

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 Alliance House
on Thursday, 8th February 1996 at 10.30 a.m.

Present: The Reverend Prebendary Alan Tanner, Mr Cashman,
Mrs Cowe, Mr Grinsted, Mr GRO-A Ms Harrington,
Mr Hodgson, Dr Mayne and Mr Palmer

In attendance: Wg Cdr Williams, Mr Williams, Mrs GRO-A
and Mrs Le Sage

AGENDA

Administration

- 96.01 Minutes of previous meetings - 21 Nov 95
- 96.02 Administrator's Report

Finance

- 96.03 Expenditure Summary to 31 Jan 96
- 96.04 Investments Summary and Administrator's
Report to 31 Jan 96
- 96.05 Forecast for FY 95-96 Annual Accounts

Assistance and Grants

- 96.06 Guidelines
- 96.07 Applications
- 96.08 Reviews

Policy Items

- 96.09 Feedback
- 96.10 Publications 1996
- 96.11 Regular Payments
- 96.12 Support for Widows
- 96.13 Meetings/Visits/Liaison
- 96.14 Newsletter 31
- 96.15 Trusteeships

As the Chairman had been delayed, Mr Grinsted opened the
meeting, formally introducing the new Trustee, Mr GRO-A
and welcoming him most warmly.

Apologies had been received from Mrs Guy.

Following a motor cycle accident, Mr Williams joined the
meeting during the late morning. The Trustees were relieved
to hear that he had only sustained an injury to his hand.

ADMINISTRATION

96.01 MINUTES OF PREVIOUS MEETING - 21 November 1995

a. Mr Grinsted invited comment on the Minutes for 21 November.

Regarding M95.47(b), Mr Cashman enquired whether a decision had been received following an application for a Section 64 grant. The Administrator reported that the matter would be referred to in the normal course of business.

The Meeting subsequently unanimously agreed that the Minutes were a true record.

b. Matters arising.

i. The Administrator reported that he had that morning received a letter from the Department of Health confirming the Section 64 grant which unusually had been approved for a three-year period but which included an increase over the next 2 years. He expressed the hope that a further application could be made in three years' time even though a Section 64 grant was usually granted once only for a three-year period.

ii. M95.49. The Administrator reported that following the meeting with the Department of Health last October, he hoped to hear from them shortly regarding the additional lump sum. Following a recent telephone call, the Department had expressed surprise that the Trust held over £5,000,000 capital, this being due to investment success.

In response to a request from Mr Grinsted, the Administrator agreed to circulate a letter to the Trustees once he had received a positive reply from the Department.

96.02 ADMINISTRATOR'S REPORT

The Administrator reported on the following:

a. **Haemophilia Society request.** The Haemophilia Society had requested to receive a copy of the Minutes. ~~The Secretary asked the Meeting for their decision and after discussion~~ the Trustees unanimously agreed that the Minutes should not be released to anyone other than Trustees and Staff.

The Chairman arrived, and took the Chair.

- b. **Department of Health Inspection.** The Department had decided that in line with current practice, a Management audit should be completed in the current financial year. This would be done by agents under contract but the date had yet to be confirmed.
- c. **Liaison with Department of Health regarding appointment/reappointment of Trustees.** The Secretary was working with the Department to rationalise the procedure for appointment of Trustees to the Trust.
- d. **Freepost.** The Trustees approved a proposal by the Secretary to introduce a Freepost second class system for members.
- d. **Staff.** Miss Funmi Hassan was expecting a baby later in the year and would therefore be taking maternity leave. As she had expressed a wish for the post to be kept open for her, he was working on that basis. He would keep the Trustees informed.
- e. **Statistics.** A summary to 31 December 1995 had been circulated and a summary to 31 January 1996 was tabled. The Administrator apologised that the word "infected" had crept back in to the statistics to 31 December and confirmed that this had now been rectified for the future.

The Trustees took note. They also noted that the number of young children registered with the Trust was decreasing and that this was due more to survival to adult age than to the number of deaths.

