

## MACFARLANE TRUST

### Minutes of a Meeting held on 28<sup>th</sup> May 2002 At Alliance House, 12 Caxton Street, SW1H OQS

<b>PRESENT:</b>	Mr Peter Stevens	Chairman
	Mr <span style="border: 1px dashed black; padding: 0 2px;">GRO-A</span>	Hon. Treasurer
	Mrs Elizabeth Boyd	Trustee
	Mr Chris Hodgson	Trustee
	Mr <span style="border: 1px dashed black; padding: 0 2px;">GRO-A</span>	Trustee
	Mrs <span style="border: 1px dashed black; padding: 0 2px;">GRO-A</span>	Trustee
	Dr Mark Winter	Trustee
	Mr Anthony Yeaman	Trustee
<b>In Attendance:</b>	Mrs Ann Hithersay	Chief Executive
	Mr Rodney Shepherd	Finance Officer
	M/s Claudette Allen	Social Worker
	M/s Carol Clisby	Benefits Adviser
	Mr Robert Finch	Department of Health
<b>Apologies:</b>	There were no apologies.	

#### 12.02 Minutes of the Meeting held on 12<sup>th</sup> February 2002

The Minutes were agreed as a true record.

#### 13.02 Matters Arising from the Minutes

##### 00.53 Prescription Charges

Dr Winter reported that he had had further correspondence with Dr Frank Hill, Chairman of UKHCDO on the matter of prescription charges. Dr Winter had drafted a letter, which it had been agreed by UKHCDO should be sent to all Haemophilia Centres. It had also been agreed that registrants should receive copies of the letter. Trustees welcomed Dr Winter's report and agreed that the office would send out three copies of the letter to all registrants. One copy could be given to the Haemophilia Centre, one could be used for HIV Centres, or possibly the GP ; the third copy of the letter would be kept by registrants for information.

##### 01.46 Confidential Report – Update

Mrs Hithersay updated Trustees on progress of the complaint made on behalf of bereaved families to the CEO of Manchester Royal Infirmary in February. The Chief Executive had confirmed that the matter would be taken seriously and addressed as a

formal complaint. Trustees asked that progress be monitored closely and if necessary, a further reminder sent to the CEO's Office regarding formal investigation of the complaint. Also that Mr Yeaman be kept informed and copied with correspondence relating to the complaint. [NB: Since the meeting there has been further correspondence and The Trust has been invited to become involved in agreeing Terms of Reference for the investigation.]

#### **06.02 Management Project – Update**

It was reported that Kat McFarlane had returned from 6 weeks study leave the previous day. It would be necessary for her to take stock, but she had agreed with the Hon. Treasurer that for the remainder of her secondment she would concentrate on the planning model that was being developed to assist the Trust to forecast future financial needs. Kat would also continue to work on designing financial reports and would develop these as much as possible in the time available. KMc had proposed that she should delay her departure until mid-July to allow as much work to be completed as possible. A Project Meeting to review progress would be arranged shortly.

#### **12.02 Haemophilia 2002. World Federation Congress in Seville**

The Chairman invited those who had attended the Congress in Seville earlier in the month to report to Trustees on what aspect they had found most valuable.

Ann Hithersay spoke of attending sessions related to treatment and problems caused by HCV, concerns about CJD and its impact on the use of blood in Europe, particularly in the UK and France, and the United States constraints on blood donors who had visited Britain within a period of years. There had been little at the Congress related to HIV, but there had been a very moving Service of Remembrance in memory of all those people around the world who had died as a result of receiving treatment with HIV contaminated blood.

Dr Winter said that 70% of people with haemophilia in the world went undiagnosed and of those who were diagnosed 80% were without regular care. He got the impression that the medical community were no longer interested in HIV. This had been something that had happened in the past and there were more pressing issues now. The World Federation was concentrating on developing more services with and for countries in the 'third world'. There was a real mixture of attendees this year; it was difficult to get the balance of delegates right.

GRO-A said this was the first time he had attended a World Federation of Haemophilia Congress. He had found it huge and bewildering. Some of the medical sessions were very difficult to understand, but some of the psychosocial sessions were excellent. Ian had found the plight of most of the people with haemophilia in the world overwhelming.

Chris Hodgson reported that the Haemophilia Society had had a stand at Congress. Leaflets etc had disappeared within a very short time of opening. The contrast between the developed and underdeveloped world was very marked. The UK Society was actively involved in the Twinning Programme.

