

## MACFARLANE TRUST

Minutes of a Meeting held on 24<sup>th</sup> April 2001  
At Alliance House, 12 Caxton Street, SW1H 0QS

**PRESENT:** Mr Peter Stevens Chairman  
Mr Gordon Clarke Hon. Treasurer  
Mrs Elizabeth Boyd Trustee  
Mr **GRO-A** Trustee  
Mr Chris Hodgson Trustee  
Mrs Patricia Latimer Trustee  
Dr Mark Winter Trustee  
Mr Anthony Yeaman Trustee

**APOLOGIES:** There were no apologies for absence.

**In Attendance:** Mrs Ann Hithersay Chief Executive  
M/s Claudette Allen Social Worker  
Mr Rodney Shepherd Finance Officer

### Introductions and Welcome.

The Chairman introduced two new Trustees:

**GRO-A** and Gordon Clarke had recently been appointed by The Haemophilia Society. They both brought new skills and experience that was welcomed by the Trust at this time.

As a 'user Trustee' **GRO-A** could help the Trust improve its understanding of the changing needs of registrants as well as bringing valuable experience to the Board. **GRO-A** said that most of his career had been spent as a Health Service Manager with responsibility for Finance and Strategic Planning. He had worked in this capacity until forced to take early retirement on grounds of ill-health. **GRO-A** was currently involved in Self Management training for people with haemophilia, HIV, HCV and other illnesses. He looked forward with enthusiasm to acting as Trustees of the Macfarlane Trust.

Gordon Clarke, currently Chairman of the European Haemophilia Consortium and Manager of the Belfast Children's Hospital; one time Vice Chairman and Treasurer of the Haemophilia Society, had been appointed as one with relevant skills to take on the role of Treasurer of the Trust. Gordon hoped to bring his strategic and financial experience to the Trust and also felt that the role would give him insight into the needs of those people with haemophilia who had contracted HIV through their treatment in other parts of Europe. Gordon believed that the Macfarlane Trust was unique and said that as far as he knew no other country still had an organisation of its type supporting people in this way.

Trustees welcomed the new appointments.

#### **01.12 Minutes of the Meeting held on 23<sup>rd</sup> January 2001**

The Minutes of the Meeting held on 23<sup>rd</sup> January 2001 were approved as a true record.

#### **01.13 Matters Arising from the Minutes**

00.53 The Chairman reported that he had approached the Royal Pharmaceutical Society for further information on prescription charging policy. A guidance note was to be sent to the Trust.

#### **01.14 Appointment of Honorary Treasurer**

The Chairman said that at the end of last year he had met with the Chairman and Chief Executive of The Haemophilia Society to ask them to seek out potential candidates for the role of Honorary Treasurer at the Trust. As a result, Gordon Clarke had become a Trustee. The Chairman asked Trustees to confirm the appointment of Gordon Clarke as Treasurer with immediate effect. The appointment was approved unanimously and Gordon was welcomed to his new role.

#### **01.15 Chief Executive's Report and Statistics**

The Report was noted. The Chief Executive reported that the response to the 2001 Census form was proving good; to date 635 forms had been sent out and there had been 342 replies. Whilst it was unlikely that many more forms would be returned, there would be some follow up of those applying for grants who had not responded to the Census. They would be encouraged to do so as part of the grant application process.

In the ensuing discussion it was suggested that a list of 'non-responders' could be sent to Centres, to see if staff could offer assistance with completion of the form. This will be done as soon as feasible.

The Report also included a note on requirements of the SORP 2000 for Charities. In particular, the SORP required Trustees to make a statement about the Risk Assessment Process in the charity. As the Trust has no formal 'risk assessment process', it would not be possible to fully comply with the requirement this year. However, the Chairman said that he hoped Trustees would agree to establish a small working party to look at this and other strategic issues and report back to Trustees later in the year.

The Chief Executive's Report also referred to the Charity Act 2000 which consolidates much previous legislation related to charities and requires charity Trustees to exercise a new duty of care in relation to investments. Again, the Chairman felt that the Working Group would be able to consider the implications of the new Act and recommend appropriate action to the Trustees.

## **01.16 Finance Officer's Reports**

### **(i) Monthly Grants Summary**

It was noted that the number and value of Single Payments had increased in the final quarter of the financial year. This was a cause for serious concern. Spending at the level incurred in this quarter could not be sustained. It was important to ask the question 'would this person's health suffer if the payment was not made?' and to relate payments more strictly to health needs only. It was also noted that the plight of widows and dependant families was placing an increasing burden on the Trust. A full review of their position should take place as a matter of urgency. It was difficult to create a notional 'budget' for Trust payments, as these were related to prevailing needs. A paper would be prepared for the next full meeting of the Board.

Regular Payments also showed a marked increase in value in the second half of the year, following higher payment levels introduced in 2000 as a result of recommendations made by the Payments Review Group.

