

**Minutes of a Meeting of the Trustees held at
Alliance House, 12 Caxton Street, SW1H OQS
On Wednesday 28th April 1999**

Present: The Reverend Prebendary Alan Tanner, Chairman
Mr C H Grinsted, Deputy Chairman
Mr K Bellamy
Mr C Hodgson
Mr GRO-A
Mr T Hunt
Mrs K Stubbs
Dr M Winter

In Attendance: Mrs Ann Hithersay
Mrs Fran Dix
Mr Rab Dallas

Apologies: Mr N Lawson
Miss P Winterton

Observer/Trustee Designate: Mr Peter Stevens

The Chairman welcomed ^{Mr} Peter Stevens who would be rejoining the Trust as a Haemophilia Society nominated Trustee at the July meeting. He was attending the meeting today to familiarise himself with the workings of the Trust once more.

99.14 Minutes of the Meeting held on 23rd February 1999

The Minutes were agreed as a true record.

99.15 Matters Arising from the Minutes

99.08 Complaint from a Registrant

The Registrant had been advised of Trust action following receipt of his complaint, and had been sent a copy of the Strategic Review Report. He was happy with the response from the Trust.

99.03 Administrators Report – Section 64 Grant

The Administrator confirmed that as yet, no written confirmation of the Trust's Section 64 Grant had been received from The Department. Trustees expressed their concern and asked that the matter of responses from The Department be raised when the Chairman meets Baroness Hayman, Minister of State for Health, in June.

99.16 Administrator's Report

'A Rose by any other Name..'

This section of the Administrator's Report referred to an issue raised as part of the Appraisal of the Administrator. She had proposed a change of title to that of Chief Executive. The Appraisal Group had agreed the change subject to endorsement by the

Trustee Board. Trustees approved the change and noted that from henceforth the Administrator would be known as the Chief Executive.

Trustee Succession

This matter appeared later on the Agenda. However it was noted with sadness that this was Mr Bellamy's final meeting, and that Mrs Stubbs would be retiring as a Trustee in July. This was because she would be taking a more demanding job following her move to GRO-C

Staff Appraisal Scheme

A Draft Appraisal Scheme to be used for all staff had been circulated. Members of the Appraisal Group had commented on the Scheme and the Draft incorporated these comments. Trustees approved the Scheme and passed it to the Appraisal Group for action.

1999 Handbook

A Draft of the new Handbook had been circulated for Trustee consideration. Staff would address textual corrections. However, Trustees were invited to comment on the content of the Handbook.

It was agreed that changes to the Handbook would be highlighted and registrants would be advised again of the importance of letting the Trust know of changes to personal circumstances. A 'How to use' Section had been introduced at the beginning of the Handbook.

A final Draft of the Handbook would be circulated to all Trustees as soon as it was ready.

99.17 FINANCIAL REPORTS

- (i) **Quarterly and Year-end Investment Summary and Asset Valuation**
A summary was tabled showing that the value of total assets as at 31st March 1999 was £7,688,365. It was also reported that when income from investments, including realised and unrealised gains, was taken into account, the yield of the average capital in the Trusts Fund during the year was 6.0%. It reflected a decrease when compared with previous years, due to dramatic falls in the market during the autumn of 1998, but in the latter part of the financial year markets had experienced a welcome pattern of recovery which was continuing. It was also noted that the policy of apportioning investments between equities and fixed interest stocks had been justified as a hedge against the worst effects of a volatile market. As a concluding observation the Trustees' attention was drawn to the Grants Summary (see below) which revealed that in making grants during the year totaling £1,975,890 the net decrease in assets was £1,576,781. Overall, it was a performance that vindicated the Trust's investment policy and commended the performance of Principal and COIF as the Trust's Investment Managers.

(ii) Monthly Grants Summaries – February & March 1999

The Finance Officer reported that he had circulated a revised version of the February Summary, to include corrections made to reports from earlier years of the Trust.

The March Summary showed a reduction in the Regular Payments total following a change in presentation of Regular Payment Advances. A separate Report on Regular Payment Advances would be circulated to Trustees quarterly.

Regular Payments were particularly high for March due to a payment being made to a registrant who had not received any payments since she was registered with the Trust in 1991.

Trustees asked if checks had been made to see whether similar errors might have been made in the past. The Chief Executive said there was work to be done in this area, which would include looking at all Special Payments II records to ensure that all those who had received a payment from The Department of Health had been registered with the Trust.