It was reported that GRO-A had been elected to the Executive Committee of the World Federation of Haemophilia. The Chairman and Trustees congratulated GRO-A on his election and wished him well in this additional and demanding role.

#### **14.02 Chief Executive's Report & Statistics**

Trustees asked that wording in Section 2 related to the Statistics Update be amended as the use of 'fortunately' might be misconstrued in the context used. This was agreed.

Trustees also asked that more statistical information be provided in time for a meeting with new Minister of State for Health, Hazel Blears, later in the year. It would be helpful to have a more detailed age breakdown of children and orphans. It was agreed that it was difficult to use death rate as a reliable method of forecasting future need, since after a period in which there had been one death in 6 months, there had been 3 deaths in a month.

#### **15.02 Financial Reports**

##### **(i) Monthly Grant Summary and Analysis of Grants**

The Finance Officer said that the new financial reports presented had concentrated on analysis of Single Grants and Regular Payments using the new cost centres and codes related to registrants' status which it was proposed to use in the Planning Model.

Trustees welcomed the new format for reports and thanked the Finance Officer saying that these were very helpful and informative.

It was observed that 25% of grants had been approved by Trustees; expenditure continued to exceed resources despite

hopes that with increased Regular Payments introduced in September 2000, demand for these would fall. One route to reduce Single Grant expenditure might be to cut back on payments made through the office.

## **(ii) Annual Grants Summary**

The Finance Officer said that there was a small discrepancy on the figures shown in the Report and those that appeared on the Draft audited accounts for the year to 31<sup>st</sup> March. This would be investigated and corrected.

## **(iii) Management Costs to 31.03.02**

It was pointed out that income was less than budget due to the PIA secondment coming to an end early in the last financial year. Receipts from Eileen Trust were also less than budget because these were based on percentages of Macfarlane Trust expenditure. Staff costs for both Trusts had been less than budget last year due to the gap between Jenny Jackson leaving the Trust and Carol Clisby taking up post of Benefits Adviser in September.

There had been an overspend on Management Costs again. This was partly due to the continuing effect of implementation of the Salary Structure Review in 1999/2000 but also because Trustees had approved replacement of computer hardware during the year. The auditors had suggested that the deficit be written off as a charge on the Trust fund. Trustees did not agree to this and asked that the matter be progressed with The Department of Health, as The Department had been asked to meet the excess salary costs resulting from the Review last year; as yet no response had been received.

## **(iv) Investment Report**

The value of investments was considerably down with very significant 'unrealised losses' in the year ended 31.03.02. The Department of Health had given a further top-up grant of £2.25 million at the end of March. This money had been placed in the Lloyds TSB high interest deposit account to await a decision on investing it, which should be made by the Trustee Board. The Honorary Officers recommended that with the continuing uncertainty in the Stock Markets, the money should remain on deposit for a little longer.

The Honorary Treasurer planned to visit Principal Investment Management very shortly. He would discuss options for investment of the new money with Principal and other investment advisers. There might be a need for Trustees to

review the present policy with regard to the equities/ fixed interest split of 70:30 adopted in 1998 and reviewed two years ago. The Treasurer also wished to look at expenditure patterns in order to see whether it would be possible to commit some funds to longer term investment. He would bring proposals to the Board Meeting at the end of July. Trustees would need to consider an alternative investment strategy and also look at other investment managers as possible alternatives to Principal and COIF.

**(v) Draft Final Report and Accounts – to 31.03.02**

The draft audited accounts were circulated to all Trustees. The Chairman's Statement and the Financial Report were still to be prepared by the Chairman and Hon. Treasurer. These would be sent to Trustees as soon as possible. Trustees were asked to refer comments on the accounts to the Chairman or Chief Executive within the next two weeks.

**16.02 Trustee Appointments Update**

At this point the Chairman introduced Robert Finch to the meeting. Robert was the first representative of The Department of Health to attend a Trustee Board meeting for many years. In the early days of the Trust, the Department had regularly been represented at Board Meetings and Robert's attendance at the meeting was a very welcome return to this practice.

Robert said that he had joined the Blood Policy Unit last August and was responsible for dealing with day to day matters related to haemophilia and other conditions. His was a new post and Robert hoped that as he would have more time to devote to these specialities, it would be possible for him to attend future Board meetings.

The Chairman reported that there had been two vacancies for Secretary of State appointed Trustees for some time; he had taken part in a selection panel that had met in April to make appointments to fill these vacancies. The panel had interviewed 6 candidates – five of whom had had careers in The Department. The sixth candidate had worked in Hong Kong where he had established and run a similar organisation to the Macfarlane Trust.