### **(ii) Management Costs to 31.03.01**

Trustees noted that there would be a deficit on management costs at the end of the year. The deficit was due to overspends related to staff costs following implementation of the Miller Brand Report on staff salary structure and pay, carried out in 1999/2000. The matter had been raised with The Department of Health and had also been referred to in last year's audit of the Trust's Accounts. The Section 64 Core Grant allowed for no leeway in management expenditure, making unforeseen changes in expenditure difficult to deal with. It was hoped that the matter would be resolved by a supplementary Section 64 Grant in 2001/2002 as discussed with Charles Lister at The Department of Health in April .

### **(iii) Investment Summary**

The Chairman reported that the Trust had received a further top-up payment of £2,500,000 at the end of March 2001. The funds had been temporarily placed in the High Interest Account at Lloyds TSB. The Chairman and Hon. Treasurer recommended that the new funds be placed with COIF, since the top-up grant made last year had been placed with Principal Investment Management Ltd. Trustees welcomed the new grant and agreed that funds should be invested with COIF on this occasion.

The Investment Summary was noted. It was agreed that the Hon. Treasurer would provide a full review of investments for the next Board Meeting in July.

### **01.17 Draft Final Report and Accounts**

The Chairman had prepared draft text for the Chairman's Statement and the Trustees' Report. He asked that any comments or amendments should be sent to him or to the Chief Executive within the next two weeks. The Annual Report and Accounts would look similar to earlier years. The Financial Review would be prepared by Gordon Clarke as Honorary Treasurer and draft accounts would be circulated as soon as these were ready. The Auditors would be coming during the first week in May and Final Accounts would be ready for presentation to Trustees at their next meeting.

### **01.18 Report on a Meeting with the Department of Health**

The Chairman reported that he, Gordon Clarke and Ann Hithersay had visited The Department at the beginning of April. Issues raised had included consideration of a revised brief for the Consultancy exercise. The original brief had been jointly agreed last September but due to lack of funding, the project had not been carried forward. An in-house management accountant had now been identified to carry out the work. The new brief was a much fuller 'root and branch' study of the Trust and how it works. This had come as a surprise to Trust representatives at the meeting. The Chairman had asked for the brief to be modified to include the original objectives, stated by Lord Hunt at a meeting in April 2000, which centred on looking at grants made by the Trust that might be met by other statutory authorities.

The issue of new Trustees was also raised and Charles Lister, the Trust's contact at the NHS Executive, had explained that Nolan principles were to be used in making Trustee appointments in future. Notification of the need for two new Trustees had been circulated to recently retired senior Department staff. The appointment process would include panel interviews with short-listed candidates. The Chairman had been invited to participate in the interview process and be a panel member. Interviews would take place in late May and early June.

The Chairman had also reported on the Core grant overspend related to staff salaries. Charles Lister had pointed out that the Trust should have advised The Department before implementing recommendations made in the Miller Brand Report. It was hoped that the matter could be resolved in the coming financial year.

The Chairman had asked whether there had been a decision on the outstanding matter of the ex-gratia payment made to John Williams, the Trust's previous Chief Executive following his retirement at the end of 1997. The payment had been made in lieu of pension contributions not made but the National Audit Office had felt that the payment should not have been made from Section 64 funds. Trustees had made the payment in good faith, following a meeting between Clifford Grinsted, Deputy Chairman of the Trust at the time, and a representative of The Department. Mr Grinsted had not been aware of any

problem arising from the proposed payment and it had been made to John Williams in April 1998.

It was planned to hold a further meeting with Charles Lister in late June and the Chairman had also asked for a meeting with the Minister before the House of Commons rose for the Summer Recess in late July.

#### **01.19 Investment Policy Review**

The Investment Policy Review, which had been raised as an issue last autumn, had been put on hold until a new Treasurer had been appointed. Following the requirements of the Trustee Act 2000 and the new charities SORP, such a review now needed to be addressed as soon as possible. Gordon Clarke had agreed that he would prepare the ground for a review within the next three months. He hoped to give a progress report to Trustees at their next meeting in July.

#### **01.20 Review of Trust Strategy**

The Chairman said that the Strategic Review had enabled the Trust to review ways in which registrants' needs had changed but a number of things had been left unresolved. Some of these had been identified at the Trustees' Update Day last November. Raising the level of Regular Payments had imposed considerable financial constraints on the Trust, making it difficult to address these outstanding issues. The needs of widows and dependants; assisted conception; alternative therapies and the educational and lifestyle needs of registrants had all become apparent. However, Trust funds were limited and it would be necessary to look carefully at these issues and prioritise them before seeking to fund such areas of work more fully than at present. The Chairman proposed that a small working group be set up to assist staff look at these issues and bring recommendations to a future Trustee Board. He proposed that the group consist of Anthony Yeaman, Gordon Clarke and **GRO-A** because they would bring fresh thinking to the Board and were not attached to any Centre.

