

**MACFARLANE TRUST**

**AG99/14**

Minutes of a Meeting of the Trustees  
Held at Alliance House, 12 Caxton Street, SW1H OQS  
On Tuesday 23rd February 1999 at 11.00a.m.

Present:

The Reverend Prebendary Alan Tanner, Chairman  
Mr C. H. Grinsted, Deputy Chairman  
Mr C. Hodgson  
Mr K. Bellamy  
Mr N Lawson  
Mrs K. Stubbs  
Dr M Winter  
Miss P Winterton

In Attendance

Mrs Ann Hithersay  
Mrs Fran Dix  
Mrs Jenny Jackson (for part of the meeting)  
Mr Rab Dallas

Apologies

Mr GRO-A  
Mr T. Hunt

The Chairman welcomed Mr Rab Dallas to the Trust as the newly appointed Finance Officer.

**99.01 MINUTES OF THE MEETING HELD ON 24.11.98**

Minutes of the Meeting held on 24<sup>th</sup> November 1998 were approved after the following amendment:

98.43 – penultimate para. - add ‘Mr Hinch expressed his opinion that.....  
generally specific managed funds were only used for the very largest  
charities’.

**99.02 MATTERS ARISING**

There were no matters arising not included on the Agenda.

**99.03 ADMINISTRATORS REPORT AND STATISTICS**

Department of Health. The Administrator reported that she had received a call from The Trust's contact at The Department confirming that the Section 64 Core and Project funding Grants had been approved. There had been no further information about the ‘Y2K’ funding applied for in 1997 and again as part of the Section 64 grant application in 1998.

Trustees welcomed confirmation of Section 64 funds, and asked that the Chief Executive write to the Department summarising total 'Y2K' costs to date and planned expenditure in the next financial year.

#### **99.04 QUARTERLY INVESTMENT SUMMARIES ASSET VALUATION**

In tabling the Asset Valuation as at 31<sup>st</sup> December 1998, the Deputy Chairman drew attention to movements in the markets during recent months. He reminded Trustees that from the falls suffered in the latter part of 1998 the market had recovered so that in the early part of 1999 markets were again bouyant. Nonetheless, they remained volatile and he commended a continuation of the strategy agreed at the June 1998 meeting whereby the division of Equities to Fixed Interest stocks should, as an objective and protective measure, be a 60/40 division respectively. The commendation was accepted. The Deputy Chairman then reported that to meet grants expenditure, and beginning in December 1998, it had become necessary to start drawing down capital from both Principal and COIF, and this would reduce future valuations. Subject to the need for liquidity the draw down would, until reviewed continue at £150,000 a month. The Deputy Chairman was thanked for his report and the Valuation was noted.

#### **99.05 MONTHLY REPORT AND SUMMARIES**

##### **99.05(i) – Summary of Grants Made**

The Finance Officer reported that reconciliation of the August Regular Payments had now taken place. The Summary Report of Grants presented today represented reconciliation against bank statements and written records. He was satisfied that problems encountered in August 1998 had now been resolved.

The Deputy Chairman pointed out that at present rates, the estimate of Trust expenditure for the year of £1,827,650 would be exceeded. Single Grants were significantly higher than for the same period last year. Were it not for the fact that fewer Winter Payments had been made, the difference between the two years would be even higher.

The Chief Executive agreed that the estimate for the year was likely to be exceeded. However she pointed out that, as the Strategic Review had revealed, and recent Allocations Committees had confirmed, needs of registrants were increasing. She did not believe expenditure for the year would exceed the £2 million, estimated as still needed each year in the Report of the findings of the Strategic Review, submitted to Government in January.

Trustees agreed that the Review had also acknowledged that more money might be required from Government to meet new needs identified in the Review.

##### **99.05(ii) . Management Expenditure Report**

The Finance Officer presented the Report. Income for the year to date was as budgeted. However expenditure on staff costs had fluctuated significantly during the year. This was due to an increase in Consultancy costs and higher than budgeted

recruitment costs, together with unbudgeted redundancy costs, and some use of Agency staff for Strategic Review related work.

The Finance Officer pointed out that he had shown Strategic Review and Year 2000 Compliance costs separately in the Report. He believed it was helpful to distinguish these costs from the routine administration expenditure of the Trust.

The Deputy Chairman expressed the opinion that administration costs could be as much as £38,000 over budget for the year. This overspend, when added to the overspend of £23,000 incurred in 1997/98 should be of considerable concern to all Trustees.

