairman.

The Chairman summarised that the key issues of the proposed policy for the Board to consider were:

- a) whether £14k was a fair assessment of the average value of receiving Income Support
- b) whether the Board accepted the recommendation to seek out the 10-12 households that were thought not to be receiving Income Support and to bring them up to a net annual household income of £14k through regular payments
- c) whether the Board accepted that the £7k net income bands were sensible and that regular payments should be reduced as net household income increases
- d) how high up the net income scale the £7k bandings should continue, bearing in mind that the regular payment values attached to each banding were illustrative and not necessarily final.

Mr Mishcon asked where the estimates of the number of primary beneficiaries in each banding came from as the numbers he obtained whilst researching his dissertation were very different. The Chief Executive replied that the numbers were obtained from the survey for stage one of the disbursement policy review and from the census form responses for those beneficiaries not receiving Incapacity Benefit. He added that because the income ranges were different for stage one the numbers had to be skewed.

The Chairman felt that this highlighted a key issue whereby no conclusions can be reached until the Board are satisfied that the numbers are accurate. He added that a well designed census form and receiving full responses to it were key to the whole exercise. Only when the banding ranges were agreed and accurate numbers could be placed to each range could the Board see the real financial impact of the policy on the Trust's spending.

Mr Hodgson asked how the Board would be able to sell the policy to those beneficiaries whose regular payments would be reduced, whether the Trust should be asking about incomes in the first place and if people would be angered by the census form. The Chairman pointed out that the new census form would be no more intrusive than the one which is already distributed, that it would be piloted first and that ascertaining levels of income was essential in order to gear increased funding towards those most in need.

Mr Dolan expressed his concerns over means testing beneficiaries. The Chairman of the NSSC pointed out that the majority of beneficiaries are already means tested in order to receive Income Support. The Chairman added that the Trust would not be replicating means testing as the Government does for Income Support in any case.

Dr Chapman stated that every beneficiary has been disadvantaged in some way due to what has happened to them and suggested that the Trust could not get away totally from the practical reality of a compensation element. He felt that it was vital to bring those at the very bottom of the scale up to an acceptable minimum level of income but that every primary beneficiary should receive something because of what has happened.

The Chairman agreed that the first requirement was to bring those on very low incomes up to the deemed level of those on Income Support and accepted that no matter what level of income a beneficiary was receiving infection with HIV had added a premium to his expenditure. However, this was not to recognise that payments made to beneficiaries were in any sense compensatory. Regardless of their perception, the hard reality was that, consistent with the Trust's charitable objective, all payments had to be made with a view to relieving need. Given the very special circumstances of the Trust's beneficiaries resulting in their suffering costs to which others were not subject, "need" could in his view be interpreted very widely. In this respect he agreed with the example given that even a beneficiary with a relatively high income was not in a position to provide for his dependants' future by obtaining life assurance cover. He added that the census would need to be repeated at sensible intervals and beneficiaries should be urged to contact the Trust if their circumstances changed.

Dr Winter broadly supported what Dr Chapman said and added that widows were an issue which had never properly been addressed.

Mr GRO-A agreed with fellow Trustees that the census form should not be too intrusive and said that there should be more income bands with narrower ranges and that regular payments to those at the top end of the scale should be frozen but not reduced.

Mr Mishcon welcomed the shift in emphasis towards those most in need and felt that the £7k steps were about right. He expressed serious concerns that the fact that the number of people dependent on an income differed between households was not being properly taken into account. He felt that the

removal of supplements would discriminate against those with more dependants. He added that he was not in favour of a £35-£42k net income band.

The Chairman summarised that the Board accepted £14k as a fair assessment of the value of Income Support, that those on very low income but not on Income Support should be brought up to an income of £14k, that the £7k income bands were sensible and that a proposition for some sort of payment to be made to all would need further discussion by the Board as would the payment of supplements for dependants.

The Chief Executive confirmed that the next step would be for the NSSC to design a census form which reflected the direction of travel of the policy and to discuss the issue of supplements. Following a brief discussion all agreed that it would not be helpful for the PG to be involved in the design process as this had caused difficulties in the past. When reliable census data has been received the Trust could then ascertain whether the policy was affordable based on the new regular payment figures currently recommended and the value of the Government grant. The Chairman added that, based on the estimated numbers in each income band and the current level of the Trust's reserves, the figures currently recommended might be affordable for only two or three years before the minimum level of reserves was reached. He added that decisions on Summer and Winter Pay could not be made until the impact of this policy had been analysed. In response to a point raised by Mr Dolan, the Chief Executive stated that once the Trust was comfortable with the numbers then they would move to help those with a household income of less than £14k.

