

Witness Name: Beverley Tumelty
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EXHIBIT WITN2412013

**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 G Lewis Mr H Lewis Mr M De la Haye Mrs C De la Haye Mr M Price Mrs C Walton
In Attendance	Martin Harvey (Chief Executive)
Apologies	Mr A Burgess Mrs GRO-A Mr P Stevens Mr GRO-A Mr GRO-A Mr R Vaghela Mrs S Vaghela Nr S Gregg

- 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 Flint from Flynn (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.

needs clarifying ?

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.

Macfarlane Trust Partnership
Minutes of Meeting
23rd October 2006
Britannia Hotel, Birmingham

Present: A. Evans (chair), A. Burgess, M. Price, M. Harvey, P. Hooper, G. Lewis, A. Evans, L. Haigh, M. Simmons, M. Beddow

Apologies: C. Delahaye, D. Delahaye, P. Stevens, [GRO-A], S. Gregg, C. Walton, A. Beesley, [GRO-A], H. Lewis, A. March, S. Vaghela, [GRO-A], M. Unwin, W. Macefield, [GRO-A]

Previous Minutes: The previous meeting's minutes were accepted with a change noted in page 1 with the addition of Amanda Beesley's details to the those present section. It was also noted that there was a slight misrepresentation on page 2 about Mr [GRO-A]'s settlement. This has not yet gone through and he has been committed for sentencing in mid December.

Chief Executive's Report: This was modelled on a report to the Trustees. Under the Staff Matters heading, on the advice of the Shaw Trust, Claudette Allen is still an employee. Ms Allen is currently consulting with her benefits advisor to ascertain if it is financially beneficial for her to return to work and the Trust are awaiting her decision. If she does return to work she will return as a visitor, however if she decides not to do so a replacement for her position will not be sought.

THT: The feedback given has indicated that all is going well despite a couple of administrative hiccups.

Business Case Funding: This was discussed at some length and members of the group understood the direction the trust was taking.

Office Procedures: There will be an away day on the 4th November. The trustees will consider the proposal to provide a 'one off' payment to individual registrant households to cover the increases in fuel prices. As the price of fuel has risen higher than anticipated this year, the Trustees believe there should be some assistance given. The scope of this payment will be considered on the 4th November.

Office Accommodation: The question was raised about reducing expenses and relocating the offices somewhere else. The Chief Executive explained that prior to his appointment, a five-year lease had been signed on the ground floor. A ten-year lease (with a five-year break clause) was signed on the first floor two years ago. The Trust is shares the 1st floor with the Skipton Fund and sublets the ground floor. If, at the end of the lease, the ground floor is not let the trust will remain on the first floor. Therefore in the short term the trust will remain in its current location.

Trustees: Mr Christopher Fitzgerald has taken the position of Trustee and incoming Chairman. It was felt that what Mr Fitzgerald said at his selection panel interview was misunderstood or misinterpreted. The second candidate interviewing for this position was Roger Evans. It was agreed that Mr Evans would have made an equally good chairman and could have offered a reach into the officials of the Department of Health.

Annual Plan: This is now in its final stages and more objectives have been met than haven't in the three-year programme.

Honeycombe Legacy: It was agreed that the Legacy's profile needs to be raised in order for it to become more widely known. The Chief Executive stated that he would propose to the board of Trustees that the Legacy be publicised to a greater measure. The question was raised whether any non-spent money in the fund could be ploughed back into the main fund. The Chief Executive said that he would speak to the Legacy's lawyer about this issue.

Trustee Election Procedure: The question concerning how trustees are elected was raised. The Chief Executive stated that of the 12 trustees, all are appointed and not elected. It was clarified that Ian Jeffries is standing down on the 22nd of January and Christopher Fitzgerald will fill his position. Peter Stevens is standing down as the chairman of the Eileen Trust and director of the Skipton Fund at the end of the financial year. There are currently three candidates for his position, one being Roger Evans. Whilst discussing this issue, dissatisfaction and concern were expressed about the lack of a social worker on the board of trustees. Concern was expressed that without a properly qualified social worker on the board the interests of the registrants are not fairly represented. The point was made that all NSSC papers are seen by the medical trustee and his advice is

taken very seriously. Despite this, the general feel of the partnership group was that there is a real need for a qualified social worker to become a trustee.