The Finance Officer then drew attention to a practice that did not appear to be equitable. Whereas fees for the management of the Principal portfolio were imposed separately and absorbed by the Management Fund, fees for management of the COIF portfolio were deducted from dividends due, and before payment to the Trust and thus absorbed within the General Fund. It followed that there was a distortion in accountability and a consequential effect on costs attributed to the Management Fund. It was agreed that this matter merited further consideration.

Trustees agreed that a full report of Y2K expenditure should be prepared for the next meeting of Trustees in April. If The Department of Health had not approved a grant to cover this expenditure, it might be possible to consider new treatment of investment management expenditure for the period of the Year 2000 Compliance exercise.

Trustees also asked to see a deficit projection to the end of March 1999. The projection should be included with financial information to the end of February.

#### **99.06 STRATEGIC REVIEW COSTS – UPDATE**

Strategic Review costs to the end of January 1999 were noted.

#### **99.07 APPLICATIONS AND CASES**

Six grants totalling £3,118 were approved for payment.

A further case of an infected 'common law Widow' who had received a payment under the terms of the MSPT II Deed in 1991, and then 'got lost' from the system, was agreed in principal. Further work will be needed to determine dates of claims for earlier State Benefits, as this will influence backdating of Regular Payments to this Infected Intimate. Trustees were concerned that there might be other Infected Intimates who had been similarly overlooked at the time MSPT II payments were made. It was agreed that staff would check this out as far as was possible.

A request for support for special fertility treatment was deferred until after AG 99.10

#### **99.08 REPORTS ON VISITS MADE**

Reports on visits made to and on behalf of Registrants by the Benefits Adviser and the Social Worker since the last meeting was noted.

## **99.09 A COMPLAINT FROM A REGISTRANT**

A complaint from Registrant 1318 was considered. The Administrator was asked to reply, emphasising Trustees' sympathy and understanding of the frustration and anger experienced by so many.

The Strategic Review had covered many of the issues raised by this Registrant, and recommendations to the Department of Health would stress the high levels of anxiety experienced by so many, and in particular, would emphasise the need for assurances from Government about the future funding requirements of the Trust.

## **99.10 RISK REDUCED CONCEPTION – AN UPDATE**

Dr Winter presented a paper summarising his work to date, researching this issue on behalf of the UKHCDO, and the Trust.

Fertility Treatment for HIV discordant couples was still in experimental stages. Methods of 'sperm washing' now used in a number of UK Fertility Centres had not yet been proven as being safe and effective in medical literature. Written evidence of treatment success had been requested from Centres practising the technique, but this had not, as yet, been supplied.

Health Authorities approached by Dr Winter about funding risk reduced conception using 'sperm washing' techniques had said that they would consider applications for funding such treatments. Dr Winter recommended that the funding of treatment was the responsibility of the NHS. It would be unwise for the Trust to take on the funding of treatments as such.

In the discussion that followed Trustees suggested that the Payments Review Group might consider the matter further, but at the present time, Trustees agreed that no further grants should be made for treatments. [NB: – this work would involve the Review Group in determining what constituted 'treatment' and where Trustees should 'draw the line'.]

Trustees should accept guidance from Dr Winter on whether or not the decision not to fund treatments should be reviewed at some future date.

Case 1205 was not covered by the current guidelines, and the registrant should be advised of the above new Trust policy.

## **99.11 STRATEGIC REVIEW – FOLLOW-UP ACTION**

99.11(i) To establish an Implementation Group

It was proposed that an alternative name be found for the Group. The Response Group was suggested. This name will be used until another is agreed.

It was agreed that the Response Group should include all those people who had participated in the previous Strategic Review Group, and that a Department of Health

appointed Trustee should be included in the Group. A Registrant should also be included to represent the 'user point of view'.

After discussion, it was agreed that Pat Winterton join the Response Group, and **GRO-A** be invited to join as a Registrant representative. **GRO-A** was also as Trustee of the Haemophilia Society and a member of the Birchgrove Steering Committee.

It was agreed that Haemophilia Society staff representatives should be present at meetings when joint activities were discussed.

A Trustee Day to look more closely at the findings of the Strategic Review was suggested.

