

T H E   M A C F A R L A N E   T R U S T

Minutes of a Meeting of the Trustees held at the Church Hall,  
St Botolph without Bishopsgate on Tuesday, 21st November 1995  
at 10.30 a.m.

-----

Present:   The Reverend Prebendary Alan Tanner, Mrs Brierly  
          Mr Cashman, Mrs Cowe, Mr Grinsted, Mrs Guy,  
          Ms Harrington, Dr Mayne and Mr Palmer

In attendance:   Wg Cdr Williams, Mr Williams, Mrs Jackson

**AGENDA**

**Administration**

95.47	Minutes of previous meeting
95.48	Trusteeships
95.49	Meeting with Department of Health
95.50	Administrator's Report

**Finance**

95.51	Expenditure Summary
95.52	Investment/Finance Report

**Assistance & Grants**

95.53	Procedures
95.54	Applications
95.55	Reviews
95.56	Guidelines

**Policy Items**

95.57	Feedback
95.58	Regular Payments
95.59	Support for Widows

**General**

95.60	Meetings/Visits
95.61	Dr Mayne's Report to Centre Directors
95.62	Newsletter 30
95.63	Any other Business

**Opening**

Opening the meeting the Chairman warmly welcomed Mrs Jenny Jackson on her first meeting, and hoped her stay with the Trust would be happy and fulfilling.

## **ADMINISTRATION**

### **95.47 MINUTES OF PREVIOUS MEETING**

a. The Chairman invited comment on the Minutes for 15th September. It was proposed by Dr Mayne, seconded by Mrs Brierly that the Minutes be accepted as a true record and this was agreed unanimously.

b. **Matters Arising.** The Administrator advised that following M95.34 an application for a Section 64 Grant for 1996-97 had been submitted and acknowledged; a decision was not normally received until February/March. Other matters arising would be covered by the current agenda.

### **95.48 TRUSTEESHIPS**

The Chairman said that Mrs Brierly's term of office ended at the end of the month, and that this was therefore her last appearance at a Trustees' meeting. He paid tribute to the commitment and effort given by Mrs Brierly in her two terms of office and on behalf of the Trustees and all those for whom the Trust worked he thanked Mrs Brierly for her hard work and wished her well for the future. The Trustees warmly endorsed these sentiments.

### **95.49 MEETING WITH THE DEPARTMENT OF HEALTH**

The Administrator reported that a meeting had taken place on 5th October, hosted by Dr Jeremy Metters, Deputy Chief Medical Officer, and members of his staff. A report had been sent to all Trustees on 12th October and the subject was included in the Agenda in order to put the meeting on formal record and to give Trustees the opportunity to comment.

The Chairman and Deputy Chairman endorsed the report and its assessment of the meeting as highly successful and productive and Mr Grinsted drew attention to the Department view that further support was more likely to be in terms of a lump sum than by annual payments. The Trustees expressed their satisfaction with the result.

The Chairman reminded the meeting that the strong reassurance given had not yet put money in the bank, and taking the previous occasion as a precedent it would be the very end of the Financial Year before anything further were known. Until then it would be prudent to bear in mind the current state of the Trust Fund.

#### 95.50 ADMINISTRATOR'S REPORT

The Administrator reported on the following:

a. **Statistics.** A summary to 31 Oct 95 had been circulated. It was noted that survivors were less than half the original number registered, and also that about half those deceased had left dependants who were thus representing an increasing part of the Trust's commitment.

b. **Staff.** Mrs Jackson had started work with the Trust on 8th November and had already firmly established herself as an effective member of the staff. Thanks were recorded to Mrs Kathy Stubbs, Social Worker at Alton and to Ms GRO-A of the Terrence Higgins Trust for their help in the test and interview stage of selection.

c. **Offices.** Some reorganisation of the office had been necessary to create satisfactory working space for the new staff structure. The Administrator had moved his desk out to the side room, but this room could still provide the facility for small meetings.

d. **Office Closing - Christmas and New Year.** Trustees approved the request for the office to be shut from p.m. Friday 22 December to the morning of Tuesday, 2 January 1996. Monitoring of the answerphone would take place daily as in previous years.

#### FINANCE

##### 95.51 EXPENDITURE

A summary to 31 Oct 95 had been circulated. The Administrator said that the increase in single payments for October was largely explainable by a seasonal rise in "Motability" deposits but even so there was a possible trend towards an increase in the level of single payments compared with the previous year. Even if this was so the growth was not yet alarming but would need to be monitored since it was possible that as time passed following the individual capital payments the pressure for additional help could increase. The Trustees noted and agreed this assessment.

## 95.52 INVESTMENTS

The Administrator said that his Financial Report for 31 Oct 95 showed a continued favourable situation which it was hoped would be maintained or even improved in the current month since in the intervening period the FTSE index had reached an all-time high. The budget could affect the market either way.

Mr Grinsted drew attention to the figures which showed that although having spent well over £1 million in the financial year the Trust assets had fallen by only £265,123 and that the earnings and capital appreciation achieved to produce this result reflected well on the management of both the Trust portfolios which the summary showed were performing comparably.

No major points were raised in general discussion and the Trustees accepted the report and assessment.

## ASSISTANCE AND GRANTS

### 95.53 PROCEDURES

A paper had been circulated which summarised existing procedures and offered some suggestions for modification. Following general discussion the Trustees agreed the content of the paper subject to some comment. The paper would now be edited into a form suitable for inclusion in the Aide-Memoire, which would give the Trustees the opportunity for final comment or agreement.

### 95.54 APPLICATIONS

Six applications were presented. The Trustees approved six grants totalling £3,224 and made rulings on two regular payments.

