

Draft

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I am very sorry that it has taken so much longer than I originally anticipated to write to you in full about the issues which we discussed at our meeting on 10 September, namely special payments for haemophiliacs infected with hepatitis C through NHS treatment, and the provision of recombinant Factor VIII. As I explained in my letter of 28 November to Tony Wilson, the issues are complex, and the emergence of concerns relating to new variant CJD have led us to revisit certain aspects of both issues before responding. I am now able to reply fully on both issues.

We promised you that we would give these matters very careful consideration, and that is what we have done. In doing so it was very helpful to us to have had the benefit of hearing the Society's views direct at our meeting last September, and at your subsequent meeting with the Baroness Jay. The many letters we have received on these subjects, not only from people with haemophilia and their families, but also from their carers and other representatives, have also helped to give us a very clear understanding of the strength of feeling about both of these issues within the haemophilia community.

On the question of a special payments scheme for haemophiliacs infected with hepatitis C through NHS treatment, I know that you will be deeply disappointed to hear that we have reluctantly decided that we are unable to offer such a scheme. This has been a very hard decision. As I hope was clear from our meeting, I do sympathise most strongly with the plight of those affected in this way and have been greatly moved by their accounts of the effect which hepatitis C has on their lives. Were it possible to view their situation in total isolation, then nothing would please us more than to be able to offer some form of financial assistance. Regrettably, however, it is simply not possible for us to take that approach [; our task is to balance the many needs which confront us and the finite resources which we have to meet those needs, both now and in the future].

It is a great misfortune if any patient who is treated with every intention of improving their health, or even saving their life, later suffers harm as a result of that treatment. However, where the ill effects could not have been predicted, or prevented, at the time, then they have to be balanced against the benefits of the treatment. Realistically, given the nature of scientific advance, we have to accept that these situations will always be with us. It is already a challenging task for the NHS to meet the treatment needs of patients from within its current resources, and we have had to ask ourselves, therefore, whether we could justify diverting a part of those resources - possibly a significant sum - to a payment scheme for those who now, as a result of past effective treatment, and where there is no fault, are now in difficult circumstances. We have come to the

conclusion that the answer must be no. Our first priority has to be providing patients with the health care they need.

A relevant factor in looking at this particular issue, is that haemophilia patients are, regrettably, by no means the only ones who have inadvertently been adversely affected by NHS treatment. Amongst these, there is, as you know, a large group of patients who contracted hepatitis C through blood transfusions. Were we to allow a scheme of the kind you are requesting, this would have to be made available all patients whose treatment was given on the basis of the best scientific knowledge at the time, but who sadly suffered harm as a result.

You would no doubt argue that there is already inequitable provision, in that there are schemes for those infected with HIV through NHS treatment, and that we should accordingly be looking to match that provision. We have always accepted, however, that that particular group of patients was exceptional. At the time those schemes were set up the consequences of HIV infection were rapid and fatal. The unique features of their situation included the considerable stigma attached to HIV and AIDS, the public revulsion surrounding all aspects of the virus at that time, the fact that the condition was so easily passed on to the spouses of those affected, and that in some cases their children were also affected. While I accept that a number of your Members infected with hepatitis C have also experienced difficulties, including - in exceptional circumstances - ostracism, I cannot accept that their situation, or that of other people infected with hepatitis C, is truly comparable to that of HIV infected people.

I am very sorry that I could not give you the answer you wanted on this.

We have also given much thought to the provision of recombinant Factor VIII. As you know, the Department of Health does not accept that the clinical case has been made for the general use of the recombinant, rather than the plasma-derived product, and that remains the case. I am, however, also very much aware that the haemophilia community's stated preference for recombinant Factor VIII arises not from any particular belief in its clinical benefits over the plasma-derived product, but from the experience of past problems with blood borne infections, specifically HIV and, more recently, hepatitis C.

It is clear from the representations I have received that concern about a new threat from some as yet unknown virus continues to run high, and that the latest developments in relation to nvCJD have fuelled those fears. The Haemophilia Society, amongst others, have highlighted in particular, the devastating effect which such anxieties have on haemophilia families with children.

We have thought very carefully about the whole issue and have decided that, while the risk of nvCJD transmission may be hypothetical, nevertheless the fear of it is clearly very real to such families. We have therefore decided that recombinant Factor VIII should be made available to all children under the age of 16 and new patients. These were, as you know, the priority groups highlighted in the guidelines produced by the UK Haemophilia Centre Directors (UKHCDO).

There is one further matter of which you will wish to be aware. The Committee on

Safety of Medicines has today advised me that, in view of the hypothetical risk of transmission of nvCJD through blood products, it would make sense to move away from UK plasma derived products where safe alternatives are available. In the light of that advice, we will be allowing the Bio Products Laboratory to import non-UK plasma to manufacture a range of blood products, including Factor VIII.

My reply will not be entirely the one you had hoped for. But I hope you will find that the issues you have raised have not been treated lightly, that we have had to make some hard decisions, and that we have been constructive in our approach to the provision of recombinant Factor VIII .

I am copying this letter to the Manor House group.