



**THE
HAEMOPHILIA
SOCIETY**

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3 March 1997

Rt. Hon Stephen Dorrell MP
Department of Health
Secretary of State
Richmond House
79 Whitehall
London
SW1A 2NS

Dear Secretary of State,

Re: Availability and Funding of Recombinant Factor VIII

The Society, along with the UK Haemophilia Centre Directors' Organisation (UKHCDO), supports the introduction of recombinant factor VIII for the treatment of people with haemophilia A. We believe it should be available to all people with haemophilia but accept that in the short term that this may not be possible. Our initial priority for treatment is children and those who have not been previously treated with a plasma derived product. The question is how quickly can it be made available and can it be made available on an equitable basis. The Society is worried that at present there appears to be a halt to the progress in its availability across the UK and that some parents who want the new product for their children are denied it because of where they happen to live.

The availability of recombinant factor VIII for children is very patchy across the country. This is because the decision on whether a child is offered recombinant is not made by the haemophilia clinician but rather by the Health Authority i.e. the purchasers. Some Health Authorities, particularly in the South have agreed to fund recombinant but others have not. Thus most children attending the haemophilia centres at Great Ormond Street, the Royal Free, and St Thomas' in London, and those attending the centres in Oxford and Canterbury are on recombinant. However, few children attending centres in the Midlands and north of England are on recombinant. As these decisions are made by individual Health Authorities it means that some children attending a haemophilia centre have recombinant but others, because they live in a different Health Authority, have been refused. This is clearly inequitable and is causing anger and resentment amongst parents who cannot understand why they are being denied a safer treatment that others are getting.

We would particularly like to draw your attention to the situation at the Manchester Children's Hospital. The consultant haematologist made the clinical decision to put a number of the children on recombinant factor VIII. The Directors of Public Health in the area met and decided to recommend that recombinant factor VIII should not be funded. Each individual Health Authority subsequently met, and most have decided to refuse funding for any use of recombinant factor VIII, even for newly diagnosed children. The Trust has decided that if the Health Authorities will not guarantee the funding of recombinant, the children will have to revert to a plasma derived product. The clinical decision of the consultant and the wishes of the parents have been overruled by the Health Authorities.

The parents of these boys are determined that they do not go back to a plasma derived product and are trying to make their supply of recombinant factor VIII last by not treating minor bleeds and curtailing the everyday activities of the boys to try and prevent bleeding. The refusal of these Health Authorities to fund recombinant is

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using considerable stress both to the parents and the young boys. So concerned are the parents that they sought a judicial review of the Health Authorities' decisions to impose a blanket ban on the use of recombinant factor VIII. Surely parents should not have to go to such extremes to try and get treatment that is readily available in other parts of the country?

As an immediate priority the Society would like the Government to intervene in the situation at the Manchester Children's Hospital to ensure that those boys with haemophilia who have been put on recombinant factor VIII do not have it taken away from them.

We believe that it is essential that the Government intervene, not just in Manchester, but on a national level so that this new safer treatment is available on an equitable basis. The Scottish Office provided funding in 1996/97 for the children in Scotland to have recombinant factor VIII and is increasing the amount in the next financial year. Why can a similar arrangement not be introduced in the rest of the United Kingdom?

The Society believes that the best solution would be for the Department of Health to provide sufficient central funding to enable recombinant factor VIII to be initially offered to previously untreated patients and those who are currently free from viral infection. This would cover most but not all children. The number of young children with haemophilia is not large; the amount of product used by young children is not high; the price differential between a high purity plasma derived product and recombinant factor VIII is no more than 50%. The additional cost of providing recombinant factor VIII for these two groups would not therefore be significant.

These two groups have been identified as a priority by the UKHCDO but we would expect the provision of funding to be extended in time to the rest of the haemophilia population. We would particularly like to see all children covered.

The Society would also like the Department of Health to endorse the Guidelines produced by the UKHCDO and encourage Health Authorities to accept their recommendations on the use of recombinant products. We believe that more Health Authorities would be more willing to allocate funding for recombinant products if they were encouraged by the Department to take note of the UKHCDO Guidelines.

The provision of recombinant products for the treatment of people with haemophilia must not simply be seen in terms of cost. The haemophilia community has been devastated by two tragedies; we have the opportunity to prevent another. The Society is calling on the Government to grasp that opportunity by funding the provision of recombinant factor VIII.

We look forward to an early reply.

Yours sincerely,

GRO-C

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