#### 99.11 (ii) A Payments Review Group

The Chairman proposed that he would Chair the Review Group. Membership of the Group should include the Social Workers (Tim Hunt, Kathy Stubbs and Fran Dix), Dr Winter and the Chief Executive. The Group would initially review Regular Payments, looking again at the costs of living with HIV, which had formed the basis of the origin of regular payments. It was acknowledged that there was also an urgent need to review Guidelines for payment of single grants in the light of needs identified by the Strategic Review.

It was reported that Tim Hunt had begun to gather information on the costs of living with HIV. The Chairman asked that information gathered at the time Regular Payments had first been introduced in 1988/ 9 should be re-examined, together with information considered by Trustees in 1993; the last significant update of Regular Payments and the costs of living with HIV.

The aim of a Payments Review would be to consider increases to Regular Payments, to review Single Grant guidelines and to significantly increase levels of some payments whilst possibly reducing others. An increase to the levels of Regular Payments would not necessarily lead to a reduction in Single Grants. The meeting with Baroness Hayman should emphasise the changing needs and lifestyles of Trust Registrants.

#### 99.11(iii) Improvement of Information to Registrants

Some Trustees were concerned that if Registrants were given too much information about the range of grants they might apply for, this might become a 'shopping list', leading to unrealistic levels of demand for grants. Higher Regular Payments might counter that trend. It was agreed that the Payments Review Group would consider how best to provide sufficient and clear information about grants to Registrants.

#### 99.12 CONFERENCES BUDGET

Tim Hunt had sent in a submission from the Conferences Working Party suggesting that two Conferences be held in 1999/2000: A Partners and Carers Weekend, which would be a sequel to the very successful and over-subscribed event in (?) 1997, and a Positive Persons Only Conference. The Haemophilia Society had also secured



funding to run a Young Persons Weekend in Brighton in the Summer. GRO-A  
HIV Worker at the Haemophilia Society, had prepared a budget for the Partners and Carers Weekend. This indicated that a Trust contribution of £7,000 would be required. As yet, there was no costing for the Positive Persons Conference.

*in capital*  
There was some uncertainty about which Conference should be held first. After discussion it was agreed that the Conference Working Party should decide which Conference would receive priority. The Trust would make £7,000 available, and if further funding was required, the Group could come back with another proposal to a subsequent meeting. It was felt that MFT members of the Conference Working Party should 'have the deciding vote' if there was difficulty deciding which Conference should be held first, because The Trust had initiated the Working Party and was providing core funding for Conferences organised by the Group.

The Deputy Chairman reminded the meeting that Conference Grants were only given on a per capita basis, and that the amount agreed would therefore be required to be divided between those attending the Conference, and recorded as individual grants, as had been the practice in the past. Any change from this procedure could necessitate a change to the Trust Deed. The Chairman agreed to raise this matter with the Minister of State for Health.

#### **99.13. ANY OTHER BUSINESS**

##### **99.13 (i) Report to Trustees from the Appraisal Group**

The Chairman reported that the Appraisal Group had met with the Chief Executive twice. Objectives had been agreed. These would be fully reviewed in September, with an interim Review taking place in May. Reports would be made available to Trustees as meetings took place.

99.13 (ii) Date of Next Meeting – Wednesday 28<sup>th</sup> April 1999. The date was noted.

##### **99.13 (iii) Trustee Succession – Retirements and new Appointments**

The Chairman reported that his time in Office would come to an end in March 2000.

The Haemophilia Society had extended the present term in Office of the Deputy Chairman from March to July 1999.

Kenneth Bellamy had written to the Chairman to advise that he would not be seeking re-appointment when his term of Office came to an end in May 1999. Kenneth's last Trustee Board Meeting would be in April; Clifford's last Trustee meeting would be in July.

These Trustee changes would have major implications for the Trust. The Haemophilia Society was considering future appointments. It would also be necessary to write to The Department of Health to ask them to nominate a successor to Kenneth Bellamy as quickly as possible.

It was agreed that a letter should go The Department advising of the appointment and re-appointment dates of all four Department appointed Trustees, and asking for an early nomination for a replacement for Kenneth Bellamy.

#### 99.14 Draft Special Newsletter

The Draft Newsletter devoted to the Strategic Review Report was considered. It was felt that something simpler was required. There should be less financial information and other areas should be expanded and explained. A revised Draft should be presented to the Response Group on 11<sup>th</sup> March.

[NB: The Response Group Meeting on 11<sup>th</sup> March was changed from 11.00am to 2.00pm.]

There being no further business, the meeting ended at 4.15pm

Ann Hithersay  
Chief Executive