

## MACFARLANE TRUST

Minutes of a Meeting of the Trustees  
Held at Alliance House, 12 Caxton Street, SW1H OQS  
On Tuesday 24th November 1998 at 11.00a.m.

Present:

The Reverend Prebendary Alan Tanner, Chairman  
Mr C. H. Grinsted, Deputy Chairman  
Mr K. Bellamy  
Mr GRO-A  
Mr T. Hunt  
Mr N Lawson (for part of the meeting)  
Mrs K. Stubbs  
Dr M Winter  
Miss P Winterton

In Attendance    Mrs Ann Hithersay  
                         Mrs Fran Dix

Apologies         Mr C. Hodgson

### 98.39 MINUTES

Minutes of the Meeting held on 15<sup>th</sup> September 1998 were approved after amending the Minutes to include apologies from Mr Kenneth Bellamy.

### 98.43 COIF PRESENTATION

The Chairman welcomed Richard Hinch, Client Investment Adviser for CCLA, Managers of COIF Charity Funds, and invited him to make a presentation to Trustees.

Mr Hinch said that CCLA provided a specialist investment management service to charities, churches and local authorities. The Company was regulated by IMRO and had funds of over £3.1 billion under management. More than 88,000 charity fund accounts were open. The Common Investment Funds and Deposit Funds had been set up in response to the Charities Act 1993.

COIF Charity Funds were classified as 'special range' investments. COIF Charities Investment Fund and the Fixed Interest funds were more suitable to long-term capital investment. The COIF Charities Deposit Fund was more appropriate for short-term cash management.

At present Macfarlane Trust had shares to the value of £2,687,681 invested in the COIF Charities Investment Fund, yielding an annual income of £96,088. A further £19,520 was currently held in the COIF Charities Deposit Fund, yielding £1,337 in a full year.

Mr Hinch went on to discuss main asset market capital movements during the year to date and said that overall gains in equities in UK, Europe and USA had overcome losses in Japan and Pacific Basin shares. The COIF Charity Equities Fund had investments of over £800 million. More than 65% of this was invested in UK Equities. Of the 14.8% investments held in Overseas Equities, only 2.5% was invested in Japan and Pacific Basin Equities suggesting a policy aimed at steady income and capital growth and a defensive spread of investments. The Fund had an excellent long-term performance record.

Questions from Trustees included asking Mr Hinch to explain the charging structure for CCLA fund management. He responded by explaining that CCLA charges were based on .26 % of the fund and were deducted before the dividend yield was paid.

A further question to Mr Hinch related to Specific Managed Funds for charities. He was asked if he agreed that if such managed funds produced higher returns then higher charges were justified. Mr Hinch agreed but said that he believed that COIF provided charities with as good or better returns than specific managed funds. Specific Managed Funds were to be found amongst the larger funds.

The Chairman thanked Mr Hinch for his presentation and said that Trustees looked forward to receiving future Quarterly Reports from COIF.

#### **98.40 - MATTERS ARISING**

##### **98.30 Regular Payments – Information to Registrants.**

A selection of items of information on Regular Payments circulated to Registrants over the years was noted by Trustees. This would be referred to when reviewing Regular Payments in the New year.

##### **98.35 JTA Financial Services**

The Deputy Chairman referred to discussion at the September meeting and said that the paper circulated to Trustees today was a draft agreement between JTA Financial Services and the Trust. Ms Daniels had indicated her acceptance of the terms of the agreement. She would be asked to sign the final draft when this had been approved by Trustees. Registrants would be advised of the new arrangement in the Newsletter, and a letter from the Trust would accompany the form to be used to authorise future Trust sponsorship of the facility provided. The Deputy Chairman emphasised that JTA Financial Services was an independent financial adviser and that the Trust could not be held responsible for any advice given.

Trustees welcomed the new arrangement and approved the draft Agreement.

##### **98.36 Conferences budget for 1999**

It had been agreed at the previous meeting that Mr Tim Hunt, together with Dr Winter and staff of the Trust and the Haemophilia Society would prepare a Conferences budget for today's meeting. Mr Hunt asked that the proposed budget be taken to the first meeting in the New Year. This was agreed.

## **98.41 - ADMINISTRATORS REPORT**

### **Staffing Matters**

The Administrator reported that staff restructuring was incomplete. The post of Administrative Secretary had been filled by Mr Stephen Ball, but the post of Finance Officer was still vacant. There were two promising candidates, but fulfilment of the restructuring plan had been put 'on hold' to allow Trustees time to review the plan. The delay in filling this important post had necessitated the use of temporary part time Agency staff.

### **Department of Health Contact**

The Administrator reported that Mr Charles Lister had taken over from Christine Corrigan, the Trusts's most recent previous point of contact with the Department of Health. Mr Lister had visited the Trust to learn more about it's work and to discuss the recent Section 64 Application and request for funds to meet the cost of the Strategic Review. Mr Lister indicated that he felt that the Macfarlane Trust was a special case for continued Section 64 funding, and he would not recommend that funds for the administration of the Trust came from any other Department budget.

Mr Lister promised to look into other matters that had been in abeyance with the Department for many months.

### **Christmas Office Closure**

Trustees noted that the Trust office would be closed between the evening of Wednesday 23<sup>rd</sup> December and the morning of Monday 4<sup>th</sup> January 1999.

## **98.42 FINANCE**

### **Summaries**

The Trustees received and noted summaries as follows:

- (i) Summary of Grants made to 31<sup>st</sup> October 1998
- (ii) Strategic Review – Budget Update

## **98.45 REPORTS ON VISITS MADE**

Trustees noted Reports on visits made to registrants by the Social Worker and Benefits Adviser since the last meeting.

