



THE MACFARLANE TRUST

Alliance House 12 Caxton Street London SW1H 0QS

Tel: 0171-233 0057 Fax: 0171-233 0839

Our Ref:1028DOH.AH

28th October 1999

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

Dear Charles

I am writing in response to our meeting with you and Dr McGovern on 12th October 1999. I am also enclosing a copy of the letter I sent to you prior to our meeting, as it identifies the issues we proposed to raise.

(i) Section 64 Core funding

This issue was discussed at the meeting. We pointed out that, as yet, we had not received formal confirmation of the Section 64 Grant applied for in September 1998, and intended to cover the period 1999 – 2002 inclusive : or three years of Core Funding for the Trust.

It was agreed that you would write to confirm the grant within a week of our meeting. It was also agreed that our third Quarter's funding would be due shortly. We normally receive this payment during the first week of November.

(ii) Funding to meet costs of outdated computer equipment

This issue was raised again at our meeting, and it was said that The Department could not identify a 'natural source of funds' to meet this cost. It was suggested that if the top-up payment required for 2000 was paid to the Trust early, interest arising from the capital, for the period between its receipt and the beginning of the next financial year, could be set against the outstanding costs. As interest rates are low at present, and the money has yet to be received, it is unlikely that this solution would fully cover the shortfall, unless the top-up amount was increased to £3 million.

(iii) Funding to meet additional needs identified by the Strategic Review

We pointed out at the meeting that the Strategic Review had identified that in order to meet current levels of payments to those registered with the Trust, top up of £2 million would be required in 2000, and a further £3 million in 2002.

The Review also referred to new health related needs arising from living with haemophilia, HIV and hepatitis C, and advances in treatment of these conditions. We suggested at the meeting that if the Trust was to honour its commitment to meet needs related to living with HIV for our slowly reducing number of registrants (455 today), and continue to support dependant children until they reach maturity, further funding will be required.

Some preliminary work has been done to identify what the cost would be of increasing regular payments in line with inflation, and the additional costs of looking at specific groups. We are also looking in more detail at specific health related costs, often arising from adverse reaction to treatments, to see what the cost would be to the Trust if these were to be met as specific grants. Examples of such costs would include clothing for people who lose or gain massive amounts of weight; replacement bedding; extra washing powder and toilet paper...

We have advised those registered with the Trust that monthly payments will be increased from January 2000, to reflect inflation since the last increase in the Spring of 1996. However, this increase will not meet new needs, and our Payments Review Group is still looking at how best to respond to these.

(iv) Strategic Review Up-date

We reported to you on the work of the Partnership Group, which includes a large number of Trust registrants. We referred to a growing dissatisfaction amongst the younger registrants, who because of their age at the time the second 'Settlement Payments' were made in 1991, received substantially less than those who were older and married, purely because of their age. We reported that it was possible that this group of younger men might seek a further capital payment to redress the situation.

The Chairman pointed out that people with haemophilia who contracted HIV through their NHS treatments remained 'a special case' for help. He referred to Lady Hayman's assurances last Summer that Government continued to recognise this.

We also reported on the work of the Payments Review Group, referred to above, and mentioned that the Trust was working with other

organisations in order to help meet needs that were outside the Trust's obvious remit.

(v) Debts and Loans

The Chairman reported that the Trust had sought advice from Solicitors to vary the Trust Deed to enable loans to be made to those registered, where poverty and debt seriously threatened their health or their home.

Trustees approved this Variation at their meeting on 19th October 1999.

(vi) Trustee Replacement

We discussed the replacement of Kenneth Bellamy, who retired last May, and the replacement of Tim Hunt, who resigned with effect from 19th October 1999.

It was agreed that The Department would seek to replace Mr Bellamy with a similarly qualified retired civil servant. Two names were suggested as possible replacements for Tim Hunt.

We look forward to learning who the new Trustees will be and when they are likely to be able to take up their appointments.

(vii) Retirement of the Chairman

The Reverend Alan Tanner, Chairman of the Trust, advised you that he would be retiring with effect from the end of March 2000. The Chairman introduced Mr Peter Stevens as his replacement. Mr Stevens was formally elected Vice Chairman at the Trustees Meeting on 19th October 1999.

The Chairman also introduced Mr Nicholas Lawson as Honorary Treasurer of the Trust, and advised that Mr Clifford Grinsted would be acting as 'Honorary Consultant to the Trust' until the end of March 2000.

(viii) Bereavement Project

You confirmed that our Project application had been received, and that a decision was likely early in 2000.

(ix) Complementary Therapies

The Chairman said that the Strategic Review had recommended that treatment with 'complementary or alternative therapies' for people with HIV and haemophilia should be readily available on the NHS. These treatments were valued by many. Some people, particularly those unable to tolerate any combination therapy, were finding alternative therapies 'the only thing that kept them going'. Because NHS funding

for alternative and complementary therapies was very patchy, the Trust was often being asked to fund these treatments. The Chairman felt that these treatments should not depend upon the availability of funds through the voluntary sector.

Dr McGovern said that there was a group within the NHS that evaluated complementary therapies, and referred us to Professor John Nicholl at Sheffield University, and mentioned that Gordon Brown was the civil servant dealing with this area. Perhaps you could advise where Gordon Brown is based.

Trustees have suggested that I write to you now, since, as yet, we have not heard from you following the meeting. If you would like further information on issue raised at the meeting, or in this letter, do please call.

With best wishes
Yours sincerely

GRO-C

Ann Hithersay
Chief Executive

Encs: letter from AH dated 4.10.99

Letter from John Williams to Christine Corrigan dated 24.10.97

Cc: Dr Mike McGovern – NHS Executive

The Reverend Prebendary Alan Tanner OBE, Chairman
Mr Peter Stevens, Deputy Chairman
Mr Nicholas Lawson, Honorary Treasurer