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Our ref: FGHH/PAM (Dictated 15.04.2003)

To: Haemophilia Centre Directors

Dear Colleague,

Re: Allocation of phased funds to allow haemophilia patients aged 23 and over to be treated with recombinant products

As you are aware the following funding will be made available:-

2003-04:	£13 million
2004-05:	£21.7 million
2005-06:	£53.4 million

This means that we have to phase the introduction of recombinant factor VIII/IX to this group.

Thank you for responding to the last request for data. This was used to inform the discussions of the Recombinant Clotting Factors Working Group set up by the Department of Health. Charles Hay and I are members of this group and the DOH are looking to UKHCDO and the database in order to plan and implement this process. It is likely that we, like the Scots, will use an age band process to implement, working upwards from the age of 23. Minutes of the first of these meetings, held on the 19th of March, are included as a separate attachment to this e-mail.

The greatest administrative challenge involved in this exercise is to ensure that the funds are distributed appropriately to the PCT paying for the patient's treatment. It has been agreed that this funding will be distributed to pay for the difference in treatment cost between plasma-derived and recombinant factor VIII/IX and VII only for patients currently using a plasma-derived product. In order to do this we urgently require further information from you – ***by the 1st of May***. The information required on all patients with haemophilia A, B or congenital factor VII deficiency aged 23 years and over *and treated with a plasma derived concentrate from April 2002-March 2003* is as follows: -

- Patient identifier for UKHCDO database
- Patient identifier for PCT
- Patient's date of birth
- PCT
- GP code
- Factor usage in last financial year
- Diagnosis (haemophilia A, B, congenital FVII) with factor level

Cont'd...

To: Haemophilia Centre Directors

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15.04.2003

If it helps, we could manage with the information on 23-35 year olds by 1st May 2003 and then the other patient data by 1st June 2003.

With potential slippage it is likely that in the first year patients age 23-33(or 35) will be changed over, but we require the data on all patients to plan the following year and start of year 3 in case we need to ask for more money. A case of need for that has to be done within the next few months. A National Contract for this extra volume of recombinant products is being explored.

It is important we achieve this. Can replies be emailed to:-

- Lynne Dewhurst (email address: lynne.dewhurst@GRO-C) and
- Frank Hill (email address: frank.hill@GRO-C).

If anyone has patients 22 years or younger not on recombinant products then this needs to be addressed with the relevant PCT/commissioner, as they should already be funded and will not be covered by this roll-out.

With many thanks for your co-operation.

Yours sincerely,

Frank G.H. Hill
Chairman - UKHCDO