<u>Notes of the meeting held on Tuesday 4th September 2007 at Wellington House, 133-155 Waterloo Road, London, SE1 8UG.</u>

Present:	Brian Bradley	Department of Health
	Roger Evans	MFT Trustee
	Martin Harvey	MFT Chief Executive
	Nicholas Fish	MFT Assistant to the Chief Executive

The meeting began with an introduction from Roger Evans and Martin Harvey reminding Brian Bradley of the plight of the Macfarlane Trust (the Trust) registrants. They informed him that when the Trust was first established it was fully expected that the registrants would die within a few years and that any money they received they were advised to go out and spend by their medical practitioners. There were a few exceptions who decided they were not going to give up so easily and invested the money in a property but the vast majority followed the advice they were given not to make provisions for the future.

There are now some 380 surviving registrants plus infected intimates who can expect to live a relatively full life albeit to a lower standard of living than the average individual takes for granted due to the combined effects of living with haemophilia, HIV, HCV and possible vCJD. It is now broadly accepted that HIV is a manageable chronic condition (it is in fact HCV that is proving to be the bigger killer of registrants) but when coupled with haemophilia and HCV "manageable" is a term which most registrants would strongly contest. The side effects of the ever changing treatment regimes prevent many from being able to work and as a result many live at or below the poverty line. It can therefore be expected that if the Trust were to continue to be funded in the current manner the Trustees would be coming back to the Department of Health (the Department) for funds for the next 40-50 years until the last remaining registrant had died. There must come a point, or a critical number of registrants, when it is no longer economically feasible for the Trust to run as a discretionary charitable body. To fund the Trust in the present manner until there are no more surviving registrants would therefore not seem to be a desirable situation for the Department.

A business case for increased funding entitled Funding Long Term Survival was submitted to the Department in November 2005 which seemed to be broadly disregarded (although at the very least it may have helped to prevent a cut in departmental funding). The Board of Trustees are in agreement that there seems little point in persisting with their attempts to convince the Department to take on board the issues raised in the business case as they are well aware that funds are tight within the Department and the Trust represents a tiny portion of the Department's overall work.

So we are left in a position where the Board of Trustees are unable to satisfactorily fulfil their objectives set out in the Trust Deed to "relieve the need of it's beneficiaries" and the Department are not in a position to increase the annual level of funding it grants to the Trust (let alone double it as requested in the business case). The purpose of the meeting was therefore to discuss ways in which this issue could be taken forward and to discuss alternative ways in which the Department could help the Trustees to fulfil their duties to their community of care.

The main idea that was put forward by Martin and Roger was for the Department to look to a time when it would no longer be economically feasible to continue funding a discretionary charitable trust through annual grants and to consider coming up with a lump sum with which to reach a full and final settlement with the remaining registrants; perhaps with a small Trust still in place to assist with any remaining widows and dependents still in need of financial assistance. A lump sum of £100 million was suggested as a crude figure and one which was not based on any formal analysis to illustrate very simply that rather than carry on paying the Trust £3-4 million to be distributed per annum over the next 40-50 years it may be better to come up with a larger lump sum in the short term and to settle the matter once and for all rather than let it drag on for decades. Such a solution would understandably create side issues which would need to be fully considered; some of those mentioned were the need for a tiered payment structure (similar to that used to calculate the amount a registrant received from the MSPT2) and the fact that certain people would be unhappy with such a settlement because they may feel they have been excluded or disadvantaged in some way (for instance a widow whose registrant husband died shortly before the payments were due to be made).

Brian concluded that he would need some time to think about the issues that had been raised and to discuss the contents of the meeting with his colleagues. He agreed that some of the issues raised made sense and that the longer term handling of the Trust needed discussion within the Department. He believes that in due course it may be useful if a case were put together between the Trust and the Department and for this to be handed over to the Department's Operational Research Branch who would be able to consider the content and determine the best way to take the issue forward. Nicholas Fish will attempt to come up with an up to date list of registrant ages and to predict, based on current and past registrant mortality rates, the number of registrants that the Trust will have in the years to come. This may help the Department to evaluate at what point the Trust would no longer be economically viable if it continued to be run the way it is at present and to potentially come up with a figure necessary to financially settle the issue with the remaining registrants.