Discussion ensued regarding the presentation of the number of grants paid to individuals, since the high numbers were mainly related to earlier years. The Administrator agreed to see if it was possible to separate the figures so that recent grants only were shown.

FINANCE

96.03 GRANTS EXPENDITURE

The summary of grants made at 31 December 1995 and a summary of grants to 31 January 1996 both of which had been tabled, were noted by the Trustees.

96.04 INVESTMENT REPORT

The Investment Summary to 1 January and a Financial Report to 31 December 1995 had been circulated and an Investment Summary to 1 February and a Financial Report to 31 January 1996 were tabled.

The Administrator drew attention to the Investment Summary to 1 January which showed the success of the investment policy. Although the major gains were the result of a considerable rise in overall market values during the year, it was a source of some satisfaction that Trust investment policies had taken good advantage of this favourable situation to produce the end result.

Mr Grinsted pointed out that the FY 1996-97 could see a reduction in the record advance of 1995-96.

The Administrator, referring to his Report to 31 January, pointed out that there had been no change in the trend since the previous report and that the income could be forecast with a reasonable degree of accuracy. He considered that it was highly probable that at the end of the Financial Year, the Trust would hold assets of over £5,000,000.

A discussion ensued about whether there was a case to sell any investments immediately while values were high. It was pointed out that with the expectation of new funds from HM Government there was no requirement for further liquidity and the Trust need not be concerned about a short-term loss of capital value which would be likely to be regained in the longer term. It was therefore agreed to continue the current investment policy and to withdraw only the dividends.

96.05 ANNUAL ACCOUNTS 1995-1996

The forecast Annual Accounts for 1995-96 were tabled. The Administrator went through the estimated Accounts and drew attention to the layout of the Accounts. He confirmed that he could forecast both the bank interest and COIF interest with confidence, whereas as Principle worked to a different quarter, their figures were already final for the year. He had assumed that there would be no more donations and that with only two more months to go, the predicted arising and use of resources were unlikely to change significantly.

The Administrator said that the final Accounts to be presented for the Trustees' approval at the end of March would be in the same sort of shape, and that there would be no major surprises.

Referring to the forecast, Mr Grinsted emphasised to Trustees that £2,000,000 will have been spent at a cost to capital of only £838,403, and that this represented the best result of any year for the Trust.

Summing up the views of the meeting, the Chairman expressed appreciation of the good management of the Trust investments.

ASSISTANCE AND GRANTS

96.06 GUIDELINES

a. Assistance with Conception. The Chairman opened the discussion by stating that this guideline had already been considered at the last meeting following which the Administrator had prepared a paper.

He asked Dr Mayne if she had anything to contribute as a result of the Centre Directors' Meeting. She said that the more she talked to different people, the more she realised that our members did need help. She explained to the Meeting that contrary to expectation, AID had a very low success rate and that sperm-washing could possibly be considered as an alternative.

Referring to the Administrator's paper, the following were discussed:

i. The Principle. The Chairman asked the Meeting to vote for the Principle "that the Trustees wish to offer help with risk-free conception, provided that a fair and equitable policy can be defined", following which 6 voted in favour and 2 voted against.

ii. Broad Policy Statement. It was agreed that the policy statement should read as follows:

"Where couples wish to have a child without risk of infection to the mother and thus possibly to the child also, the Trust will now contribute towards the costs involved, provided that the treatment is approved by the Human Fertilisation and Embryo Authority (HFEA) and available from the NHS. The Trust will not contribute towards the costs of problems of fertility."

6 voted in favour and 2 abstained.

iii. **Level of Support and Detailed Conditions.** The following conditions were agreed:

1. The form of treatment must be available through the NHS, and applicants must satisfy the NHS criteria.
2. Applicants should apply through NHS and satisfy counselling requirements. If NHS treatment is approved in principle but subject to delay in practice, the Trust will then contribute to costs of obtaining the treatment privately.
3. The Trust will contribute 75% of the cost towards one course of treatment only, up to a maximum of £1,000.

