

# Central Manchester and Manchester Children's University Hospitals



NHS Trust

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Miss K Jones  
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CRMH/tah

29 August 03

Ms A Hithersay  
The Macfarlane Trust  
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12 Caxton Street  
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Dear Ann

I am very grateful to you for sending us your list of patients with Haemophilia who have died and who were HIV positive so that we could reconcile with the National Haemophilia Database and identify any potential discrepancies.

I thought you would be interested to hear what we found. Comparing your Database with ours, we found that the National Haemophilia Database had not been notified of 16 deaths. We have now amended our record accordingly. In two cases registered with The Macfarlane Trust, we had not been notified that they had HIV. One of your registrants has never been registered with the National Haemophilia Database. Two patients registered with The Macfarlane Trust have been recorded in the National Haemophilia Database as repeatedly testing HIV sero negative and so I am not sure why they are registered with you. Two further Macfarlane registrants have been reported to us as not yet having been tested. When we examined your results, we found that we had records of 70 HIV positive patients who are dead but who do not appear in your list. Presumably either they or their relatives did not register with The Macfarlane Trust or possibly they died before the Trust was created. These include 57 patients with Haemophilia A, 2 with Haemophilia B, 1 patient with von Willebrand's disease and 10 with various other diagnoses, mostly vWD.

I am pleased that the discrepancy is not greater.

With best wishes.

Yours sincerely

**GRO-C**

Dr CRM Hay  
Director, Haemophilia Comprehensive Care Centre  
Honorary Senior Lecturer in Medicine

cc: Dr M Winter, Kent & Canterbury Haemophilia Centre, Kent & Canterbury Hospital, Ethelbert Road, Canterbury, Kent CT1 3NG  
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