The interviews had been very interesting; they had been run on 'Nolan principles' with an Independent Adviser. The panel had agreed on a short-list of two candidates, with reserve and fall-back reserve candidates as well. The previous Minister, Yvette Cooper, had apparently queried the gender balance of the candidates and current Trustee Board. Proposals together with

her comments would now be passed to the Permanent Secretary who would review procedures before Department approval could be given. It was likely that there would be a further short delay. However, it was hoped that appointments would be made in time for the July Trustee Board Meeting.

It was reported that Dr Winter had received a letter confirming his re-appointment as Trustee for a further two-year period. He had accepted the appointment.

The Haemophilia Society had re-appointed Mr Chris Hodgson to serve as Trustee for one further year. Mrs GRO-A will be standing down as Trustee in December. This means that it will be necessary for the Society to identify suitable candidates to fill the impending vacancies towards the end of the year.

## **17.02 Department of Health Funding Update**

The Chairman reported that the Trust had received top-up funds of £2.25 million at the end of March 2002. The money had placed on deposit in the Lloyds TSB high interest account, as referred to in the Investment Report. The Department of Health had indicated that annual funding top-up for a further three years had been budgeted for. However, the sums in the budget did not include any increased expenditure that might be asked for as a result of projections based on the planning model, or on a more detailed analysis of the needs of widows and dependants.

The application for further Section 64 management funding had been submitted in September 2001. The Trust had heard that the full amount asked for would not be forthcoming in the current financial year, but as yet no precise information on the size of Section 64 grant in 2002/2003 had been received. It was likely that the award would be reduced by approximately £17,000. When the figure was known, the management budget for the year would be examined and a plan agreed to make appropriate savings in the current year.

## **18.02 Fertility Treatment Update**

Dr Winter reported that he had written to The Chelsea and Westminster Hospital, whose work in the field of sperm-washing and other fertility treatment for couples where one party was HIV positive was the most advanced in the UK. Whilst it was clear that treatment was safer and more reliable, the success rate was still not high and the treatment was costly. The question remained one of whether or not the Trust should fund such treatment.



Trustees needed to bear in mind both the current financial position of the Trust and whether or not the registrant's health would suffer if treatment was not made available. If the Trust was not supporting safe ways for couples to have a family, it could be argued that health was being put at risk. There were unfortunately many positive partners being supported by the Trust who were proof of the level of risk involved in 'unsafe methods' of becoming pregnant. Statistics showed that at least three treatment cycles were needed and even then the success rate was only about 30%

Fertility treatment was not an alternative to mainstream medicine in the way that complementary therapies were. Some health authorities were funding such treatment; others were not.

Dr Winter posed two questions:

'Would the Trust fund fertility treatment if the Health Authority would not?'

'Would the Trust fund fertility treatment after the Health Authority had funded three treatment cycles and these had been unsuccessful?'

Mr GRO-A said that most couples were successful in persuading health authorities to fund fertility treatment, but it was sometimes necessary to take the case to appeal. He suggested that the Trust might help registrants with the appeal process. GRO-A also pointed out that the additional costs of undergoing a course of treatment could be as high as £3/ 4,000. He believed that the Trust should not fund treatment but could make grants for ancillary costs of travel, hotel expenses etc.

After discussion it was agreed that the Trust should write to each Health Authority to find out what their policy was on funding fertility treatment for HIV positive couples. The Trust should also put pressure on the Department of Health to provide funding for fertility treatment for Trust registrants and should call upon the UKHCDO and the Haemophilia Alliance to support this move.

The Trust should be prepared to fund ancillary costs related to treatment and should also assist couples to apply for Health Authority funding and to appeal against decisions not to fund. GRO-A was prepared to assist with the appeals process. It was agreed that the Chief Executive would prepare a briefing paper for the next meeting of the Trustee Board in July and Trustees would take a final decision based on the paper at the meeting.

## **19.02 Partnership Group Update**

The Chairman reported that the February meeting of the Partnership Group had been better attended than the two meetings that had preceded it. Dr Mark Winter had updated the Group on the Haemophilia Alliance. Other issues discussed had included data protection, the Macfarlane Trust investment policy and fertility treatment.

