

**THE MACFARLANE TRUST
THE PARTNERSHIP GROUP**

**Notes of a Meeting held on the 13 December 2004
At the Novatis Foundation, 41 Portland Place, London W1**

Present

GRO-A (In The Chair)
Mrs GRO-A
GRO-A
P Stevens
GRO-A
GRO-A
GRO-A (Haemophilia Society)
GRO-A
GRO-A
Mrs GRO-A
GRO-A
GRO-A
GRO-A
W Payne (By invitation)
GRO-A
Mrs E Boyd (By invitation)

In Attendance

M Harvey Chief Executive
J Cohen Head of Support Services

Apologies

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

1. Introduction & Welcome

The Chairman welcomed Mrs E Boyd (Trustee) and Mr W Payne (Trustee) to the meeting.

2. Apologies

The apologies were noted and recorded.

3. Notes of the previous meeting

The notes of the meeting held on the 1 October were signed as a correct record. It was agreed that notes of future meetings would be e-mailed and sent by post. The content of the notes were judged by some members not to fully represent the debate and, for those members who could not attend meetings, it was difficult to follow the context of the debate that lead to the minutes.

(Chief Executive's Note: Notes (or minutes) of meetings are to record decisions arising and can never be expected to fully reflect the contents of the debate leading up to the resolution)

4. Matters Arising

1) **GRO-A** – The Group noted that Mr **GRO-A** had not resigned from the Partnership Group.

6) Long Term Review - The Chairman reported that he had not received any advice or guidance from members in respect of his observations on the Partnership Group Review of the Long Term Review.

9) Future of the Partnership Group – It was resolved that the Chairman would write a “roadmap” paper on the possible way forward for the Group to achieve a more formal consultative or formal role.

The e-mail from **GRO-A** was circulated. A copy of the e-mail is attached.

Point 1

The Chairman of the Trust confirmed that regular payments would not be cut (1) without prior consultation or (2) without the knowledge of the individual.

The Chief Executive drew attention to Trustees Aide Memoire (laid around the table) page 2.1.2. The penultimate paragraph in respect of current policy was put to members of the Group as follows:-

“To give extra support to those whose health is poorest, at the stage where costs imposed by living with HIV escalate significantly”.

The Chief Executive drew members attention to the need to ascertain those registrants who might be in need of additional support. This one of the prime reasons for the introducing the regional support worker network.

It was agreed to recommend a review of the notice period where widows were to receive reductions in the amounts of regular payments.

Regional Support Workers (RSW)

It was further resolved that there would be a debate within the Partnership Group about the ethos and rationale behind the introduction of the RSW network. This debate would take place within the strictures of the policies of the Macfarlane Trust.

The Partnership Group would seek advice and guidance from registrants as to how they would envisage the job description. The mode of funding the regional support worker network would appear on the website in the same manner that it has been appeared in the winter newsletter.

Point 2/3

That letters in respect of single grants, where receipts were requested, would no longer contain the paragraph about converting the grant payment into a loan if receipts should not be forthcoming.

The HSS explained why it was deemed appropriate to mention the sanction in the first letter as it afforded (audit) protection to the registrant and the Trust and made the point clear from the outset.

Following a lengthy discussion, it was agreed that the sanction about conversion to a loan would be exercised a follow up letter should that letter prove necessary.

The HSS confirmed that procedures were in place in respect of this area of communication and would feature on all grant information documents.

Office Guidelines

These would be available in January and sent to all registrants under separate cover and published on the website.

The support currently available to widows was confirmed.

Point 4

It was resolved that there will be a mode of electronic communication for registrants with trustees. The permission of trustees will be sought first.

Point 5

The thrust of the point was accepted.

5. The Birmingham Meeting

The Chief Executive reported that he had nothing further to add to that already mentioned in electronic and other communications.

6. HSS Report

Apart from matters that had already been discussed, HSS reported as follows:-

The current and apparent investigations by fraud units into the affairs of registrants.

7. Haemophilia Society Report

The report from the Society was laid around the table and is attached.

8. MFT Events

GRO-A reported on the programme of events that have been scheduled for 2005. Full details will be made available in due course and will feature on the website.

9. The Bereavement Project

Mrs E Boyd (trustee and member of the Bereavement Group) spoke about the Project and the annual event it runs for those that are bereaved.

The need to introduce carers as a specific project was discussed.

Mrs [GRO-A] made a statement of case for the bereaved and how the Trust might consider helping them in the future.

The next Bereavement Group newsletter will be made available.

10. Department of Health

The Chairman of the Trust advised members that there was to be a meeting with the DoH shortly. It was agreed that [GRO-A] should be present at the meeting if possible. [GRO-A], [GRO-A] and [GRO-A] said they would be deputise if necessary.

11. Any Other Business.

[GRO-A] spoke of the need to ensure that exchanges of correspondence between parties remained confidential when asked for.

The next meeting will be held on the 4th March 05 and that future meetings should start at mid-day.

That there would be a meeting with the Chairman of the Group and the Chief Executive to establish a budget for 005/06.

That Mark Simmons (Social Worker) and other Centre Social Workers would be invited to future meetings of the Group.

The meeting terminated at 5.30pm.