The Macfarlane Trust.

Meeting with the Department of Health 7th September 1989.

A copy of the notes on this meeting was sent to the Department of Health, who have commented as follows:

First, on page 3, item 1/2. The references to the interpretation of the Trust Deed might be taken by an outside reader to mean that the Trustees should go beyond a reasonable interpretation of the Deed. I do not think that either of us had that in mind since it could leave the Trustees in a difficult position and I assume that what is said in the note is in the context of being within the reasonable interpretation of the Deed. The point we were making was that we would not commend an amendment of the Deed to make explicit all those eligible for help since this could become a very laborious exercise and difficult to carry through successfully. Instead we would commend the Trustees to interpret the broad descriptions in the Deed in a way which favoured inclusion rather than exclusion.

Second, on page 4, item 8. The point was we think only mentioned briefly. If the aim is to give the Trustees assurance that the Department know of your general approach the agreed note of our meeting may be sufficient. On the other hand, if you wished to consult informally on particular points, and to make a note of our response because it was helpful to you, that is fine by us.

Third, on page 4, Life Assurance. Neither Roger Moore nor myself have been able to recall the point. John Canavan has I understand recently written to John Williams to tell him so.

Fourth, on page 4, Audit. I think the position is that while I do not expect the Government to exercise its right to carry out an audit annually or even regularly, we would retain that right and might do so at some time.

THE MACFARLANE TRUST

Notes of a meeting at the Department of Health, Richmond House, London on Thursday 7th September, 1989.

Present:

Mr. S. Heppel (Deputy Secretary)

Mr. J. Canavan (Principal - Health Service Division)

The Reverend A.J. Tanner (Chairman of the Trust)

Mr. C.H. Grinsted (Deputy Chairman)

Wing Commander J. Williams (Administrator)

INTRODUCTION:

Mr. Heppel invited the Chairman to open the meeting, and the Revd. Tanner explained that the meeting had been requested so that we could place before the Department the policies, schemes, and practices that had been adopted by the Trustees from the time the Trust was established in March 1988 and, if justified, to receive from the Department an assurance that such policies and practices were rightly fulfilling the objectives envisaged by the Government in setting up the Trust. The meeting could also be a useful forum for discussion of certain principles and interpretations that required to be addressed by the Trustees, with the benefit of any guidelines that the Department felt able to give. It had also been noted that the regular written reports to the Department had received no response, and the Trustees wondered if the reports were acceptable?

In response, Mr. Heppel assured those present that Ministers and the Department appreciated and valued the work that was being done, and it was not Government's wish to interfere in any way in the administration of the Trust. The periodic reports were welcome and appreciated. This would be confirmed in writing.

ADMINISTRATION:

Wing Commander Williams then gave a resume of the methods of making grants, and tabled the latest summary of expenditure as at August 1989. He drew the meeting's attention to the annual growth rate of expenditure, and highlighted the principle areas of grants expenditure including the relief of stress, mobility, protection of health, housing, self-employment, education, and living conditions of dependants. W/Cdr. Williams also explained the method by which potential beneficiaries were assessed for regular weekly support, and he drew attention to the fact that most of those registered with the Trust qualified for the maximum grant, which was an indication that many of the Trust's community suffered a low standard The Department were advised of the recent decision of the of living. Trustees, effective September, to raise the maximum weekly amount. need to which the Trustees had given much time and thought as a policy, was the need for housing, and W/Cdr. Williams referred to the deliberations of the Trustees that had led to the establishment of a mortgage assistance policy.

Following a brief summary of the policy, the following were tabled and copies left with the Department:

- a) Mortgage Policy document (Ref:MORT/POL/8907)
- b) Mortgage Offer document (Ref:MORT/PUR/8906)
- c) Mortgage Offer document (Ref:MORT/SUBS/8907)

FINANCE:

Mr. Grinsted first tabled a summary of the Investment Portfolio as at August 1989. He then explained that the Trustees had appointed Investment Managers, and with their advice, and after reserving monies required for immediate cash needs, the balance had been invested in Government stocks. The policy was i) to obtain as good a rate of interest as possible and ii) to maintain and, if possible, enhance the capital sum. The Trust, like all other institutions, was seeing a reduction in the immediate realisable value of the stocks, but at the same time a high running yield was being obtained. The Trustees did not see any immediate cause for a major change in the investment policy, but were concerned about the prospect of additional funding (see below).

On completion of these presentations, Mr. Heppel expressed satisfaction and further expressed the belief that Ministers also would have no major observations to raise.