Grant Expenditure: A number of views were expressed concerning this issue. There seems to be a conflict of viewpoint between the Board of Trustees and the members of the partnership group. The trustees' view is that a level of reserve must be retained in the fund and this constitutes at least one year's running costs. However the members of the partnership group feel that there is a genuine need to spend the maximum budget and that the Trustees are adverse to any major impact on the reserves. It was also noted that it is becoming more difficult for registrants to apply for grants and therefore spend the budget. The general feeling of the group was that the Trustees are being overly cautious and have not dipped sufficiently into the reserve funds. The Chief Executive accepted and understood these points of view and said he would relate this to the Trustees. The point was also made that the block grant is received in instalments, which negatively affects the interest earned on the grant. Therefore the ability to generate cash earnings from the block grant is prejudiced. The Chief Executive stated that the Board of Trustees do maximise what can be done in the disbursement of the fund but he reiterated that he would take the group's viewpoint back to the Trustees. M Price made the comment that applications for grants have increased and registrants have been struggling. He feels that the fact this group of people is the largest cohort of long term survivors in the UK and consequently their needs are far greater, is being overlooked by the Trustees. He also made the point that he feels that there is some capping occurring i.e. registrants achieve a level of applications and then can not make any more. The Chief Executive replied saying that the guidelines do allow some capping but that fairness is applied across the board. The Chief Executive also raised the issue of fundraising. He reported that he is trying to raise external funding outside of the block grant. This is to try and reduce the pressure put on the block grant to fund events that would benefit and support the registrant community. He has been approaching grant-making trusts but has not yet much success to date. In total, the trust spent 300 pounds more this year than last year.

Winter/Summer Payments Respite: The decision regarding the winter/summer payments has been deferred until the autumn meeting. The members of the partnership group raised concerns that with a tightening of the respite grant and with no decision concerning the summer payments, many respite grants are being turned down. This issue will be considered in the Policy debate on the 4th November. A Evans raised the point that is a long time between now and the summer payments next year and respite grants have been cut way back. He stated that it seems the policy is in place but questioned whether there would be an interim measure until the summer payments take effect. The Chief Executive stated that the policy had not been changed and it was not definite that the summer payments will increase but the strength of feeling about this issue will be reported back to the trustees. The issue of confusion over the interpretation of convalescence and respite was also raised. The Chief Executive proposed to introduce a debate on this area in the 4th November meeting.

Events: Richard was absent from this meeting and sent his apologies. In his place, Andrew Evans provided a summary of the Bereavement weekend. He reported that the format of the weekend was different to previous weekends but they had received good feedback. There was a good session by Mike Beard and it was also reported that there would be a radio 4 programme in the future entitled living stories: blood brothers.

Skipton Fund: The Chief Executive provided background information concerning a registrant whose wife tested positive for Hepatitis C. After a short while his wife naturally cleared. The registrant assumed his wife would qualify for payment from the fund and undertook expenditure in that respect. This however had not been confirmed by the fund due to confusion over the date of the processing the wife's claim. The wife's Hepatitis C had been caused by sexual transmission, which is rare. The Chief Executive stated that he did not involve himself in the Board's decision making process as he felt the registrant had a possible case. Therefore he had to declare his interest and not take part in the board's debate. The Directors asked for the genotype to be confirmed, as this would support the case for sexual transmission. This established that the wife had naturally cleared and she had cleared extremely quickly. As she naturally cleared, due to the rules of the scheme, she did not qualify for receiving any funds. The registrant is appealing this decision and is asking the appeal panel to consider the sequence of dates at the time his wife was tested. The Chief executive has persuaded the registrant to await the appeal panel's decision as the situation could happily resolve itself.

Staff Issues: Concern was raised over the lack of support workers at the moment. The Chief Executive refuted that saying that there is a wider service provided than in the past, ensuring demands from the beneficiary

community are met and that a number of visits are dealt with at a time. The question was also raised as to why administration staff had increased. The Chief Executive responded that the headcount had not actually changed and staff costs have fallen away dramatically. Concern was expressed that there used to be advisers for registrants and not to have them anymore is a retrograde step. The feeling was that there is a need for social workers to be back in place.

The issue of registrants' payment was raised. Concern was expressed that registrants' pay is not in line with inflation rates and it is unfair that they have not received a pay rise. The group requested that the Trustees consider a pay rise.

Tainted Blood: It was requested that the Board of Trustees look into having a representative on NSSC meetings and meetings like the 4th of November, who is democratically elected. The desire to hold an AGM sooner rather than later was expressed, as they want to apply for charity status. The Chief Executive agreed to write a formal proposal.

Complaints Procedure: There is no further news on the complaints procedure.

New Trustee: Andrew Evans reported that he has met the new Trustee who is doing an Masters degree and wishes to do his dissertation on the historical aspects of the MFT funding. He would like to use the dissertation to put something forward about the need of funding. He requested permission to send out questionnaires to registrants in order to ascertain areas where their needs may not be met. The members of the partnership group agreed their permission for him to send the questionnaires.

Expense Forms: Members of the group were reminded to get their expense claims forms to Linda within a month or they will not get paid.

Dates and Locations of the next four meetings:

February 5th: Novartis Foundation, London

April 16th: Britannia Hotel, Birmingham

July 16th: Novartis Foundation, London

October 15th: Britannia Hotel, Birmingham