Charles
Disease
Haemophilia.

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MW/SP

4 July 2001

Yvette Cooper, MP
The Department of Health
Richmond House
79 Whitehall
London
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Dear Ms Cooper

The Haemophilia Alliance

The Haemophilia Alliance is a recently established partnership between health care professionals involved in the care of haemophilia working together with patients with haemophilia. One of the major goals of the Alliance in its early stages has been the establishment of a national service specification for haemophilia and related disorders, which I enclose.

This document is seen as being a substantial landmark in the future development of haemophilia care as it sets out for the first time agreed standards which all patients with haemophilia – wherever they might live in the country – should reasonably expect. The document carries the full support of the haemophilia community.

Haemophilia commissioning is currently being taken forward by a major consortium in London, who have been appointed as lead commissioners in the UK. They have now produced their own specification which is more or less taken verbatim from the Haemophilia Alliance's service specification.

We would therefore welcome the opportunity to come and talk to you about this important document and the implications for haemophilia care. In particular, you will be aware of the continuing major concerns of the haemophilia community about the possible transmission of viral agents through the continuing use of plasma derived blood products. Adults with haemophilia resident in England – unlike those in Scotland and Wales – must continue to rely on plasma derived blood products and this is not only iniquitous but also remains a matter of major concern given the very serious outbreaks of viral transmission that have occurred in patients with haemophilia over the past twenty years.

Supplies of recombinant factor VIII are not sufficiently secure at this time for us to recommend that the Department should try and commit to providing genetically engineered factor VIII for all patients with haemophilia. However, we would very much like the Department to now accept the principle that – supplies allowing – all patients with haemophilia in the UK should have access to recombinant blood products. Not only would this make the situation in the UK more equitable but it would also bring us into line with other developed countries such as the USA and Canada which are now more or less exclusively recombinant in their treatment of haemophilia.

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Our perception is that supplies of recombinant factor VIII should allow a gradual transition to recombinant usage over the next say 2-3 years. Previous transitions to improved therapy in haemophilia have caused significant unrest and anger within the haemophilia population, particularly amongst those unfortunate haemophiliacs who had been infected with HIV as they have often found themselves of the lowest priority in terms of receiving improved care.

We believe that the Haemophilia Alliance has a substantial part to play in facilitating the inevitable transition to the use of recombinant blood products and we would like to offer our services to the Department for this exercise, as and when it happens.

We have a meeting to discuss these issues with Charles Lister and his colleagues within the next few days and would very much welcome the opportunity to come and meet you to discuss these important matters further.

With all good wishes.

Yours sincerely

GRO-C

Dr Mark Winter
Co-Chairman
The Haemophilia Alliance

Cc

Karin Pappenheim, Chief Executive, The Haemophilia Society
Chris Hodgson, The Haemophilia Society
Vicky Vidler, Haemophilia Nurse Specialist, Sheffield Childrens Hospital
Dr F Hill, Haemophilia Centre Director, Birmingham Childrens Hospital
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