In addition the Trustees agreed that assistance would be given once only. Usually this would be for childless couples, but exceptionally may be agreed where there is already a child in the family.

Mr Grinsted expressed a concern that the relationship should be stable. The Administrator stated that this would be established during counselling.

The Trustees agreed that treatments which were still experimental in nature and therefore not recognised by the BMA/NHS and treatments available only outside the UK would not be recognised.

iv. **Retrospectives.** It was agreed that Trustees would consider reimbursement of costs, subject to the previous conditions, to those who had paid for such treatment having requested help from the Trust before doing so but having been refused financial assistance.

b. Central Heating and Boiler Replacement.

Mr Williams put forward a suggested amendment to the current guideline covering central heating installation as a small number of applications had been received in the last few months for boiler replacement which the current guideline did not cover.

The Trustees agreed a maximum contribution of up to £1,000 for boiler replacement and ancillary items, and a maximum contribution of up to £1,500 for central heating. In the case of flat dwellers, a maximum of 66% of the above totals would be paid.

96.07 APPLICATIONS

8 applications were presented. The Trustees approved one grant totalling £1,110 and two six-month back-datings of regular payment. One further case was deferred subject to further enquiry by Dr Mayne.

96.08 REVIEWS

The Administrator reported that there were no reviews. One application from the previous meeting was still outstanding and could possibly be revived once a decision had been obtained from a Building Society.

96.09 FEEDBACK

The Administrator reported that no letters for feedback had been received. He had however to report that difficulties continued with one particular Social Worker.

Mr Williams reported that the new Doctor's form which was sent out requesting information in lieu of a letter had proved successful as doctors had found the form easier to complete as a consequence of which replies were received quickly.

96.10 PUBLICATIONS

The Administrator introduced his paper regarding Trust Publications 1996-97 and asked for their approval which was as follows:

i. **Annual Report.** The Trustees agreed that the style and method of publication used for the last two years should be continued for 1996.

ii. **Handbook.** After discussion it was agreed that the Handbook for 1996 and in the future should be only a "help guide" and should be published not later than the end of March. It was also agreed that the abbreviated annual report giving statistical information should not be included as some members preferred not to see this statistical information. It was further agreed that following the publication of the Annual Report, a special edition newsletter should be sent out to provide the information contained in the Annual Report.

iii. **Newsletters.** Due to the upgrading of the office DTP software, newsletters could be printed at only fractionally higher cost than the previous photocopied versions. This not only allowed for use of colour for contrast and emphasis, but also the inclusion of photographs or graphics. The Trustees approved the new format.

iv. **Members' Exchange.** The Trustees considered, but decided against, a suggestion that a publication providing for exchange of views between members be set up. They thought that the Haemophilia Society's Bulletin would be a more suitable place for such an exchange, and asked the Administrator to approach the Haemophilia Society.

96.11 REGULAR PAYMENTS

In introducing his paper on regular payments, the Administrator expressed the hope that it gave the consensus view of the last meeting. He hoped, too, that sufficient agreement in principle could be reached so that a final decision could be taken by post once notification had been received from the Department of Health about additional funds to be allocated to the Trust, without having to wait for the May meeting.

In response to a comment from Mr Grinsted, the Administrator confirmed that he was proposing an across-the-board payment of £10 to members on regular payments, £5 to widows and dependants plus an additional £5 to those on the health supplement.

The Trustees approved the Administrator's paper as a basis for further stages of review.

- i. Referring to Annex A of his paper, the Administrator pointed out that the last increase in the regular payment main system was three years ago and that the proposed levels of increase were barely in pace with inflation. Initially the monthly cost would rise, but any annual increase would be likely to be very small. The figures would be refined in further examination.

All Trustees approved further work on this basis.

- i. Regarding Annex B of the paper on the proposed simplification of regular payments on the main system, the Administrator suggested that an improved modular system would be easier to understand and to justify. He drew the Trustees' attention to the anomaly that those on the standard rate who were married with children, unlike those on additional rates, received no extra family payment, even though this group was often the hardest hit. He proposed that the 3-tier structure should continue, though pointed out that some members would not gain as much as others.

