

THE MACFARLANE TRUST

MINUTES of a meeting of the Trustees held at The Bishopsgate Institute, 230 Bishopsgate, London EC4, on Tuesday 12 April 1988

Present: The Revd A J Tanner, Dr P Jones, Mrs N Guy, Mrs V Demmery, Mr C Grinsted, Mrs C Leitch, Mr C Knight, Mr S Taylor, Mr P Stevens.
In attendance: Dr R Moore, DHSS; Mr D Watters, The Haemophilia Society.

AGENDA

- 88.10 Apologies for absence
- 88.11 Minutes of the meeting held on 29 March 1988
- 88.12 Matters arising
- 88.13 Administration
- 88.14 Life Insurance/Mortgage Protection
- 88.15 Investment Policy
- 88.16 Allocation Policy
- 88.17 Any other business
- 88.18 Date and place of next meeting

88.10 APOLOGIES FOR ABSENCE were received from Mr Palmer.

88.11 MINUTES OF THE MEETING HELD ON 29 MARCH 1988 had been circulated in advance and were unanimously approved as an accurate record of proceedings at that meeting having been proposed by Mrs Leitch, seconded by Mrs Guy.

88.12 MATTERS ARISING

(a) Reports circulated:

- (i) Rapid Response Questionnaire: Mr Watters made it clear that the results shown in this report should be taken as showing a broad, but not accurate, picture of the position of people with haemophilia who are HIV ab+; the section on socio-economic groupings was perhaps the most helpful section.
- (ii) Medical Background Paper: This document had been greatly valued by the Trustees and in reply to further questions Dr Jones stated that, in his opinion, there would be further seroconversions over the next two years - possibly up to ten. He further estimated that some 2% of those who are currently ab- could proceed to develop AIDS.

(b) Social Fund: Mr Palmer had sent a written report which indicated that the Social Fund Manual would be amended so that Social Fund Officers should not refer applicants to the Trust, nor should they refer to the Trust themselves. This news was welcomed.

(c) Grants made by the Society on behalf of the Trust: Mr Watters tabled a detailed document giving details of grants made by the Haemophilia Society in response to applications for financial assistance arising from HIV infection in people with haemophilia. The total amount so expended was £25,671. After discussion it was resolved nem con that this sum be refunded to the Society and, further, that the Trust appoint the Case Committee to act on their behalf regarding the allocation of grants pending the finalisation of an Allocations Policy and the establishment of an Allocations Committee. All the above was subject to the legal ability to so act and those matters were proposed by Dr Jones and seconded by Mr Grinsted. Mr Watters will check whether there are legal obstacles to that course before implementing this decision.

- 88.13 ADMINISTRATION:** The Chairman stressed the importance of pressing ahead with the establishment of a sound administration and the appointment of staff to carry out the work of the Trust.
- (a) Section 64 Grant Application: The provisional application made by the General Secretary of the Haemophilia Society had been circulated in advance and this was approved by the Trustees.
- (b) Staffing - Draft Job Descriptions: Draft job descriptions had been prepared and circulated by Mr Watters. Those were discussed and it was agreed that certain amendments should be made to each paper and the venues for advertising were also discussed. It was agreed that the following serve on a sub-committee to look at the appointment of an Administrator: The Revd Alan Tanner, Mr Grinsted, Mr Stevens and Mr Taylor. It was further agreed that a similar sub-committee be established in relation to the appointment of a Social Worker and that Mrs Leitch, Mr Palmer and the Chairman serve on that committee. Re-drafted job descriptions will be circulated when amended in accordance with the wishes to the Trustees.
- (c) Office Premises: A number of options were being explored by Mr Knight, the Chairman, Mr Stevens and Mr Watters. Mr Watters suggested that if all else fails the Trustees should consider serviced offices. In this connection he also mentioned that a Post Office Box had been applied for in London SE1. The Chairman expressed his wish to be kept informed of all developments on this front so that a speedy decision could be made at an early date.
- 88.14 LIFE INSURANCE/MORTGAGE PROTECTION:** Mr Stevens reported that he had begun formal explorations of this question and mentioned the various difficulties for the insurance industry and he further highlighted many of the difficulties which would confront the Trustees when it came to defining policy on such matters. It was agreed that Mr Grinsted, Mr Stevens, Dr Jones and Mr Knight form a sub-committee to look into this whole matter in greater detail.
- 88.15 INVESTMENT POLICY:** Mr Grinsted outlined his initial thoughts and emphasised the importance of the Allocations Policy in relation to investment planning and ability in the future. In conjunction with Mr Stevens he would look further into investment possibilities and report further at the next meeting of the Trustees.
- 88.16 ALLOCATION POLICY:** A wide ranging discussion took place on this subject and it was established that Trustees wished to see further submissions to that circulated by the General Secretary of the Haemophilia Society; those wishing to put in papers were asked to let Mr Watters have them as soon as possible so that they could be circulated as widely and as soon as possible. It was also established that Dr Jones would draft and circulate a proposal for a registration card which would also be finalised at the next meeting, after being circulated in advance. It was also agreed that this card should be distributed through the Society's mailing list as well as through Centres, in the usual manner, along with a statement about the Trust.
- 88.17 ANY OTHER BUSINESS:** There were no items of other business.
- 88.18 DATE AND PLACE OF NEXT MEETING:** It was noted that the next meeting would be held at 2 pm on Monday 9 May at The Bishopsgate Institute. It was further agreed that the June meeting be held on Tuesday 7 June 1988 at 2.30 pm at The Bishopsgate Institute.

Approved as an accurate record of the proceedings

GRO-C

The Revd Alan Tanner (Chairman)

7 June 1988