### 95.55 REVIEWS

The Trustees reviewed two applications which had been referred back for further examination. On one they agreed, subject to stated conditions an increase from £7,000 to £9,750 for a grant towards a home adaptation. On the other concerning housing and mortgage they took note that further progress was not possible until a decision was obtained from a building society.

## 95.56 GUIDELINES

Trustees again considered the subject of assistance with conception, the discussion being based on a draft note which had been circulated. They agreed that this was a reopening of the debate rather than continuation of an open subject, and that there was no real change of overall circumstances and hence most of the reservations previously expressed still applied. Nevertheless they accepted that the subject continued to be raised, both in principle and in specific applications for help.

For this reason a majority were amenable to further consideration provided that a firm policy could be quickly identified which could delineate what the Trust would or would not do without involving itself in any 'judgmental' differentiation between one case and another and which could therefore be defended in public should this be necessary.

The Trustees considered the various principles, particularly the distinction between treatments for fertility and aid to conception. There was a developing consensus though not all the details were covered. Dr Mayne agreed to continue her enquiry with Centre Directors.

It was agreed that, based on further enquiry and consideration, a positive and final decision on this subject could be possible at the next meeting.

Redrafts of the guidelines on Motability, Education and School Uniforms, which had been prepared following discussion at the September meeting, were approved for inclusion in the Aide-Memoire.

## POLICY ITEMS

### 95.57 FEEDBACK

a. Letters. Four letters were considered and replies agreed as follows:

1. A complaint that the new continuity payment for widows was not backdated to all. - To explain that for financial and other reasons policy changes could not be made retrospective.
2. A general complaint from a widow feeling financial constraint. - To offer help in maximising income, limiting outgoings and to identify any specific need which the Trust might be able to help with.
3. A complaint about Trust's DI/IVF policy (see M95.56).

4. A query from the widowed mother of a deceased adult. - The Administrator's letter (which had explained ineligibility of non-dependant relatives for financial assistance, but which had answered specific factual queries and offered advice and practical help) was approved.

b. Reports of failures of Hospital Services. Two widows had reported to the Trust with indications of poor or at best insensitive care of their husbands in the terminal stage of illness. Dr Mayne had taken up both cases at the request of the Administrator. Dr Mayne reported that she had obtained better acknowledgement of the inadequacies of the system and reassurances of action to make improvement than the widows had themselves been able to obtain.

As expected no actual fault had been admitted, and in fact neither widow wished to go to Court or even to demand disciplinary action against specific individuals.

Dr Mayne expected that the subject could shortly be closed and would be writing again to the ladies concerned.

The Trustees expressed their regret that events of this nature could still occur, and satisfaction that the Trust through Dr Mayne could exert some influence to alleviate the relatives' distress and to improve matters for the future. The Chairman thanked Dr Mayne for her considerable efforts and these thanks were endorsed by all the Trustees present.

#### 95.58 REGULAR PAYMENTS

A yellow discussion paper had been circulated which suggested that the time was appropriate for a further review of the regular payments system, and made some suggestions on priorities for examination.

The Trustees welcomed the factual information summarised in the paper and agreed the proposal for a further review. There was considerable discussion covering individual rates of payment, differentials between individuals and the overall costs.

The Trustees were in principle amenable to consideration of higher (per capita) rates of expenditure, but would not make any final decision until it was known what further funds HM Government would make available.

Based on the discussion the staff were asked to prepare a green paper defining more closely the options for decision. It was accepted that final decision on actual rates of payment might involve a further stage of discussion.

#### **95.59 SUPPORT FOR WIDOWS**

Trustees discussed this subject based on the paper which had been circulated. They agreed that there was a need for progress in developing the support given to widows, and that this must be visible not only as discussion by the Trust but as results to be seen by potential beneficiaries.

There was general agreement on the areas for development but no specific programme, list of priorities or dates for action or publication were agreed.

The staff were tasked with producing a list of firm proposals for consideration at the next meeting.

#### **GENERAL**

#### **95.60 MEETINGS AND VISITS**

A list of recent meeting and future programme had been circulated for information. The Trustees took note.

#### **95.61 DR MAYNE'S REPORT TO CENTRE DIRECTORS**

The 1995 AGM of the UK Haemophilia Centre Directors was the last during Dr Mayne's tenure as a Trustee, and accordingly she had made a formal report to her colleagues. A copy of this report had been circulated to Trustees. Dr Mayne pointed out that due to a higher priority engagement she had been unable to attend this meeting, and her report had therefore been delivered by a colleague. Thus although she was aware that the meeting had been receptive to the information and suggestions made, she did not yet have any feedback or comment from individual colleagues. She would be pursuing this matter by speaking to as many Directors as possible and would particularly seek views on the subject of DI/IVF (see M95.56).

The Chairman thanked Dr Mayne for this report and for her active representation of the Trust to the Centre Directors during the whole of her time as Trustees. The meeting concurred.



**95.62 NEWSLETTER 30**

No draft had been prepared but a list of items had been circulated and this was explained by the Administrator. The list was approved, and Trustees agreed to notify the office of any additional items.

A draft would be circulated for comment, aiming at publication early in December.

**95.63 ANY OTHER BUSINESS**

There was no further business.

The Chairman thanked all present for their contributions, and put again on record the Trust's thanks to Mrs Brierly for her work as a Trustee. He offered Christmas greetings to all Trustees and staff, and following a mutual exchange of good wishes the meeting was closed.

GRO-C

8 February 1996

The Reverend Prebendary Alan Tanner  
Chairman