(iii) Management Fund – Income and Expenditure

A Report showing actual and budgeted Income and Expenditure for the year ended 31st March 1999 was tabled and considered. When excluding the cost of the Strategic Review and year 2000 Compliance, there had been an excess of expenditure over income of £3,343, whereas when cost of the Strategic Review (£17,559) and Year 2000 Compliance (£16,768) were taken into account, there was a deficit in the year of £37,670. Trustees noted that while accounting practice would cause a deficit to be shown in the audited accounts for the year, the Government had undertaken to reimburse the costs of the Strategic Review in the sum of £23,000 as a Project Grant (see below), which sum would be received in the new financial year. Reimbursement of year 2000 Compliance remained unsettled. (see below)

(iv) Year 2000 Compliance Expenditure

Year 2000 Compliance expenditure was also shown as a separate item in the Report. Trustees asked whether The Department of Health had responded to the request to make a grant to the Trust to cover these costs. Upon learning that no reply had been received to letters sent asking for funding to cover this 'extraordinary expenditure', the Chairman reminded Trustees of correspondence he had had with Strachan Hepple of the NHS Executive at the time the Trust was set up in 1987. This correspondence had assured the Haemophilia Society at the time, that all administrative costs related to the running of the Trust would be covered by The Department of Health.

Trustees asked that a full Report on costs to date of the Compliance Project be circulated, and that the Chief Executive write again to the Department enclosing the Report and asking for a decision in writing. The Chairman undertook to raise the matter informally when he met the Minister in June.

(v) Strategic Review Expenditure

Expenditure to date totaled £21,063.14 for the year. However, £3,508 of Section 64 Underspend for 1996/97 had been approved by The Department for expenditure on the Project. The Section 64 Project Grant had been approved and funding would be made available in 1999/2000.

(vi) Management Fund Budget for 1999/2000

A draft budget was presented. Attention was, in particular, drawn to the following:

- ☐ Total staff costs were included, part of which would be recovered from secondment.
- ☐ As intimated above, costs of the Strategic Review would be recovered as a Project Grant.
- ☐ Cost of year 2000 compliance remained unsettled and pressure for reimbursement will continue to be undertaken in fulfilment of the Government undertaking referred to above.

Following discussion, and upon a proposal from the Chair, an Expenditure Budget of £228,850 for the year 1999/2000 was approved.

99.18 A DEED OF VARIATION TO PROVIDE THE TRUST WITH POWERS TO MAKE LOANS TO REGISTRANTS

Trustees were reminded that at a meeting held in September 1998 between the Chairman, Deputy Chairman and Chief Executive on the one hand and Paisner & Co(the Trust's solicitors) on the other, advice had been received that the Trust Deed as it stood did not include a power to make long term loans to registrants. Previously the Trust had assisted registrants by making advances of Regular Payments or taking an 'Equity share ' of the registrant's property by way of a legal charge on the property. This assistance had been provided under General powers in the Deed " to do all such lawful things as may be calculated to further the attainment of the Trusts' objects". However Paisners recommended that if Trustees were minded to continue to making long term loans on terms requiring repayment, and if appropriate, creating a charge on assets, then the Trust Deed would have to be modified to include an enabling power.

As a consequence, Paisner & Co had submitted a Deed of Variation, and a draft Loan Agreement specific to the case that provoked the enquiry, which documents were now before the Trustees. Trustees were also in possession of written observations made by the Deputy Chairman on both documents, and the response of Paisners thereto.

The Chairman invited comment, and amongst other things, it was observed

- That whereas legally the proposed modification did not require the prior consent of the Secretary of State, none the less, the granting of long-term loans of the type proposed would be a departure from previous practice, and there was a case for obtaining from The Department an understanding that the practice (if adopted) would have the support of Government.
- That if the new enabling power was adopted, it was critical that clear guidelines were set for the granting of such loans.
- That as a result of the Strategic Review it was hoped that Government would recognise that many younger registrants had exhausted 'Special Payments I & II', were financially distressed and in need of continuing support.

The Chairman invited Mr Stevens to contribute his views:

Peter Stevens reflected that Regular Payments had originally been introduced to help meet the costs of living with HIV. To make loans repayable by deductions to Regular Payments changed the nature of what the Trust was doing. A move from grants being made to meet illness-related costs to meeting a wider range of difficulties. What would happen if the registrant died before the advance was repaid? As he saw it, the alternative to introducing powers to make loans into the Trust Deed was for Trustees to determine not to make loans.

The Deputy Chairman was also invited to comment:

Mr Grinsted acknowledged that the Strategic Review had identified new needs; amongst which were those arising from financial distress. The Chief Executive had reported that these were few in number at present, not more than 4 – 5 in the past year. However the Deputy Chairman was concerned that in order to overcome the problems of a few, Trustees did not take steps that might later be regretted in the loss of flexibility in the availability and use of cash resources. The Deputy chairman felt that the enabling power was too wide, and amongst other things, should be restricted to registrants only.

The Chairman summed up the discussion and said that the Trust Deed had been drawn up to meet a specific situation which had prevailed at the time when the cheque for £10 million had been given to set up the Trust. At that time some people had wanted the money divided up between the surviving registrants. However, it had been decided to set up a 'Hardship Fund' to be administered by the Macfarlane Trust. At the time the Trust was set up, life expectancy had

been thought to be short. For those survivors today, the current situation was very different. The quality of life and needs of registrants had changed significantly. Terminal illness was often extended and costly. More help was needed by many to cope with the new situation. He concluded that Trustees were not in a position to endorse the Variation to the Trust Deed just yet. The Chairman agreed to raise the principal of making loans to registrants when he met Baroness Hayman, Minister of State for Health, in June. He would also arrange a further meeting with Paisner & Co and report back to Trustees at the July Meeting.