Following a request, the Administrator said that he would look at the number of single people who were on Housing Benefit.

The Trustees agreed in principle to the revision of payment levels on a modular system.

- iii. Referring to Annex C of his paper regarding regular payment to widows, the Administrator explained that a system would be more difficult to set up especially as some widows were already out of the system and would need to be drawn back in. However, he hoped to be able to propose a system more in line with the main system which would enable widows to understand and accept it. The Administrator was less able to predict the financial commitment.

He said he would be very glad to receive any suggestions especially as in percentage terms the commitment to widows was increasing. The Chairman asked the Trustees to send their written suggestions to the Administrator.

96.12 SUPPORT FOR WIDOWS

The Administrator presented his paper for Trustees' consideration and reported that following a useful discussion CRUSE had agreed that contrary to their usual practice of personal approach, the Trust could initiate the preliminary approach. The Administrator said that a CRUSE leaflet was sent out to widows at the time of bereavement but to date he had received no feedback.

96.13 MEETINGS/VISITS/LIAISON

a. Regional Days. Mr Williams reported as follows:

- i. **West Midlands.** Of the 80 invitations sent out only 4 positive replies had been received. The proposed meeting had been cancelled although the idea of a West Midlands meeting had not been entirely shelved since one person had offered the use of her home for a small meeting.
- ii. **Glasgow.** Of 72 invitations sent to those in Scotland and Northern Ireland, only 13 replies had been received, 6 of which were positive. As experience showed that of those intending to come to a regional day, several would drop out. This would make this particular meeting unviable in terms of expense and time, and hence it had been cancelled. Individual visits would be offered instead.

Mr Williams considered that members' enthusiasm for Regional Days was questionable and that therefore different options would have to be considered.

b. Benefits 'Clinics'. It was planned that one to one contact with Mrs GRO-A or Mr Williams regarding benefits needs should be set up at different Centres. The Administrator had already paved the way with the Oxford Centre, and Liverpool and Leeds were to be approached next. It was felt that the social work and nursing staff might also like to have some basic instruction on benefits, and this had been included in the Oxford programme.

c. Visits to Alliance House. Meetings arranged at Alliance House were working well and achieved a useful purpose. On average two office and two home visits were taking place each week.

d. Relationships with Manchester. The relationship with a Nurse Counsellor had broken down to such an extent that a meeting between her and the Administrator and Mr Williams had been arranged. Although the meeting appeared reasonably successful, complaints from her were still being made and it was difficult to know what to do next.

Ms Harrington raised the idea of a Centres' meeting and the Chairman said that this would be put in hand.

e. Relationships with Newcastle. It was reported that the situation had improved.

f. Co-ordination with Haemophilia Society on grant applications. In order to eliminate confusion which had at times arisen regarding grants, it was suggested that a more clear-cut policy should be set out and it was therefore proposed that a meeting should be arranged for this purpose.

g. Hepatitis Group. The Chairman reported that the campaign run by the Haemophilia Society had reached the stage where a presentation was to be made to the Secretary of State.

96.14 NEWSLETTER 31

A draft newsletter was circulated following which it was agreed that one more draft would be produced eliminating the reference to assistance with risk-free conception. The Chairman asked the Meeting to let the Administrator know if they had further suggestions for inclusion in this newsletter.

96.15 ANY OTHER BUSINESS

In bringing the meeting to a close, the Chairman asked that his grateful thanks to the retiring Trustees, Dr Mayne, Mr Palmer and to Mrs Guy (who would be returning on a 'rotating' basis) for the work they had so generously given to the Trust and the people whom it serves, be placed on record. He hoped that a way would be found to keep in touch. The meeting unanimously endorsed the thanks and good wishes to the departing Trustees.

GRO-C

Draft by
21 March 1996

John Williams
Administrator