Ref: PJ/LM

24th November, 1987

Mr. B. Dowdeswell, Unit General Manager, RVI.

Dear Barrie,

I assume that Liam Donaldson is still so tied up with the Cleveland enquiry that he has not had a chance to think about the questions that he was going to ask in relation to factor VIII/IX usage. However, I thought it might be helpful to jot some of the problems we face on paper for you to think about in the long term.

Firstly, it looks as though we are going to be about a million units down on our usage this current year from 6½ million units to around 5½ million units. I must emphasise that this is only a prediction because of the amount of treatment prescribed for patients on home therapy, some of which will of course not be used before the end of the year.

Peter Hopley will be able to supply you with variations in cost in the two years in terms of pence per factor VIII unit. Factor IX is no longer a problem because it is all supplied from Elstree in an acceptable heat treated form.

For England and Wales I am afraid the position is still very bad in the sense that only 20% of the requirement for factor VIII is being met from the old Elstree. However, the first production runs have now taken place in the new plant and hopefully there will be a rapid build-up in National Health Service product during 1988/89. Whether or not this prediction can be maintained depends on continuing supplies of quality plasma once the initial stockpile has been used up.

The Haemophilia Centre Directors are insistent that they retain the right to prescribe the product of choice for each individual patient and do not have their prescribing rights confined to the Elstree product. The reasons for this are obvious, the principal one being that we must ensure the patients receive the product which is known at the time to be the least harmful. This may well be synthetic material made by recombinant DNA technology. Initial trials are presently taking place in the States and the results look good.

However, comparable technology is not likely to be available in this country for some time and we may be forced to buy at commercial rates from America. It is anyone's guess how much this material will cost per unit.

Cont'd . . .

The Haemophilia Centre Directors are currently giving thought to the use of more expensive products which have been shown by clinical trial to be viral-free in terms of both human immunodeficiency virus (HIV) and non-A non-B hepatitis. To date there is only one such product and that is factor VIII concentrate made by Behringwerke which will probably retail at about 30 pence per unit. Another product which is about to go on clinical trial here is a solvent detergent factor VIII concentrate which again is expected to retail at 30 pence per unit.

I am afraid that it looks very much as though all the dry heated materials made commercially may soon have to be withdrawn from the market because of HIV sero-conversion. This is not absolute but I think that you should be warned because the wet heated materials (through which heat is dissipated more evenly and extensively) are considerably more expensive. The material we are using at present for our sero-negative patients is currently 18 pence per unit but there is evidence that this transmits non-A non-B hepatitis and better products are on the way. They too are expected to retail at 30 pence or more per unit.

All in all the cost of haemophilia therapy is likely to rise considerably in the next two years. The cost to the Health Authority will only be tempered by (a) the advent of increased supplies of the National Health Service product if this continues to be acceptable, given that it is dry heat treated and (b) the diminishing number of severely affected haemophiliacs in our community because of death from AIDS.

The Cxford Returns for last year are still not available and so I cannot compare our usage with those of my colleagues. However, as you know, our position in the league table of Centres in terms of factor VIII units per patient per year has varied considerably within the past decade. Newcastle does not stand out as being a heavier than normal user of commercial concentrates.

For the moment we are continuing our surgical programme which includes joint replacement and it is difficult to see any humane way in which this programme could be curtailed. It is also difficult to see how one can curtail the use of factor VIII in individual families and cut-backs on the home therapy programme would simply increase the use of hospital facilities.

When the Oxford Returns are to hand and we know more about the suspected sero-conversions in the presently available dry heat treated material, I may be able to give you a more balanced prediction of usage and expenditure in 1988/89. For the present, however, I hope you will understand that the number of variables involved, most of which are beyond our control, make any prediction difficult.

I have sent a copy of this letter to Dr. Jill Sanders in the hope that she will be able to have a word with Liam and draw up a list of questions to which Region would like an answer.

Kind regards,

Yours sincerely,

PETER JONES Director

cc. Dr. J. Sanders