

MACFARLANE TRUST

STRATEGIC REVIEW - RESPONSE GROUP

Minutes of a Meeting of the Response Group held on Monday 24th May 1999 at Alliance House, 12 Caxton Street, SW1.

PRESENT:

The Reverend Prebendary Alan Tanner OBE, Chairman
Mr Clifford Grinstead, Deputy Chairman
Mr [GRO-A] Trustee
Mr Chris Hodgson, Trustee
Mrs Patricia Winterton, Trustee
Mr John Williams, Trust Administrator, retired

In Attendance:

Mrs Ann Hithersay, Chief Executive
Ms Karin Pappenheim, Chief Executive, Haemophilia Society
Mr [GRO-A] Haemophilia Society HIV Worker

1. Apologies for absence:

Apologies for absence were received from the following members of the Group:

Mr Tim Hunt; Mr [GRO-A]; Dr Mark Winter; Ms Fran Dix.

2. Minutes of the Meeting held on 11th March 1999

The following amendments were made:

Min 3 – Involvement of Registrants

It was pointed out that Mr [GRO-A] *represented those people registered with the Trust.* That he was also a member of the Birchgrove Committee and a Trustee of the Haemophilia Society were seen as an added bonus; however he did not represent either of these bodies in his membership of the Response Group.

Min 4 – Joint Recommendations

It was pointed out that the role of the Partnership Sub-group would be *'to make proposals for planning implementation of the Joint Recommendations...'*

Min 5 – Fertility Treatment

[GRO-A] said the organisation referred to was The *British* HIV Association..

Subject to these amendments being noted, the Minutes were approved as a true record.

3. Matters Arising from the Minutes

Min 3 Distribution of the Report – World Federation of Haemophilia

It was confirmed that a copy of the Report had been given to Mrs GRO-A of the Haemophilia Society of Australia, to take to a recent meeting of the World Federation. The Group felt that a further copy should be sent with an accompanying letter to the World Federation.

Min 4 Payments and Fertility Treatment

GRO-A reported that he had approached the National Aids Trust with regard to 'the extra costs of living with HIV', but they had no information on the subject.

GRO-A also referred to BHIVA Treatment Guidelines that were currently being drafted, and said that he hoped that the Guidelines would cover fertility treatment for people who were HIV positive.

5. Reports from Subsidiary Groups

(i) Partnership Group

The Partnership sub-group had held its first meeting on 14th May. The role of the group included agreeing tasks and proposals that would result in planning and implementation of the joint recommendations included in the Strategic Review Report.

The first task of the group would be to organise Feedback Meetings for registrants to update them on the results of the Strategic Review. Feedback Meetings would be held in Manchester and London, and after these had taken place, the Group would review the position to see whether further Feedback meetings would be required. The first Feedback Meeting would be held on 21st June in Manchester.

The Partnership Group had also set up task groups to prepare preliminary information on other joint recommendations contained in the Review. The Group would meet quarterly, and the next meeting would be held on 23rd September 1999.

(ii) Payments Review Group

The Payments Review Group had met for the first time on 20th May 1999. John Williams, the Trust's first Administrator, had joined the Group, and provided valuable information about the origins of Regular Payments.

A further 'special payment' had been discussed. Some members of the Group had felt that some registrants, particularly those who had been children at the time when the earlier payments had been made, should be given another payment. The Chairman had pointed out to the

Group that he was of the opinion that a request for a further 'capital payment' from Government at this time was 'a non-starter'. This was mainly because of the recent refusal by The Secretary of State to offer any kind of payment to those with haemophilia who had become infected with hepatitis C through their treatment. In the light of this decision, it would be unwise to ask for a third payment at this time.

The Payments Review Group had suggested that the Trust could make a one-off capital payment to each registrant from Trust funds. However, if this was to be contemplated, it would be necessary to ask for guidance from Paisner & Co as to whether or not the Trust Deed would allow such an 'across the board' payment to be made.

Members of the Strategic Response Group discussed issues reported and added that a Public Enquiry was currently underway in Ireland, looking into aspects of HIV and other blood borne infections that had occurred as a result of treatments given. A similar Enquiry was being sought in Scotland as well.

It was also pointed out that the last Regular Payment Review had taken place in 1996. It was therefore likely that a further increase was needed. However Single Grants were increasing in number and range, and the Payments Review Group needed to look at both grant areas before making recommendations to Trustees on the best way forward to meet increasing needs of registrants.

In particular, it was felt that there was growing evidence of the increase in costs of terminal care. Whilst these costs would normally be covered by Health or Social Services, where additional top up was required from the Trust for terminal nursing care, the period that this was needed for was extending. It was agreed that information should be sought from Centres about this area of need.

(iii) Conferences Working Party

It was reported that two conferences were planned for 1999: A Weekend for young people, to be held in Brighton in June, and a Positive Haemophiliacs weekend to be held in Bath during the late Summer. The Working Party would be meeting in June to start planning the Partners and Carers Weekend which, it was hoped, would take place early in 2000.

The Birchgrove Situation

Whilst not on the Agenda, the Chief Executive of the Haemophilia Society felt that the Strategic Response Groups should be aware of a possibly changing situation with regard to the relationship between the Haemophilia Society and the Birchgrove Group.

Up until now the Birchgrove Group had been a 'Special Interest Group' of the Haemophilia Society. The Group had recently been considering whether it might be in their best interests to seek more independence status. If this took place, it could be regarded as a positive move, and could streamline the way in which organisations worked together. However a change would almost certainly mean that the group would need to seek independent charitable status. It was understood that at present membership of the Birchgrove Group stood at:

Wales: 30 Manchester: 40

There was also a mailing list of some 300 names. It was understood that only about 50% of Macfarlane Trust registrants were in touch with Birchgrove Group.

Karin Pappenheim was talking to the Birchgrove Group about banking arrangements because the Society had recently changed its bankers, but the Birchgrove Group did not wish to change their bank. Most of the Welsh Branch of the Birchgrove Group's activities were funded through 'Wales specific funding'. The recent devolution of government in Wales and Scotland would have an impact on UK organisations where specific funding arrangements would change. The Haemophilia Society had set up a 'devolution working party' and Birchgrove Group was represented on this.

5. Future Action

- (i) Meeting with Baroness Hayman, Minister of State for Health
The meeting with Lady Hayman was due to take place on 17th June 1999 at Richmond House. The team that would represent the Trust would be led by the Chairman, and would include Mr Grinsted, Mr Hunt, Dr Winter and the Chief Executive. A first briefing meeting had taken place on 20th May 1999.
- (ii) A Budget for the Strategic Response Group.

No specific budget had been included for meetings of the Group. The Section 64 Project Grant had included funding for Feedback Meetings for registrants, but no funding had been applied for to cover implementation work.

The Chairman felt that Trust funds were sacrosanct and should not be used to meet the cost of meetings connected with implementation of the Review. The Chief Executive was concerned that the Management Budget could not bear the additional cost of further meetings of the Strategic Response Group and the Subsidiary Groups.

It was agreed that the Groups should continue. The Chief Executive and Chairs of the Subsidiary Groups would work out costings for meetings during the current financial year. If necessary, the Trust might apply for Section 64 Project funding for implementation of the Review.

Date and Place of next Meeting:

1st September 1999 at 2.00pm at Alliance House, 12 Caxton Street SW1.