

**THE MACFARLANE TRUST
THE PARTNERSHIP GROUP**

**Notes of a Meeting held on the 10 April 2006
At the Novatis Foundation, 41 Portland Place, London W1**

Present

Mr A Evans
Mr GRO-A
Mr GRO-A
Mr GRO-A
Mrs GRO-A
Mr GRO-A
Mrs GRO-A

In Attendance

Martin Harvey (Chief Executive)

Apologies

Mr GRO-A
Mrs GRO-A
Mr P Stevens
Mr GRO-A
Mr GRO-A
Mr GRO-A
Mrs GRO-A
Nr GRO-A

1. The Chairmanship

The Chief Executive took the Chair. He advised members present that there had been just one nomination, from many members, for the chairmanship of the Partnership Group and that was Mr Andrew Evans. By general acclaim, Mr Evans assumed the chairmanship.

2. The Minutes of the Previous Meeting

The minutes of the meeting held on the 12 December 2005 were signed as a correct record subject to the one amendment. It was GRO-A from GRO-A (minute 4).

3. Matters Arising

There were no matters arising from the minutes.

4. The Succession Process

The Chief Executive advised members of developments pertaining to the succession process. He explained that the selection process had produced a suitable candidate who had expressed interest in the chairmanship and that was Mr Christopher Fitzgerald.

Following discussions after the selection process, Mr Fitzgerald had advised the Chairman that in his opinion, it would be sensible to await the outcome of the business case for increased funding and the funding situation in general

after the 3 year "Blears Settlement" and to await some form of resolution to the situation in respect of the Skipton Fund.

The Partnership Group were disappointed that the putative Chairman felt unable to assume his responsibilities in line with the published time-frame and asked the Chief Executive to communicate those views to the Chairman.

It was the Chief Executive's understanding that Mr Fitzgerald was still interested in becoming Chairman. He further reported that there would be, in time, a hand-over process between the incoming and outgoing Chairman and that there had been no expressions of interest in the chairmanship from the (pre-interview) board of trustees as constituted before the succession process was agreed..

He went on to report that there were now three additional trustees and they are Mr Philip Dolan (Haemophilia Society) Dr Simon Chapman, (suggested as a suitable departmental nominee and subsequently accepted as such) and Mr Russell Mishcon (MFT).

5. The Business Case for Increased Funding

The Chief Executive reported that the case had been formally submitted to the minister and officials before Christmas and had now been formally acknowledged. He understood that there would be a meeting with the minister in either April or May 2006 but this had not been confirmed.

He went on to report that he understood the block grant for support in 06/07 would be £3m but this had not been confirmed. When questioned how the Trust might continue to make provision for support in the absence of any funding announcement, he replied that earnings from the investment of reserves that were above the maintained level, in line with current policy, were transferred to the support grant account. Arrangements had been made with the Trust's bankers to have an overdraft facility in place for continued funding after April in the unlikely event that such a facility would be required.

Some members felt that the Trust should take a forthright approach to the funding question and exhaust the reserves to the point that the department would be forced to recognise the predicament arising from that action. The view was expressed that because of the reasons the Trust came into being, there should be sufficient funding to meet all registrants' and beneficiaries' needs, according to the Trust Deed document.

The Chief Executive explained that, in respect of the reserves, the views expressed would be counter to current policy in respect of the management of funds and would not find favour with the authorities. It was policy to maintain one year's forward expenditure to support the community of care and to anticipate liabilities in the event of the Trust ceasing in its current form.

The Partnership Group felt that if there was no positive re-action to the business case for increased funding then it was likely that registrants might take some form of affirmative action to express their concerns and some

members present felt that the trustees should present a more robust argument in support of the business case even to the point of resignation.

The Chief Executive whilst having a degree of sympathy with some of the views expressed felt that a mass resignation of the board would be unlikely and may well prove counter productive in terms of the way support might be administered should such an event occur.

The Chief Executive went to say that if the £3m funding allocation was confirmed then it has to be accepted that what £3m purchased there years ago was less than what £3m would purchase now. He suggested that the rate of inflation in respect of goods and services purchased by the Trust was in excess of the national published rate of inflation according to the retail price index and that some action would have to be taken but that the matter should be considered by the Trust as a whole. There was little point in decisions being taken without the "community of care" having an input in these most difficult of circumstances.