#### **98.46 RISK REDUCED CONCEPTION**

Dr Winter said that the subject of 'risk reduced conception' was most complex. After years of illness, many young men were now seeing some kind of a future for the first time, and wanted to start families. The question was what role the Trust should play in helping registrants to achieve this. Gene therapy may become possible for the infected partner, and there were now other routes to conception using the infected partner's sperm that were said to reduce risk of infection being passed to partner and unborn child to acceptable levels. There were 7 or 8 Centres in the UK practising 'sperm washing' techniques pioneered in Italy. The Trustees had previously taken a decision not to support this treatment; however, the Centres using the technique had the support of their Ethical Committees who had indicated that the new treatment was acceptable to them.

The UKHCDO had asked Dr Winter to prepare a paper on the subject of risk reduced conception. He had approached a Health Authority for guidance and had been told that criteria for approval of funding were already in place. Dr Winter proposed to take a test case to the health authority for funding. He would prefer to await the outcome of such a test before making recommendations to the Trust on future policy changes.

The Chairman said he had that day received a letter from the Trust's solicitors on the matter; this would be circulated to Trustees.

It might be appropriate for a campaigning organisation such as the Haemophilia Society to become involved this issue. Trustees felt that it was unlikely that the Department of Health would produce a policy on the matter of funding therapies to reduce risk of HIV infection being passed to mother and child at the time of conception.

#### **98.47 - STRATEGIC REVIEW - DRAFT FINAL REPORT**

Trustees considered the draft Final Report:

Dr Winter said it was clear from the information gathered that the needs of people with HIV were growing. He felt there should be a substantial increase to Regular Payments and a simplification of the Single Grant process. The Chairman endorsed this view, and said that this was why he had undertaken to Chair all Allocations Committees for a period. It had become apparent that Allocation Committees were finding it difficult to make decisions in more complex cases, and he believed it would be advisable if Registrants were given more control of funds through increased Regular Payments. Single Grants should mainly be given for health related reasons.

Mrs Stubbs felt that the Review was much bigger than the question of Regular Payments. She believed that Trustees needed to decide what the role of the Trust should be. The Trust should not be paternalistic, and should seek to give independence to registrants to manage their own funds wherever possible. However,

there were some registrants who were unable to cope with this level of independence, and it would still be necessary to help those who could not manage.

It was pointed out that the highest level of grants given still related to health matters; however all priority areas identified in the Review should be fully funded by Government.

Trustees discussed whether or not to recommend a further capital payment. This was seen to be particularly important for those men who had been children at the time of infection. However, there was a strong feeling that in the present climate it would not be wise to ask for a third Special Payment.

Trustees believed that Recommendations contained in the Review should be more specific about what funds were being asked for and what would be done with the money, if it were granted.

It was agreed that an Annex should be included with the Report to show how the trends in types of payment made had changed over the ten years since the Trust was set up.

It was important to emphasise in the Report how Registrants depended on continuing support from The Macfarlane Trust. The Trust therefore needed to be assured by The Department of Health that funding equal to that given over the past decade would continue to be forthcoming.

Trustees agreed that there should be a further review of Regular Payments and proposed that Mr Tim Hunt and Mrs Kathy Stubbs, together with the Trust's Social Worker, should examine again the additional costs of living with HIV. These costs had been the basis of revised Regular Payments made to registrants since 1993.

It was also suggested that perhaps the Board of Trustees should include someone with Haemophilia and HIV. In response to this proposal the Chairman said that this had been tried in the past but by being a Trustee, such a registrant could not continue to receive benefits from the Trust.

[NB: the Charity Commission is reviewing its policy on this subject. The Administrator has given the name of the Trust to the Commission's researcher working on the issue.]

It was agreed that some editing of the Report was needed as the next step. It was proposed that Mr Bellamy, with his long experience of report writing within the Department of Health, would be able to help with this process.

It was agreed that all Registrants would be thanked for their contribution to the Review in the next Newsletter.

It was felt that it would not be possible to present the Report to the Department of Health before the end of the year, as had originally been intended. It would therefore be necessary to write to the Minister to ask for a delay. Department of Health appointed Trustees who had worked in the Department felt that such delays were usual, and there should be no cause for concern.

However it was pointed out by the Administrator that HM Government would be completing work on a National HIV Strategy early in the New year. Baroness Jay had indicated in response to the Chairman's letter advising the Department of the Review last March, that she would ask her Officials to ensure that the Trust's Reports were circulated in order that a consistent approach was maintained. The Administrator believed it was important that the Trust's Final Report was not delayed too long. It was likely that there would be funding from the Department to cover costs of the Strategic Review in the current financial year. She had indicated to the Department that it would be possible to complete all work originally proposed by the end of 1998.

#### **98.44 APPLICATIONS AND CASES**

Twelve applications for grant funding were considered by Trustees.

Two advances of Regular payment were agreed;  
Grants totalling £1442 were paid to four registrants.

When the final application to this meeting was brought forward, being an appeal for back-dating of the health supplement introduced in 1993, it was reported that the appeal had been withdrawn. The Deputy Chairman was asked to send a suitable acknowledgement in response.

#### **98.48 ANY OTHER BUSINESS**

- (i) Dates of Meetings for 1999 were agreed as follows:

Tuesday 23<sup>rd</sup> February

Wednesday 28<sup>th</sup> April

Wednesday 12<sup>th</sup> July

Tuesday 19<sup>th</sup> October

- (ii) Trustees continued to meet in Private Session until approximately 5.00pm

Ann Hithersay  
Administrator

11<sup>th</sup> February 1999