396.09

Long Term Funding Working Party (LTFWP)

In the absence of Mr Evans, the Chief Executive reported on the informal meeting he and Mr Evans had attended with DH officials on 3 December. He said that one of the main objectives of the meeting was to make it clear to the DH that the Trust was fully aware of the long term funding implications and at some point it would be necessary to weigh up the level and number of beneficiary disbursements against the administration costs of running the Trust. They had presented the DH with a copy of the LTFWP's first stage report and explained that it sought to consider alternative solutions which would provide primary beneficiaries with financial support that they would otherwise have received from the Trust based upon age and other factors, that it was not compensatory and that it sought to remove the notion of "charitable giving" which remains a source of frustration for the community of care. He went on to say that officials felt that the suggested capital costs may well be prohibitive but, when considered on an accrual basis over a

given period of years, the impact was lessened. He concluded by saying that officials had retained a copy of the report for internal discussion and that a follow up telephone call made on 21 January confirmed that the DH were not totally averse to what had been proposed. The Chief Executive went on to say that the LTFWP would consider sanctioning a second stage report by First Actuarial (FA) only after the DH had responded with their thoughts on the first stage report. A further update will be given to the Board at the April meeting.

The Chief Executive reported that FA had made a presentation to the PG at their meeting in December regarding this issue and that the group were supportive of the proposals. They also agreed that the first stage report should not be widely reported because others would not have had the benefit of the briefing from FA. If anybody wanted a copy of the report they could contact the office at which time they would receive a background briefing. Unfortunately somebody published a copy of the report on the Trust's website which caused a lot of unnecessary confusion. Dr Chapman stated his view that this represented a breach of confidence and that the PG should not be briefed on such matters again.

397.09 Employment Affairs Committee

There was no business undertaken by the Committee during the third quarter.

398.09 Risk Strategy & Assessment 08/09

The Chairman mentioned that the policy had been attached to the Board papers on a number of separate occasions. He invited views on the first two sections which he felt were adequate for purpose. This was agreed. Referring to the third section, which would be considered at the next Board meeting, the Chief Executive informed the Board that the biggest risk to the Trust was its dependency on electronic payments.

Dr Chapman said he would like to consider the policy once a year so that it received a more focused attention. The Chairman agreed and stated that it should be placed at the top of the agenda at the Board meeting held around the time of the audit, that is in April each year.

The Chief Executive again drew the attention of the Board to the health & safety report produced by Judicum following their inspection of the Trust's office on 15 December. He reiterated that no significant problems had been identified.

399.09 Strategy Paper – “Meeting the Challenges – making the Changes”

The Chairman referred to the paper “Meeting the Challenges – Making the Changes” which was formulated following the Strategy & Development day in October and which was circulated with the agenda.

Due to time constraints it was agreed that the Chief Executive and Chairman, when arranging the agenda for the Board Meeting in April, would place strategy towards the start of the meeting along with the risk assessment paper and financials.

400.09 Any Other Business

The Chairman referred to the upcoming re-appointment of NSSC members and reminded the Board that the process required the Board to nominate 5 Trustees. If more than 5 Trustees are nominated then the Board will need to vote to decide which 5 will comprise the committee. This process needs to be completed by the Board meeting in April but ideally it should be done before the NSSC meeting at the beginning of that month. The Chief Executive will send out the necessary nomination papers and terms of reference. The Chairman suggested that the terms of reference be amended so that the re-appointment of all NSSC members would not all fall in the same year. He would invite the Board to consider varying their terms of office so that 3 members serve for 2 years and 2 serve for 1.

On behalf of the Board, the Chairman took the opportunity to say farewell and formally thank Mr Hodgson and Dr Winter for their enormous efforts over the years as they will both be standing down as Trustees at the end of March.

Mr Hodgson has served a total of four terms as a Trustee, his first being before official records began. He has done an enormous amount for the Trust during his time, especially amongst the bereaved community. He is widely regarded as the conscience of the Trust and the Board will miss him greatly.

Dr Winter has been with the Trust since 1996, a total of 13 years. He has done an enormous amount of work dating way back to the beginning of this disaster. The work he has done to guide the Board during his time has been invaluable and the evidence he gave at the Archer Inquiry was telling. It is hoped that he will continue to give advice and support in the coming years.

The next meeting of the Board of Trustees will be held on 27 April at Alliance House, as will all subsequent meetings until further notice. Mr Dolan provided his apologies for this meeting.

At this point the meeting was adjourned for lunch during which the following item was taken.

401.09 Partnership Group (PG) Report

The Chairman welcomed Mr [GRO-A] (Representative from the Partnership Group) who was deputising for the Chairman, Mr [GRO-A]. Mr [GRO-A] circulated a note of matters arising from the last meeting of the PG held on 15 December 2008. Mr [GRO-A] reported the following:-

- that he, the Chairman of the PG and various other members of the group were extremely angry with whoever published a copy of the LTFWP first stage document on the website and that they will do all they can to ensure that a similar incident does not occur again. He added that those present at the meeting were very positive about the proposal and he hoped that the actions of one or two individuals would not ruin what the Trust was trying to achieve;
- that due to a lack of remaining funds in the budget, the PG would be unable to afford a fourth meeting in the current financial year. The PG would like to request a budget extension to cover the shortfall to enable a meeting to go ahead in March;
- that the PG would like to make a formal request to the Board to consider doubling the one-off winter payment due to the exceptionally high increases in fuel costs.

The Chairman suggested that rather than extend the budget, the first PG meeting of 2009/10 be brought forward to April. He said the request to double the one-off winter payment would be considered.

Mr [GRO-A] personally thanked Dr Winter and Mr Hodgson for all the hard work they have done over the years for the Trust.

The meeting terminated at 2:20pm.