Meeting between The Macfarlane/Eileen Trust and DH 629B Skipton House 10.30 Wednesday 25 September 2002

Present:

Peter Stevens Macfarlane/Eileen Trust Ann Hithersay Macfarlane/Eileen Trust

Charles Lister DH Robert Finch DH

Minutes of last meeting

1. Ann Hithersay (AH) asked for the discussion in agenda item 5 to reflect that the Trust felt that the increase in top up funding to £3m per annum would only allow them to meet current demands for funds and not enable the Trust to meet fully the needs of such registrants as widows and and dependents.

Matters arising

- 2. There were a number of matters arising.
- Management project update: Following on from Kat Macfaralne's departure a new finance assistant had been employed who was keen to take forward this work. The trust were currently trying to get hold of Kat so that she might return to the Trust for a day or two to undertake some hands on training on the model she had left behind. Charles Lister (CL) asked if it was possible to formally receive notification about the end of the project and a copy of Kat's report to the Trust. It was also noted that the end of the project was to be the impetus for a meeting with the minister however Peter Steven's position paper would now do this and would be discussed further down the agenda.

Action: AH to write to DH with notice of the end of the project and enclose a copy of the final report.

- II. Publicity for Eileen Trust: DH had placed a note in the September edition of the CMOs Update which is disseminated to all doctors in England.
- III **Special payment to minor:** AH updated that research into the financial history of this case was still ongoing.

Action: AH to update at next meeting.

IV Income tax query: DH had not got any further with this query. Robert Finch (RF) would ensure progress was made before the next meeting.

Action: DH to inform the Trust of the advice when received.

V Payment to positive daughter: DH were still awaiting legal advice.

Action: DH to inform the Trust of the advice when received.

VI Payment to orphan son: It now appeared to all that there had been monies put into trust for this man, however confusion over his name had left clarification still being needed. Master Turner's office had supplied a spreadsheet of payments that seemed to confirm payment.

Action: RF to contact the Solicitors cited in the correspondence and confirm that this man had now received the monies and was now no longer a registrant of the Trust. RF to inform the Trust of the outcome.

VII Legal Services Commission: DH had not got any further with this query.

Robert Finch (RF) would ensure progress was made before the next meeting.

Action: DH to inform the Trust of the advice when received.

VIII Section 64 Grants: DH apologised for the delay in confirming approval of the three year grant. RF had been given the explanation from the Grants Administration Unit that due to various staffing problems the checks that needed to be made to grant awards of over £100k had still to be made. RF had arranged for a second interim payment to be made and would liaise with AH about payment.

Action: DH to ensure second interim payment is made and to inform the Trust when the checks for the full three year grant had been made.

3. Meeting with Hazel Blears - Proposition paper drafted by the Trust.

PS had drafted a paper (which had been disseminated in advance) which sought to give an overview of the Trusts and where they might head in the future. With the 15th anniversary of the Macfarlane Trust in 2003 PS's paper sought to consider where the Trust is now and where it might go in the future. The lifespan of the Trust had obviously changed in the intervening 15 years and this was thought to be a good time to step back and consider the future direction. The Trust were not convinced that they were fully supporting the registrants to the extent they would like, however it was acknowledged that there may be a gap between what the Trust view of this was and the DHs. And that there was both a legal and political interpretation of their commitment.

CL felt the paper was very helpful. CL felt that it would be helpful at this stage to get a legal view of the Trust deeds and what the DH commitment is to the Trust. It would also be helpful to consult those who were involved in the original drafting of the deeds.

It was agreed that the paper could be redrafted to make it more strategic, highlighting the key points that could be the basis for a meeting with Hazel Blears.

Action: DH to seek legal views on the commitment to the Trust in relation to the deeds. PS to redraft the paper in consultation with the other trustees to fully understand the Trusts view. AH/PS to write to Hazel Blears using the redrafted paper as a basis for a meeting (with the idea of a meeting taking place early in the new year).

4. Charity Commission correspondence and complaint regarding HCV

This issue had now resolved itself. It had stemmed from a complaint made by HCV sufferer about a payment made by the Trust to cover a taxi expense when going to receive treatment for HCV. The complaint was that the Trust could only make payments relating to HIV. The Trust argued that this was not the case and the matter was referred to the Charity Commission who has thrown the complaint out.

5. Trust recognition of homosexual partners

The Trust had received a request that would give homosexual partners of registrants the same rights as those of spouses or as mentioned in the deeds 'common law wife'. CL stated that he felt that this would be appropriate and that a common law wife could reasonably expected to be of either sex.

Action: DH to seek legal clarification and inform the Trust in time for the next trustees meeting on 29 October.

6. Any other business

PS raised the problem of registrants gaining insurance. A case had become involved in a case where a man had received insurance but hen when he needed treatment the insurance company is refusing to pay. The registrant is now possibly facing a bill of over \$100k.

Action: DN did we say we'd do anything?

7. Date of next meeting

The next meeting will take place on Tuesday 10 December at 10.30am in Room 678D in Skipton House.