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Roddy Morrison Chairman The Haemophilia Society Chesterfield House 385 Euston Road LONDON NW1 3AU 2 April 2004

Dear Roddy

## Skipton Fund - ex gratia payments scheme

Thank you for your letter of 2 April, which was awaiting me on my return from a few days abroad.

The current position concerning the two points that you raise, about which the Society's Trustees are particularly unhappy, is not precisely defined, but my understanding is as follows:

- Martin and I have been told by Richard Gutowski that the requirement to offset monetary awards from other sources in respect of Hepatitis C against the ex gratia payments has been dropped. I do not know whether this is going to appear as part of a Ministerial statement at any stage, so I am unclear whether we were told on a confidential basis. For the time being I ask you not to disclose this publicly for example, please do not let it be included in one of John Morris's newsletters but I see no reason why your Trustees should not know provided that they do not bring it into the public domain (apart from anything else, embarrassment is not, in my view, a way of ensuring Ministerial acceptance of officials' opinions).
- the legal waiver is somewhat more in limbo. I would draw to your attention that it was not mentioned in the original August statement of John Reid nor in his longer January announcement. We have been told by our lawyer, after he had met with a Department of Health lawyer, that this waiver has also been abandoned, but I do not know how authoritative that statement is. I know that the DoH people have been considering it for some time with their lawyers and appear to have been having great difficulty. It is my personal belief that this requirement will also be dropped, but I cannot be certain. Again, please treat this view with discretion.

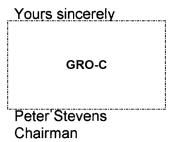
Both these points were considered when the Trustees of The Macfarlane Trust considered the request that the Trust's experience and skills should be applied to the administration of the ex gratia scheme; it was also noted that the Society did not regard either requirement as acceptable. The Trustees noted that position but did not make their assistance with the administration conditional upon the requirements being withdrawn.

I am happy, therefore, to do – more correctly, to continue doing - what I can to bring about the withdrawal of these requirements; and, as you will note from what I have already said, I believe that in practice neither requirement will appear in the scheme that Skipton Fund finally implements. But I am not now going to make our continued participation conditional upon their withdrawal.

Progress towards the start of Skipton Fund's operations remains slow. I believe that there will be another consultative meeting with patient groups, including the Society, within the next couple of weeks to review the latest version of the application form. I would be surprised if further revision were not then needed. It is my understanding that, following final acceptance of the application process by those groups, that process will need to be reviewed and accepted at Ministerial level in all four administrations.

There are still a number of technical details of the scheme, concerning various aspects of eligibility and of virus transmission routes, that remain unresolved; I cannot estimate how long that resolution will take, but believe that it is not on the critical path.

I hope that this letter goes some way to reassuring you and your co-Trustees about your concerns. I am sorry that I cannot give firmer reassurance, but repeat that, in my view, your anxieties are now unnecessary. However, I will continue to press the officials to make a publicly-available decision soon.



Cc (by Email) Gordon Clarke, Stuart Gregg, Tracey Morgan, Bill Payne, Tony Yeaman