The Chief Executive said that regular payments should remain together with the winter and summer payments. It was not a case of reducing the cash sums available but seeing if there was room to extract greater value. He cited one or two illustrations such as "Central Heating Grants" and "Replacement Windows" where the qualifying time-frame for a new installation might be extended. He went to include the situation in respect of "Respite Breaks" where the current value would remain but the process for applying for respite breaks would have to be strictly applied and subject to trustee determination.

Members present felt that it was the Trust was in an impossible position in that it was difficult to budget against predicted needs when the medical condition of registrants, co-infected and otherwise, could not be in any way accord with the normal budgetary disciplines. There was clearly a divergence of views between those that the trustees had to take account of and the perceived needs of the registrant community.

It was resolved by members present that the trustees be urged to delay any such review until the business case had been decided upon and the block grant for support (exclusive of the business case) had been agreed.

(Chairman's Note: The Chief Executive had consulted with him on the text of a statement in this respect but it had, inadvertently, been circulated to members of the Partnership Group. He would be issuing a statement that this should not have occurred)

The Chief Executive said he would report the feelings of the Partnership Group accordingly.

6. Mini PG Update

There was no report as the group member preparing the business case was currently unwell. It was resolved that discussions would take place between the members of the steering group to determine how to proceed.

7. MFT Exemptions Update

The Chief Executive reported that the 1991 DSS letter detailing the treatment of benefits in relation to payments by the Trust had been updated and was now on the website.

The Chairman read an e-mail from 1534W that referred to several issues in relation to how care costs might be treated. The Chief Executive would report this to the DWP and seek to have the point raised clarified for possible inclusion at a later date. In the meantime, he suggested that where Trust payments in relation to care costs were a difficulty, they should be reported to the Trust office on a case by case basis so that the matter could be addressed and resolved.

He stressed that all Trust payments should be kept in separate accounts.

8. MFT/THT Update

The Chief Executive reported that the current arrangements were working well. A member said that there could be difficulties in certain areas; the Chief Executive responded that this was the reason that a payment regime had been agreed to try, as far as possible, to negate this area of difficulty.

He went on to report that the delivery of support services was largely a management exercise and the "skills" surrounding the delivery of support services were now contracted out to meet the needs of the individual.

The service level agreement, under preparation by the THT, was still awaited.

9. The Complaints Procedure

The Chief Executive reported that the current procedure was by direct letter to the Chairman of the Board of Trustees.

Members present felt that this was not an appropriate or dispassionate procedure if a complaint was to be lodged. A member present expressed her concerns about the way a complaint had been managed in that it was her wish that it should have gone to the full board of trustees as she had requested.

It was resolved that the Chairman of the Partnership Group would write to the Chief Executive expressing the concerns of the Partnership Group in the sense that it was right that there should be a wider and more transparent process to register a complaint on processes and procedures and, where necessary, personalities. One of the members of the Partnership Group had been working on a complaints procedure, and this would also be submitted to the Chief Executive to pass on to the Trustees as a possible way forward.

10. Haemophilia Society Report

There was no formal report from the Society nor were any Society representative present. A member present, who was a Society trustee, gave a brief update of developments within the Society.

It was resolved that the Chairman of the Partnership Group would write to the Chief Executive of the Society to establish their current level of interest in the Group and that their presence was required.

11. Chief Executives Report

The report which covered many of the items discussed at the meeting was noted and the Chief Executive felt that he could not add to the document circulated.

12. Events Report

The report was noted. Members felt that the events coordinator should be present at future meetings of the Group. The Chairman undertook to write to the coordinator in that respect.

13. Any Other Business

The Newsletter compiler reported that there would be a slight delay in the publication of the Easter newsletter.

It was agreed that members should be allowed to purchase their own lunch arrangements and that a ceiling of £5.00 should be allowed.

The savings in respect of the purchase of rail tickets was mentioned and he Trust should be encouraged to apply to join the Virgin Charity Line concession.

The next meeting will be held on the and the likely venue will be in Birmingham.