



THE MACFARLANE TRUST

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4th September 2003

Dear Dr Hay

Thank you for your letter of 29th August about the Haemophilia Database. I was very surprised by some of your findings! In particular that there are 2 patients registered with the Trust who have consistently tested seronegative. As far as I am aware, all registrations made in the early days were of patients who had been confirmed to the Trust as being seropositive by their Centre Directors. I believe that amongst our archives there will be registration cards for all these patients. Perhaps you could let me have the names of these two patients so that this can be checked. Perhaps you could also let their Centre Directors know, as if these people believe they are HIV positive when they are not, it would be good to let them know of their true status.

Our latest two registrants, one deceased in 1997 and one still alive but with von Willebrands rather than haemophilia, who 'slipped through the net', may well not have been known to you until now. It has taken some time to gather records in both cases.

It would also be very useful to have names of the 70 deceased patients not recorded on the Trust's database. This is a large number of people not to be recorded and we need to investigate why and try to trace their families. Even if these patients died before the Trust was set up, payments should have been made by Government to their families. We will certainly pursue the matter on their behalf.

I suppose that we also should be pleased that the discrepancy is not greater; however, I am very disappointed that it is so large! I think that The Department of Health will also be alarmed at the prospect of making payments to the families of 70 new eligible beneficiaries of the Trust!

I look forward to hearing from you again soon.

With best wishes
Yours sincerely

GRO-C

Ann Hithersay
Chief Executive

Ccs: Peter Stevens, Chairman; Dr Mark Winter, Trustee