Dr Winter said that he felt the discussion on the Haemophilia Alliance had not been a happy experience. Members of the Partnership Group were remorseless in their criticism of the Haemophilia Alliance. The way the Group operated was negative and critical and Dr Winter questioned whether the registrants should have any responsibility for the Trust's Investment Policy. He felt that the format of the Partnership Group was too open. There needed to be more structure. Collaborative projects where it could be demonstrated that Trustees and registrants were working towards a common goal would be more constructive.

The Chairman said that he would raise the purpose and format of the Partnership Group with members at their meeting on Thursday 30<sup>th</sup> May and would report back to Trustees in July.

## **20.02 Bereavement Project Presentation**

Mr Chris Hodgson introduced Joanna Fenning and Sylvie Boulay, the two bereavement counsellors who were working with the Trust to provide counselling and support to partners and families bereaved through haemophilia and HIV. Joanna Fenning then opened the presentation by summarising her involvement with the Bereavement Project. This had begun in the summer of 1999 with writing to all families who had been bereaved since the beginning of 1994. As a result of this mailing a group of people had been identified in the South East who wanted to get together for mutual support and counselling. The first meeting of the first bereavement group for partners had been held in the South East in January 2000; this had been followed by the establishment of a group for parents in the spring of that year. The two groups had developed well over the first year. In 2001 the partners had suggested that a residential weekend be held to allow other families to meet in a safe environment and identify more ways in which the Trust could help them come to terms with what had happened. The weekend had taken place in September 2001 and had been attended by more than 40 bereaved people supported by a strong team of counsellors and social workers. A further support group had started in the North West as a direct result of the weekend.



Sylvie Boulay spoke of her introduction to the Project just prior to the residential weekend last autumn. She had found the experience very moving, and had subsequently worked with Joanna to facilitate the North West support group and was also seeing a number of people for counselling on a one to one basis.

Trustees were advised that although the Trust had applied for Section 64 Project funding from The Department of Health for 3 years in succession and although The Department had acknowledged the value of the Bereavement Project, funding had been refused due to lack of money in the 'Blood Policy' allocation of Section 64 funds. Trustees were asked to fund the work of the Bereavement Project for a further year. Costs would include another Residential meeting in the autumn and financial support to groups in the South East and North West.

Trustees agreed to fund the Bereavement Project for a further year. Likely expenditure would be in the order of £21,000. Trustees also asked for an update presentation in a year's time and suggested that this might take place earlier in the year so that any continuing funded could be included in a Trust Fund budget for the year. The Chairman said it was impressive that so much could be done for bereaved families for so little cost.

## **21.02**

### **Applications and Cases**

#### **(i) Application for a secured loan – 1512**

A loan of £4,500, to be based on an exchange of letters agreeing that the loan would be repaid when the house was sold or when it was no longer needed by the registrant or his family, was approved. However it was pointed out that although a Moving Home grant could be paid in this case, a second Setting Up Home grant would not be appropriate.

#### **(ii) Application for a flexible secured loan – 1226W**

An application for a flexible loan to enable a widow to repay capital as well as interest on her mortgage was refused on the basis that Trustees felt unable to commit their successors to expenditure of this nature for a period of up to 20 years. Such a loan would have set a precedent that would be impossible to follow in similar cases.

#### **(iii) Cases**

Ten cases were considered including two appeals against earlier decisions not to pay a second Setting Up Home grant. Both appeals were turned down on the basis that the Setting Up Home Grant had originally been intended to help registrants setting up home for the first time. The only reason for making a second grant that could be considered was when family breakdown made it necessary for a home to be set up once more.

Three grants totalling £4,315 were approved. Additional information was asked for in a further two cases. An advance of Regular payment was agreed in another case and two grants were refused.

## **22.02**

### **Social Worker's Report**

The Social Worker's Report was accepted. A recommendation to ask for receipts for all items costing £250 or more was approved. This requirement will be spelt out in the next Trust Handbook.

Trustees also noted the recommendation for more assistance for families caring for orphans and asked for a detailed report on the circumstances of each family for the next meeting.

## **23.02**

### **Benefits Adviser's Report**

The Benefits Adviser's Report was noted. Trustees welcomed the opportunity to meet Carol Clisby and were pleased to learn that she and Claudette Allen sometimes made joint visits to registrants.

## **24.02**

### **Any Other Business**

#### **(i) Date of next Meeting – 30<sup>th</sup> July 2002**

It was noted that the next meeting would include final approval of the audited accounts for the year ended 31.03.02, consideration of proposals related to fertility treatment and a review of orphans supported by the Trust.

There being no further business, the meeting closed at 3.50pm.