

GRO-C

Leeds

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13th March '98

Dear Mr. Blair,

I refer to a recent letter we received from the Haemophilia Society with regards to a meeting with the Rt Hon Frank Dodson, Minister of Health. This told us that it had been decided to make recombinant Factor V111 available to all up to the age of 16.

My wife and I have an 11 year old son with haemophilia A. The medical problem is treated by regular injections of Factor V111, and by doing so an almost normal life-style is achieved. During his early years we lived in fear, hearing the tragic stories of others who had been effected by contaminated blood products.

Three years ago we were delighted when it was decided to use Kogenate a recombinant Factor. As this is synthetic it contains none of the contamination risks of plasma blood products which we have heard of in recent years. The product is not only safer but very efficient. As we do the 'home treatment' that is we do our own injections rather than having to rely on a doctor. It is very traumatic to have to inject directly into a vein causing at times severe discomfort! Also we have the situation where we see the syringe emptying into the blood stream. With donated blood products there was always the apprehension and feeling of guilt that this could be the one that might be contaminated. With synthetically manufactured products we feel very confident.

As parents we are very concerned about our own son when he reaches the age of 16. After eight years of receiving recombinant Factor, he may then be required to go back to the plasma derived products and the risk of blood-borne infections. Even though Mr Dobson does not accept the case made for recombinant Factor V111, it must be appreciated that this was not the cause of all the infections, but the products taken from donors.

Our boys deserve help and safer medication beyond the age of 16. This genetic problem is no fault of theirs, but they look to us to help provide them with a quality of life equal to others.

The most frightening aspect of this is that a Ministerial decision could curtail their outlook and life expectancy.

One thing we find it very difficult to understand is than on plasma donated products there is no VAT. Yet there is a charge on recombinant factor. Surely this added cost to the various Health Authorities is going to make budgeting even more difficult.

As our Prime Minister we would like to ask you to use your influence on our behalf and other parents who face the same dilemma to approach the powers in Parliament and ask them to help our sons beyond the proposed cut off date of 16 years and into adult life.

We hope you will be able to help us.

Yours sincerely,

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*Rt Hon. Tony Blair MP,
Prime Minister
10, Downing Street
London*