cc Dr Charles Lister R08/2002
Copy Dr Troop
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MW/SP

24 December 2002

Professor Sir Liam Donaldson
Chief Medical Officer for Health
Department of Health
Richmond House
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Dear Professor Donaldson

Recombinant factor VIII for all patients with haemophilia

The Haemophilia Alliance is a partnership between healthcare professionals involved in the delivery of haemophilia care and patients with haemophilia. Over the past few years the Alliance has been influential in setting standards for haemophilia care and has written the first ever national service specification for patients with haemophilia.

We are writing to you because of our great concern about the wholly unreasonable and distressing situation affecting adults with haemophilia in England. As you must be aware, patients with haemophilia have been very badly served by the National Health Service over the past twenty years. More than 1200 patients with haemophilia were infected with HIV through their treatment; more than 70% of these patients have now died. Around 3000 patients were also infected with hepatitis C and many of these patients have gone on to develop significant chronic liver disease and cirrhosis.

These infections were transmitted by plasma-derived concentrates of factor VIII and factor IX. This system is an inherently vulnerable one as the concentrates are derived from the blood of many thousands of donors. The UK has never been self-sufficient in concentrate supply and has had to rely for many years on importing commercial plasma-derived concentrates which have previously been shown to have a higher chance of viral transmission.

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Professor Sir Liam Donaldson 24 December 2002

Recombinant factor VIII for all patients with haemophilia

Although all blood donors are now screened for known viruses, and although plasma-derived concentrates are treated to eliminate any viruses, there is continuing concern about the risks of possible transmission of as yet unknown infectious agents through this mode of treatment. These real concerns have obviously been enforced by the evolving story of variant CJD. Although at this time no patients with haemophilia have been reported as being infected with variant CJD, it is known that the prion that is the cause of variant CJD circulates in the blood stream and therefore on theoretical grounds there is great concern that patients with haemophilia might have been exposed – or may be exposed – to the variant CJD agent.

Recombinant (genetically engineered) concentrates of factor VIII and factor IX have been available for a number of years. A wholly invidious situation currently exists in the UK concerning access to recombinant concentrates in that whereas all patients with haemophilia who live in Scotland, Wales and Northern Ireland are treated with recombinant therapy, in England funding has only been provided for the care of children with haemophilia.

This situation is extremely distressing for patients with haemophilia who have had to put up with so much over the past twenty years. Some patients are actually refusing to take plasma-derived concentrates, for fear of possible further viral infection, even though they are aware that they are placing themselves at significant risk of serious internal bleeding.

This is a classical case of treatment by post code, which the government is quite rightly committed to abolishing. The Department of Health has been promising the haemophilia community a decision concerning the provision of funding to allow all patients with haemophilia in the UK to have therapy with recombinant concentrates but we have become very concerned about the continuing delays and the lack of any announcement from the Department.

You will agree that this is a thoroughly unreasonable way to treat a group of patients who have already suffered greatly as a result of infections they acquired through treatment on the National Health Service.

Formal costings for the transition from plasma-derived to recombinant concentrates for adults in England have been submitted to the Department and it is accepted that the transition should be phased in over at least three years, starting with an age group of 16-30 years. In this way the total cost of the transition – which we believe to be around £45-50 million at current usage and current prices – can be phased in appropriately.

We expect the Department of Health to provide funding to allow all patients with haemophilia in the UK to be treated with recombinant coagulation factor concentrates and would be grateful if you could reassure that a decision on this matter will not be delayed any further.

With all good wishes.

Yours sincerely

GRO-C

Dr M Winter
Co-Chairman
The Haemophilia Alliance