



**THE
HAEMOPHILIA
SOCIETY**

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The Baroness Jay of Paddington
Minister of State
Department of Health
Richmond House
79 Whitehall
London
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Dear Lady Jay,

May I take this opportunity of congratulating you on your appointment as Minister of State and Deputy Leader of the House of Lords and to send you my best wishes as you take up these important responsibilities.

There are two major issues facing the Haemophilia Society that we discussed with Chris Smith MP and Kevin Barron MP before the Election. Firstly, the question of financial recompense for those people with haemophilia infected with hepatitis C through contaminated blood products as part of their NHS treatment. You very kindly spoke in support of these people in a debate initiated by Lord Ashley in the House of Lords.

However, despite the efforts of the Society and considerable support from MPs, the then Government refused any form of financial support to those infected or the dependents of those that have already died. While in Opposition Chris Smith MP gave an undertaking that a Labour Government would review the situation (see enclosed letter from Mr Smith dated 9 December 1996). Given the urgency of the situation we hope that the new Government will act quickly and set up such a review.

The second issue concerns the funding and availability of recombinant factor VIII, a new safer treatment for people with haemophilia A. This new treatment is synthetically made rather than derived from human plasma and hence does not carry the risk of transmitting blood borne viruses. The UK Haemophilia Centre Directors' Organisation has published guidelines recommending the use of recombinant factor VIII, particularly for children. However, a number of Health Authorities have decided not to fund this new safer product. This has led to widespread inequality in its availability and the grotesque situation of some boys in a hospital receiving this safer treatment but others, because they live in a different postal district, not getting recombinant factor VIII. Many parents of young boys with haemophilia are desperate for their sons to have this safer treatment and cannot understand why it is given to some children but not others.

The Society believes that the internal market is an inappropriate model for funding complex, specialist services like haemophilia. It is also an inappropriate mechanism for ensuring the equitable

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introduction of new expensive treatments like recombinant factor VIII. The Society is therefore very interested in Labour's proposal for a national commissioning framework for certain diseases and to take up the offer of discussing these proposals as suggested by Chris Smith MP (see letter dated 26 April 1997).

We have already written to Frank Dobson MP, the Secretary of State, on these matters but given that your responsibilities include blood and that you already have an understanding of the Society's concerns I thought that you would not mind my writing to you.

If possible we would very much welcome the opportunity of discussing these issues with you.

Yours sincerely

GRO-C

The Rev. Prebendary A.J. Tanner
Chairman of the Haemophilia Society