ADDITIONAL FUNDING:

The Revd. Tanner brought to the Department's attention the most crucial item that would be raised at this meeting; namely the prospect for additional funding of the Trust. The Trustees were well aware that direct charitable expenditure was exceeding the income received by the Trust from money invested, and that capital was being withdrawn to meet the deficiency. Nevertheless, the Trustees approved such action in the belief that the requests for assistance were wholly justified. In addition, the Trustees faced requests, particularly in the support for dependant children, that contemplated long term commitments. It followed that the Trustees wished to raise the question whether, if the Trust fund was exhausted, any additional funding would be made available by the Government to meet the longer term needs of people with haemophilia and HIV infection, and their dependants. Without such additional funding future expenditure could be considerably inhibited.

Following discussion, Mr. Heppel responded that Ministers would not want the Trustees to make more limited offers of help than they would otherwise consider reasonable, simply to conserve funds, and that each case would continue to be judged on its merits. However, the request for additional funds was a matter of timing, and he advised the Trust that the right time to approach Ministers about additional funding would be when the Trust funds were sufficient to meet commitment for only 2/3 years. An approach at the present time would be too early. This advice was gratefully received, and would be confirmed in a formal exchange of letters.

By way of supplementary observation, Mr. Heppel intimated that even if the present demand by litigants for compensation was successful, it would not, in the opinion of the Government, diminish the work of, and the need for, the Macfarlane Trust, albeit that compensation would be a factor taken into account when assessing need.

SECTION 64 GRANT:

W/Cdr. Williams explained that whilst the Trustees would continue to ensure that ongoing costs were kept to the minimum compatible with effective administration and budgetary control, experience so far showed that administrative costs had exceeded the S.64 grant, and any overrun was a drain on the Trust fund. He asked if the full funding of costs could be met by the S.64 grant, or by other means. The parallel of the Independant Living Fund was quoted. It was suggested that as the rules of the S.64 grant had been relaxed both in principle and in the percentage costs paid to the Trust, there might be a case for going the whole way in funding running costs. In particular, W/Cdr. Williams asked whether the 3 year rule would also be overridden? Mr. Heppel agreed that some further thought would be given to this item.

INTERPRETATIONS/DISCRETIONARY ACTION:

The meeting gave attention to areas of interpretation of the Trust Deed and, in particular the effect that such interpretation was having upon those who were held not to qualify for help. In discussion of this item the following, inter alia, emerged and are worthy of record in this note:

- 1. The Department did not commend an amendment of the Trust Deed, in an attempt to recognise formally all persons who were deemed to qualify for assistance.
- 2. Instead, the Department wished the Trustees to exercise discretion, and in doing so there should be a benevolent view favouring inclusion, rather than exclusion.
- 3. The term 'Spouse' should be generously interpreted to include a long term partner who had co-habited for a continuous period of not less than 2 years.
- 4. Upon the death of a registered beneficiary, a dependant of that person would cease to be a dependant qualifying for help, when the surviving dependant was seen to be financially independent.
- 5. However, if the dependant is himself/herself HIV positive by reason of association with the deceased, help can continue to be given so long as there is a need established in compliance with the Trust Deed.
- 6. In the case of Widows, it is the Department's view that after a reasonable period in acknowledgment of bereavement, further assistance should only be given when it is clearly demonstrated that the ongoing need is traceable back to the HIV condition of the deceased husband.

- 7. Generally, the Department did not wish to see the creation of precedents, and hoped that the Trustees would act in a responsible and sympathetic manner to all requests, on a one-to-one basis.
- 8. The Department agreed that a memorandum of understanding to record the type of discretionary decision exercised by the Trustees, would be helpful, so that the Department would be informed in advance of areas where queries were likely to arise.
- 9. It was agreed that assistance to groups (block grants), should only be made where benefit to specific individuals could be shown. The Trust must not be seen to give support to other bodies, particularly those which are themselves registered charities.

LIFE ASSURANCE:

The subject of assistance with life assurance was discussed. It was apparent that there was no Government action in hand which would be likely to bring any early relief. There was a difference in recall between Mr. Heppel and the Revd. Tanner as to what assurances had been given by the Minister on this subject at the time the grant was made, and Mr. Heppel agreed to make further inquiry. From enquiries that the Trustees had made, it was very clear that Insurance companies were not interested, and no help would be forthcoming from the industry.

AUDIT:

The Revd. Tanner intimated that at the end of its first financial year, a statutory audit of the Trust's financial affairs had been carried out and found to be satisfactory. A copy of the audited accounts had already been sent to the Department. Shortly, the first full Annual Report of the Trust would be published, and a copy would be lodged with the Department. In answer to a query, Mr. Heppel confirmed that whilst the Government retained the right to carry out an audit, it was not a right that was automatically exercised, and it was unlikely that it would be applied to the Trust. Nonetheless, the Revd. Tanner intimated that a representative of the Department would be welcome at any meeting of the Trustees, and there was an open invitation.

CONCLUSION:

The Revd. Tanner thanked Mr. Heppel for the opportunity to have the meeting in such a helpful way, and he felt sure the Trustees would feel encouraged.

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