



THE HAEMOPHILIA SOCIETY

The Haemophilia Society
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Frank Dobson MP
Secretary of State for Health
Department of Health
Richmond House
Richmond Terrace
79 Whitehall
London SW1A 2NS

12 May 1997

Dear Secretary of State,

As this is our first communication since you became Secretary of State may I take this opportunity to congratulate you on your appointment and to send you my good wishes as you undertake this new responsibility.

Over the last few months the Haemophilia Society has been in contact both with Chris Smith and Kevin Barron over issues affecting people with haemophilia and we would now like to take these up with you.

Firstly, the question of financial recompense for those people with haemophilia infected with hepatitis C through contaminated blood products given as part of their NHS treatment. Over 3,000 people with haemophilia have been infected; over 50 have already died; many others are ill and have had to give up work and are unable to support their families. The Society is looking for financial recompense for those infected with hepatitis C and the dependants of those that have died, along similar lines to the settlement made for those people with haemophilia infected with HIV. Chris Smith (see enclosed letter dated 9 December 1996) pledged that a Labour Government would undertake a review of the situation. We realise that this does not constitute a commitment to making a settlement but we hope that the new Labour Government would recognise the justice of our case and make a quick settlement. We know there is considerable support amongst Labour MPs, and indeed across all parties. An EDM tabled during the last Parliament was signed by over 270 MPs.

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 same 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, under the current arrangements of the internal market a number of Health Authorities have decided not to fund this new safer product. This had 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.

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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 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. We would therefore like to take up the offer made by Chris Smith (see letter dated 26 April 1997) to discuss these proposals.

We realise that you will have many calls on your time, but given the positive response from Chris Smith, we hope you can find time to meet representatives of the Society to discuss these important issues.

We look forward to hearing from you.

Yours sincerely,

GRO-C

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