



THE MACFARLANE TRUST

Alliance House 12 Caxton Street, London SW1H 0QS

Tel: 0171-233 0067 Fax: 0171-233 0839

Our Ref: 1004CL.DoH.AH

Charles Lister
NHS Executive
Wellington House
135 - 155 Waterloo Road
London SE1 8UG

4th October 1999

Dear Charles

**Re: Meeting between representative of the Macfarlane Trust and the NHS
Executive on 12th October 1999 at Wellington House.**

I enclose a note of the issues that will be brought to our forthcoming meeting next week by the Trust.

Perhaps, if there are issues you would like to bring up when we meet, you could give me a call, so that we can come prepared.

I look forward to our meeting,
With best wishes
Yours sincerely

GRO-C

Ann Hithersay
Chief Executive



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DEPARTMENT OF HEALTH – MEETING WITH CIVIL SERVANTS. 12.10.99

Issues for Discussion.

1. Outstanding issues from June Meetings:

Financial matters:

- (i) Section 64 Core Grant:
No formal letter confirming Section 64 Core Grant for current financial year and years 2000/2001 and 2001/2002.

Current 'interim payment' of £90,000, made in September, is based on previous year's Core Grant.

The delay in making Core Grant payments has meant that administrative expenditure has been met from the General Fund, and interest to the fund has been lost over the first 5 months of the financial year.

- (ii) Payment for costs of replacing outdated computer equipment – previously referred to as Y2K Expenditure.

Lady Hayman agreed that this payment should be made; however to date no payments have been received.

- (iii) Top-up Requirements – General fund

Confirmation that the Trust has asked for two top-up payments over the period 1999 – 2004, and these amounts have been agreed in principle by the Department as:

£2 million in 2000
and £3 million in 2002

Progress Reports:

- (i) Implementation of Recommendations:
Reports on work of Partnership Group and Payments Review Group.

Partnership Group:

Organisation of two 'Strategic Review Feedback Meetings' in London & Manchester.

The Partnership Group has met twice.

The Group includes representatives of The Haemophilia Society; the Birchgrove Group and other registrants, as well as Trustees and staff of the Trust.

Issues raised include:

- a) greater involvement of registrants in Trust policy and decision-making
- b) possible provision of computers for all registrant to allow them to access web-sites with up-to-date treatment information and other means of support
- c) more financial help for families of those who were single or children when initial Special Payments were made, but now have family responsibilities. A group of registrants feel strongly that a 'third Special Payment' should be made by government, in line with similar payments in Ireland and Canada.
- d) The Trust should be represented on the Haemophilia Alliance, in order that the specific needs of those with haemophilia and HIV are adequately considered.

The Payments Review Group

The Group has met twice, and has gathered information on trends in grant payments, together with feedback on new areas of financial need. Recommendations from the Group will go to Trustees at their next meeting.

Proposed action includes increasing regular monthly payments to registrants in line with inflation; increasing payments to those receiving the basic rate of £80 per month (89 people) and increasing payments to widows with dependant children from £73 per month to £100 per month (81 people).

The Group has also determined to approach computer companies and Trusts to find a way to provide registrants with computers so that they can access the Internet.

(ii) Debts and Loans

As reported in the Strategic Review, a small but significant number of Trust registrants are experiencing very severe financial problems. The Trust is continuing to explore ways to assist in these cases. As mentioned at our June meeting, options include the possibility of making a loan, as an 'advance of a

proportion of regular payments', repayable over a period, to alleviate extreme cases.

In the past, the Trust has made larger loans based on taking an 'equity share' of the registrants' property, to reduce serious indebtedness where homelessness is a likely outcome if such action is not taken. This practice was discontinued a year ago, and is being reconsidered by the Trust at the present time.

An Independent Financial Adviser provides specialist advice and negotiates debt management packages where appropriate. This service is funded by the Trust within guidelines agreed.

(iii) Trustee Replacement

Mr Kenneth Bellamy, Department of Health appointed Trustee, retired last May. A replacement needs to be appointed as soon as possible.

2. New Issues

- (i) The forthcoming retirement of the Chairman, The Reverend Prebendary Alan Tanner in March 2000, and appointment of a successor.
- (ii) Retirement of the Deputy Chairman, Mr Clifford Grinsted in July 1999, and appointment of Mr Nicholas Lawson as Honorary Treasurer
- (iii) The role of Mr Clifford Grinsted as Consultant until 31.03.00.
- (iv) The forthcoming resignation of Mr Tim Hunt as Social Work Trustee. Replacement Nomination required from Department of Health. We have discussed the possibility of appointing Shiela Bowyer of the haemophilia centre in Glasgow.
- (v) Bereavement Project Submission.
- (vi) Possible Relocation of Trust Office
- (vii) Funding of Complementary therapies as alternatives, or additional to traditional treatments for those with haemophilia and HIV. The Trust believes that the Department of health should make such therapies available to patients under the National Health, and should not expect treatments to be funded by the voluntary sector.

Ann Hithersay
Chief Executive
4th October 1999

GRO-C

Copies to: The Reverend Prebendary Alan Tanner, Chairman
Mr Peter Stevens
Mr Nicholas Lawson, Honorary Treasurer