

## THE MACFARLANE TRUST

Minutes of a meeting of the Trustees held at The Bishopsgate Institute, 230 Bishopsgate, London EC4, on Tuesday 7 June 1988

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**Present:** The Revd Alan Tanner, Mrs Demmery, Mr Grinsted, Mrs Guy, Dr Jones, Mr Knight, Mrs Leitch, Mr Palmer and Mr Stevens.  
In attendance: Mr Watters.

### AGENDA

- 88.27 Apologies for absence
- 88.28 Minutes of the meeting held on 9 May 1988
- 88.29 Matters arising
- 88.30 Administration
- 88.31 Policy Matters
- 88.32 Any other business
- 88.33 Date and place of next meeting

**88.27 APOLOGIES FOR ABSENCE** were received from Mr Taylor.

**88.28 MINUTES OF THE MEETING** held on 9 May 1988, had been circulated in advance, amendments were made as follows: Minute 88.23(b), final paragraph to read "It was further agreed that an Allocations Committee be appointed consisting of Mrs Leitch, Mr Palmer, Mrs Demmery, the Chairman, Mrs Guy and Mr Knight, along with the General Secretary of the Haemophilia Society as an adviser, and that this Committee be authorised to begin forthwith its function of receiving applications and authorising grants. In addition the Allocations Committee be empowered to give further consideration to the question of allocations and present a concise recommendation to the next meeting of the Trustees. 88.23(c) (line 13) where the following sentence was inserted to replace that referring to the track record of Manex. "Mr Grinstead pointed out that Manex had a good track record and, because they were not seeking discretionary powers, they welcomed the wish of the Investment Committee to be closely involved in the implementation of policy." After those amendments the adoption of the minutes was proposed by Mr Palmer, seconded by Mr Stevens and agreed unanimously.

### **88.29 MATTERS ARISING**

- (a) Grants made by the Society on behalf of the Trustees: The General Secretary of the Haemophilia Society reported that at their May meeting grants totalling £11,610.62 were approved by the members of the Case Committee on behalf of the Trustees.
- (b) Mailing to potential claimants: It was reported that the registration document had been mailed to everyone on the Society's mailing list, all Haemophilia Centres and local Groups of the Society. Approximately one hundred and twenty registrations have been received to date. There was discussion on the further information required and the progress being made with drafting the appropriate form.
- (c) PO Box Number: It was noted that the PO Box number of the Trust was 467, London SE1 7HU. The General Secretary reported that the mail was delivered to 123 Westminster Bridge Road each morning. If the Trust was to be relocated within a different postal district it would be necessary to take a new PO box number.

**88.30 ADMINISTRATION**

- (a) Staff: The Chairman reported that approaches were being made through the Officers Association and Charity Appointments for the selection of an Administrator. Mr Grinsted reported on the possibility of help being available through the good offices of the National Westminster Bank plc.

In connection with the appointment of a Social Worker it was reported that the advertisement would be placed in THE GUARDIAN and COMMUNITY CARE on Wednesday 15 June. It was hoped that selection interviews could be held on 20 July 1988.

- (b) Premises: It was reported that no progress had been made in this matter. Dr Peter Jones suggested that it may be possible to obtain accommodation at a central London Teaching Hospital and felt approaches to the Unit General Managers could be worthwhile.

**88.31 POLICY MATTERS**

- (a) Insurance/Mortgage Protection: Mr Stevens was unable to take this matter any further since he needed to know numbers involved and size of mortgages, etc. The Chairman suggested it could be worthwhile approaching Professor Wilkie who had acted on behalf of the insurance industry in the recent past. It was agreed that approaches be made to Professor Wilkie.

- (b) Allocations: The Chairman reported that the Allocations Committee had met earlier in the day and at his invitation Mrs Leitch made a presentation of the proposals from that Committee. In considering this matter the Allocations Committee had looked at special categories of need faced by people with haemophilia who are HIV antibody positive and, in addition, had given due consideration to the applications received and handled so far by the Case Committee of the Haemophilia Society on behalf of the Trustees. In considering "stress" and the relief thereof the committee had paid particular attention to problems which could be removed by an injection of cash and the use of money to achieve positive attitudes to living with HIV and HIV infections. After looking at different types of payment the committee wished to recommend an "extra needs payment" to those whose income fell below certain defined levels, including those in low paid employment. This would be paid to people with haemophilia who were HIV antibody positive. In addition single payments would be available to all persons with haemophilia who, as a result of treatment, were HIV ab+ and for the purpose of such payments the financial standing of the household unit would not be of such great importance. It was proposed that the extra needs payment, to help with ongoing costs such as diet, heat, etc - should be of the nature of £20 per week and, additionally, should be backdated to 16 November 1987, the date when the Trust was announced in the House of Commons.

When it came to considering management of the monies it was proposed that the Administrator and Social Worker should be empowered to make decisions in accordance with criteria established by the Trustees - certainly empowering them to make grants of up to £300, or in certain cases payments for specified purposes. It was also proposed that there be an appeal structure so that those who were dissatisfied with such decisions, either by the staff or the Allocations Committee, could appeal directly to the Trustees. In response to a question it was proposed that dependants and spouses be entitled to single payments, subject to further definition. Agreement to the foregoing in principle was proposed by Mr Grinsted, seconded by Dr Jones, and agreed unanimously.

The Allocations Committee will assume responsibility for grant applications with effect from 20 July 1988, on which day they will meet at 3 am to consider applications for financial assistance (the meeting to be held at 123 Westminster Bridge Road).



There was further discussion concerning giving publicity to the criteria in an attractive way which would encourage people to apply for payments.

Further consideration was also given to the question of HIV antibody positive spouses and it was clarified that the General Secretary of the Society should pursue this question with the Trust's Solicitors since it was not altogether clear from the Trust Deed whether such persons would be included. At the request of Dr Jones it was agreed that the enquiry would also extend to include HIV antibody positive, but non-dependent, girlfriends who were symptomatic.

- (c) Investments: Mr Grinsted reported that £8m had been released for investment through Manex. While, at the present time, a certain amount of this sum had been placed on the Market it was a case of waiting for the appropriate moment to make further investments. Mr Grinsted was adopting a cautious policy in this connection. The money not already placed on the Market was on overnight call. The balance of £2.1m was held at the local National Westminster Bank in Westminster Bridge Road.

Mr Grinsted stressed that it would be useful to the Investments Committee if the Allocations Committee could give an early indication of their anticipated cash flow.

- 88.32 ANY OTHER BUSINESS:** Mr Grinsted raised the question of future funding arrangements. This was discussed in some detail and finally it was agreed that it would be inappropriate to fund raise in order to support the work of the Macfarlane Trust and that further recourse, when necessary, should be made to the Government. It was also agreed in this connection that the Trustees would not approach the question of the unpaid interest (of some £250,000) which would have accrued between the granting of the Trust and the receipt of the cheque.

Dr Jones undertook to investigate the question of Health Authority funding for artificial insemination - for which two applications had been received by the Trustees.

- 88.33 DATE AND PLACE OF NEXT MEETING:** Wednesday 20 July 1988 at 5 pm at 123 Westminster Bridge Road.

Agreed as an accurate record of the proceedings:

GRO-C

The Revd Alan Tanner  
(Chairman)

20 July 1988