



The Royal Free Hampstead  
NHS Trust

Pond Street  
Hampstead  
London NW3 2QG

GRO-B

HAEMOPHILIA CENTRE AND HAEMOSTASIS UNIT

GRO-B

Dr CHRISTINE A. LEE, MA MD FRCP MRCPPath  
Consultant Haematologist

Ref: GRO-B

GRO-B

GRO-B

Social Worker  
The Macfarlane Trust  
PO Box 627  
London, SW1 0QG

Dear GRO-B

Re: GRO-B

GRO-B

I am writing to you about this lady to see whether there is any possibility of her registering with the MacFarlane Trust. She is a carrier of Haemophilia A but she has a very low Factor VIII level of 9% which effectively means that she has moderate haemophilia. She is now a resident in this country with her husband and a young baby. She had an operation in 1984 on the thyroid gland in Turkey and received Factor VIII and subsequently sero converted to HIV between GRO-B and the GRO-B GRO-B. She is at the present time asymptomatic. However, she has a baby who was born on GRO-B and who is also anti-HIV positive with P24 antigenaemia. This baby is currently under the care of GRO-B at GRO-B GRO-B.

I see Mrs. GRO-B regularly. At the present time she is not requiring any treatment and is asymptomatic, but quite clearly there are concerns for the future; should she become ill, who is to look after the baby, etc. She has obviously been seen by GRO-B GRO-B here.

We are wondering whether she could register with the MacFarlane Trust. I would describe her as somebody with haemophilia. I think the only difficulty is the fact that she had the Factor VIII transfused whilst in Turkey. However, she is now a National

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Health Service patient and resident in this country. So, on those grounds it would seem to be legitimate. Do you think you could let me know what you think and perhaps we can discuss this over the telephone. GRO-B suggested I write to you first rather than getting her involved until we have clarified the situation.

Yours sincerely,

GRO-C

Christine A. Lee  
Acting Director

cc: GRO-B



THE MACFARLANE TRUST

P.O. Box 627 London SW1 0QG. Tel: 01-233 0342

Our ref: **GRO-B**

Dr C A Lee  
Haemophilia Centre and Haemostasis Unit  
The Royal Free Hospital  
Pond Street  
Hampstead  
London NW3 2QG

**GRO-B**

CONFIDENTIAL

*Dear Doctor Lee,*

Your patient: **GRO-B**

Your ref: **GRO-B**

The reply to your query in the letter at reference is I regret that the lady is not eligible for assistance from the Macfarlane Trust or for payment from either of the Special Payments Trusts.

We could probably accept your description of her as a "person with haemophilia" as we have done for a very small number of similar cases. Being a foreign national would not disqualify her as we also have a number of registrations in this category.

The crucial point is that she did not receive the infection from treatment in the UK. (Please see the enclosed extract from the Trust Deed).

The *terms* obviously had to be written that way or there could have been an international open door. Sadly it even excludes a few British Nationals who were expatriates at the time of their infection.

I am sorry to disappoint you, I am afraid it is an area where there is no scope for discretion by the Trustees.

*Yours sincerely*

**GRO-B**

Administrator

Encs.

The Macfarlane Trust

Extract from Deed dated 10th March 1988

the same or any part  
the moneys produced thereby in or upon  
investments hereby authorised

4. THE objects for which the Trust is established are to relieve those persons suffering from haemophilia who [as a result of receiving infected blood products in the United Kingdom] are suffering from Acquired Immune Deficiency Syndrome or are infected with human immunodeficiency virus and who are in need of assistance or the needy spouses parents children and other dependants of such persons and the needy spouses, parents, children or other dependants of such persons who have died

5. IN furtherance of the above object but not further or otherwise the Trustees shall have power to:

(i) provide or assist in the provision of financial aid, holidays, food articles or



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GRO-B

Mr GRO-B  
Administrator  
The MacFarlane Trust  
PO Box 627  
LONDON SW1 0QG

Dear GRO-B

Mrs GRO-B  
GRO-B

Thank you for your letter about this lady with regard to whether she could be supported from the MacFarlane Trust.

She was treated with factor VIII concentrate in Turkey and almost certainly that will have given her HIV. However, when she was transferred to GRO-B's care, she did actually receive a total of 220 units of cryoprecipitate between the GRO-B and the GRO-B. Of course as you will well remember, this was before blood was regularly tested for HIV which started in October 1985. Thus we have no proof that she acquired HIV from the factor VIII in Turkey although of course, it is highly probable. It is possible that she could have been infected from one of the 220 units of cryoprecipitate that she received in this country. As you know, there are a number of patients in this country who have received HIV infection as a result of blood transfusion.

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GRO-B

I wonder whether it would be possible to reconsider this lady on these grounds. Quite obviously, you have to follow very tightly what it says in your Déed but, I think one could make a case that she became infected from blood products in this country in order for her to receive some support. Perhaps it might be easier for you to discuss this on the phone with me. I am afraid I have been away rather a lot, but I should be around for a bit.

Yours, sincerely

GRO-C

Christine A Lee  
Acting Director

GRO-B



THE MACFARLANE TRUST

Our ref: **GRO-B**

P.O. Box 627 London SW1 0QG. Tel: 071-233 0342

Dr. C. A. Lee  
Acting Director  
Haemophilia Centre and Haemostasis Unit  
The Royal Free Hampstead  
Pond Street  
London  
NW3 2QG

**GRO-B**

*Dear Doctor Lee,*

Your patient **GRO-B**

Thank you for your letter dated **GRO-B**. As the Trustees were meeting on the day we received your letter I was able to show them the correspondence and sound out their views.

Whilst not entirely ruling out the possibility that Mrs **GRO-B** might be eligible for assistance the Trustees asked me to point out that this would rest not on the "possibility that she may have been infected by treatment in the UK" but on the major "balance of probability that she was so infected".

Your letter alone would not seem to suggest this "balance of probability" rather the reverse, especially in view of the timescale of sero conversion.

Is there a detailed record of the batch of cryoprecipitate used for her treatment in UK? and are there grounds for believing that this was a suspect batch?

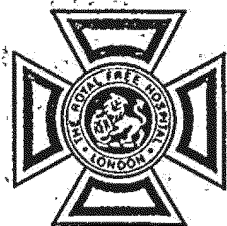
Whilst having the greatest sympathy for anyone so infected the Trustees have a responsibility to ensure that the Trust operates only within its express objectives. Hence they cannot allow any precedent to be created which could lead to a widening of the eligibility and/or a dilution of the capacity of the Trust to serve those for whom it was intended. Sadly the needs of any particular individual are not relevant until after the decision is made on eligibility for registration.

Please call me if you would like to discuss any further representation you would like me to make to the Trustees.

*Yours sincerely*

**GRO-B**

Administrator



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Mr. GRO-B  
Administrator  
The Macfarlane Trust  
PO Box 627  
LONDON SW1 0QG

Dear GRO-B

Re: GRO-B

Thank you for your letter of GRO-B and for asking the Trustees to consider Mrs GRO-B as a special case. I have to agree with you that the "balance of probability was that she was not infected by treatment in the UK". There are absolutely no clinical grounds for believing that the cryoprecipitate used for her treatment in the UK transmitted the HIV - I just wondered whether it might be a means of obtaining assistance for this lady. Quite clearly as Trustees, you have to ensure that the Trust operates only within its express objectives.

Anyway, thank you very much for considering this lady's case. I accept the decision and I will transmit this information to her.

Yours sincerely

GRO-C

Christine A Lee  
Acting Director

cc

GRO-B