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Royal Free Hospital

HAEMOPHILIA CENTRE & HAEMOSTASIS UNIT

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CAL/MJ

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Dr K C Calman
Chief Medical Officer
Department of Health
Richmond House
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Dear Dr Calman

It is exactly two years since you intervened on the high-purity factor VIII issue for haemophilia treatment. I would be grateful if you could consider a problem that is emerging for haemophilia treaters. I am hopeful that perhaps if you had a view about this matter and it were to prevail, you might be able to change government policy.

I am enclosing for you, a copy of a letter that our administrators have received about one of my patients. The background to this is that he is a patient who received recombinant factor VIII in the context of a trial. As you probably know, this product was licensed in the summer and we now have to buy it. The increased cost per year for an average user of factor VIII, would amount to some £10,000. I do not therefore feel I can argue the case to provide this money within our own trust for this one patient. However, I think that I in common with many of my colleagues who see large numbers of patients with haemophilia, do have a concern that we continue to use blood products that are derived from plasma when there now is a licensed synthetic, non plasma-derived equivalent. We cannot in all honesty, say that the present products we are using have exposed our patients to risk but, there are reports from time to time for example, of hepatitis A transmission and more latterly, of parvovirus or B19 transmission. There therefore lurks in the minds of both the haemophilia treaters and the patients, a concern that there may be some hidden virus with which they could become infected.

I am sure that you have been made very much aware of the high profile that hepatitis C has had during the last few days in the national press. This was particularly brought home to me because on Monday I had land on my desk, the first set of papers of a patient who was infused with factor IX concentrate in 1979, when he was aged two, and is now suing The Royal Free Hospital for the use of that treatment, because he got infected with hepatitis C.

INTERNATIONAL TRAINING CENTRE OF THE WORLD FEDERATION OF HAEMOPHILIA

Dr KC Calman

It seems to me that compensation is not the issue. Quite clearly, these patients have been saved from a bleeding death from treatment with blood product up to 1986, before it was adequately sterilised.

However, what I do think is that the government could begin to take the view that for the future, it might be worth putting money into haemophilia treatment, in order that we can afford to use recombinant products. The problem nationally, compared to other medical problems, is of course small. It is estimated that there are about 1,500 people with severe disease so, if we are talking about £10,000 extra per year, that is 1,500 times that sum which in national terms, is very small. However as you well know, haemophilia has to be coped with in the contracting process. There is no way in our local circumstance, that this institution for example, can afford to buy synthetic factor VIII. However I am sure if there were an intervention at your kind of level to suggest that for the future, patients with haemophilia should be treated with recombinant products to prevent any possibility of viral transmission for the future, the government would clearly listen. As you know, haemophilia is always an emotive issue, particularly because of the terrible tragedy of HIV. I think it is also significant that John Major was the person who actually enable the funds to be provided to support those who were infected with HIV, when he first came into office.

I hope you do not mind me writing to you about this issue - I would be very interested to know what your views are and I will be very happy to provide you with any further information that you might want to have. I know that the Chairman of our Haemophilia Centre Directors' Organisation, Dr Colvin, is going to be meeting with The Department of Health in due course. My reason for writing to you personally, was that I know how effective and interested you were two years ago. I am also reminded of the sorry plight of Jean-Pierre Allain and I wonder if in a decade's time, people would wonder why on earth we were not using recombinant factor VIII when we had it available?

With kind regards.

Yours sincerely

GRO-C

Christine A Lee