Trustees approved the proposal and the group agreed to meet with the Chairman and Chief Executive to plan how they would develop the work.

#### **01.21 Partnership Group Report**

The Chairman reported that the Partnership Group had met in February. At the meeting it had been agreed to throw the group open to any registrant wishing to participate. If numbers became too great for the group to be effective, it would be necessary to revisit the issue of 'membership constituencies' once again. However the Chairman felt that as the prime aim of the Partnership Group was one of communication, it was important that those who wished to be involved could do so. The Group was due to meet again in May.

## **01.22 Support Services - Budget Proposals**

### **(i) Bereavement Project - Increased Funding and Residential Weekend.**

Two Section 64 Project Grant applications had been made to support the Bereavement Project; unfortunately both had failed due to lack of funding in The Department of Health Section 64 budget. The Bereavement Project had started in summer 1999 with a letter to all families bereaved over recent years. As a result of responses, a 'pilot support group' had been started in the South East at the beginning of 2000. The Group had continued to meet regularly since then, and a second group for parents had also started in the region.

A proposal for a residential weekend for bereaved families had arisen from the partners group, and this also had been included in the Section 64 application submitted in 2000. Letters inviting those interested in participating in such a weekend had been sent out last September to families bereaved since 1994. Fifteen families had shown an interest in attending, a number of which included distressed teenagers and young people.

Two proposals related to the Bereavement Project were presented to Trustees: one to support development of further support groups in the Midlands and North West, and another to cover the cost of a Residential Weekend for around 35 people in the autumn of 2001. After much discussion it was agreed that proposals met needs covered by the Trust Deed and funding of £5,000 to develop support groups and £7,000 towards the Residential Weekend were approved.

### **(ii) Young People's Weekend, Manchester 2001.**

The previous two weekends for young people, jointly organised by the Trust, The Society and the Birchgrove Group, had been fully funded by grants arranged by The Haemophilia Society. This year Babs Evans, HIV Co-infection worker at The Society, was applying to the Trust for funds to cover incidental expenses related to the proposed Weekend. A grant had been secured from the Elton John Foundation to cover most of the costs, but incidental costs up to a maximum of £2,000 were needed to cover registrants' travel and other expenses.

Trustees had welcomed the Report of the previous Young People's Weekend and felt that such weekend were of great value to those involved. The grant was approved and it was agreed that amounts would be applied as individual grants to those registrants taking part in the Weekend.



**(iii) Focus Group for Partners.**

Following a successful weekend for Partners, held in June 2000 and organised by the Trust and The Society, a number of issues had been identified as continuing needs for partners of those with haemophilia and HIV. Babs Evans had reported on these to the last meeting of the Partnership Group and had proposed holding a Focus Group for 10 partners, representing the diverse needs of this group, in order to identify more precisely their needs and bring forward recommendations to the Trust and The Society. A request to fund the cost of a residential Focus Group meeting at a central location was put to Trustees.

After discussion, it was agreed that this proposal also met the aims of the Trust Deed and that funding could be met as per capita grants to individuals participating in the Focus Group. A grant of £2,130 was approved.

**01.23 Applications and Cases**

Trustees considered nine applications for Single Grants. Grants to five registrants, totalling £4,119 were approved. Additional information was sought for two more cases. The Chairman agreed to write to Abbey National about another case and Trustees decided against a change of policy related to sperm washing in another case. A further case for an increased central heating grant was refused. However it was agreed that a loan, secured by a charge on the property if necessary, could be advanced to the family.

Trustees accepted that the wish to have children was an important issue and agreed to seek further information and to refer the present case back to the Health Authority. Assisted conception was one of the issues identified at the Trustee Update Day last year, and one that the working group looking at Trust Strategy would consider and make further recommendations to Trustees in due course.

**01.24 Social Worker's Report**

The Social Worker's Report was noted.

**01.25 Benefits Adviser's Report**

No Report had been circulated.

**01.26 The Chairman's Visits to Centres**

The Report was noted.

## **01.27 Any Other Business**

### **(i) Coroner's Inquests**

It was reported that, whereas in the past there had been guidance from the Westminster Coroner, Paul Knapman, to the effect that Coroners Inquests for people with haemophilia and HIV were no longer necessary, it appeared that there had been a recent change of view on this subject. At least 6 inquests had taken place following such deaths in the past year. In a number of cases a verdict of 'misadventure' had been recorded and the Coroner had, on two occasions, mentioned 'negligence'. Coroners Inquests caused families great suffering. Publicity, particularly where the death was of somebody living in a small community, could be devastating.

It was agreed that the Anthony Yeaman and Peter Stevens should seek a meeting with the Westminster Coroner to clarify the current position and seek his help, as given in the past, to issue guidance relating to the death of people with haemophilia and HIV, through the Coroner Association.

**There being no further business, the meeting closed at 3.20pm.**