99.19 STRATEGIC REVIEW

(i) Agenda for the meeting with Baroness Hayman

The draft Agenda was agreed following amendments to reduce volume and include informal issues to be brought up under Any Other Business. These might include the issue of loans to registrants, a further capital payment to registrants, and Trustee Succession.

(ii) Trust Representation at the meeting with Baroness Hayman

The Chairman proposed that a small group should attend the meeting. He suggested that this include himself and the Deputy Chairman together with Dr Winter to present medical issues, Mr Hunt to present psychosocial issues and the Chief Executive to cover administrative issues.

It was suggested that the group also include 'user representation'. However, the Chairman felt that this was a meeting for Trustees and the Minister, so representatives from the registrants might more appropriately meet with other levels within The Department.

Briefing Papers on medical, psychosocial and financial issues would be prepared. A briefing meeting for Trust representatives would be held immediately prior to the meeting at Richmond House on 17th June 1999.

99.20 STRATEGIC RESPONSE GROUP REPORTS

(i) Payments Review Group

The Group had not met on the agreed date due to illness. A new date had been set for Thursday 20th May at 1.00pm. Papers identifying how 'the Costs of Living with HIV' had originally been worked out had been collected, and would be updated.

(ii) Partnership Sub-Group

Mr Hunt had agreed to convene this Group. A multi-Agency approach would be adopted, bringing together representatives of the Trust, The Haemophilia Society, the Birchgrove Group and other registrant representatives.

The Group would initially prepare plans to feed back results of the Strategic Review to registrants. This might be done by holding two Focus Groups, as had been proposed to the Department of Health as part of the Section 64 Project grant application, but might also include 'Trustee/Staff Surgeries' to be held in different parts of the country.

The initial meeting of the Partnership Sub-Group would take place on Friday 14th May at 11.30am. The Agenda would include an item on a budget for the Group, and for the Focus Groups.

(iii) Conferences Working Party

There had been no full meeting of the Conferences Working Party since the last Trustees' Meeting. However, costings were now available for a Weekend Conference for 'Positives Only'. The Conference would be held in Bath and would be for those long-term survivors with Haemophilia and HIV. It was expected that approximately 40 people would attend.

Funding of approximately £220 per head was approved.

The Women's Weekend, for which funding had been approved at the previous meeting, was expected to take place early in 2000. Firm plans had not been developed yet.

99.21 APPLICATIONS AND CASES

Three cases were presented to Trustees.

1147 A Grant of £600 was approved.

1427 Trustees asked that the Social Worker met with the registrant and discuss alternative ways to assist him work out appropriate lifestyle changes.

1758 Trustees agreed to cover the costs of bankruptcy charges for the registrant and his wife. It was also agreed that the Chairman write a letter to the Chief Executive of Abbey National plc asking for mortgage arrears to be waived due to exceptional circumstances. Arrangements should also be made for continuing financial supervision and social work support to be provided locally to the couple. Trustees asked for a further update to be provided for the next meeting.

99.22 REPORTS ON VISITS MADE

Reports on visits made by the Social Worker and the Benefits Adviser were noted.

99.23 ANY OTHER BUSINESS

(i) Trustee Succession

The Chairman noted with regret that this was Mr Kenneth Bellamy's final Trustees Meeting. He was reluctant to let Kenneth go. Mr Bellamy had been a great asset to the Trust in the short time he had served as Macfarlane Trustee. In particular, Kenneth had been able to provide wise counsel and assistance on matters related to the preparation of submissions and reports to The Department. He had also provided a steadying influence to the Appraisal Group and guided approaches on other matters. However, the Chairman had recently learned of the amount of time taken for Mr Bellamy to come to London for meetings, and hoped he would be able to spend the time more fruitfully. Trustees expressed the gratitude to Mr Bellamy and wished him well.

The Chairman also noted that the Deputy Chairman would be retiring at the meeting in July, and that Mrs Stubbs would also be standing down at that meeting. Mr Stevens would be joining the Trust in place of Mr Grinsted in July.

The Chief Executive confirmed that she had written to the Department of Health and the Haemophilia Society about impending vacancies, and hoped to receive information about new appointments soon.

(ii) Report from the Appraisal Group

The Chairman reported that the Appraisal Group had met a number of times to continue the appraisal of the Chief Executive. They had also been asked to consider other matters relating to staff structure and salaries. The Chairman was therefore asking Trustees for approval to widen the brief of the Group to enable it to review staff salaries and terms and conditions of service.

(iii) Date of Next Meeting

The next meeting of the Trustee Board would be held on Monday 12th July 1999.

Ann Hithersay
Chief Executive
12.05.99