HAEMATOLOGY TREATMENT CENTRE

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FAX TRANSMISSION COVER SHEET

Date: 16 December 1997

To: DR CHRISTOPHER LUDLAM, HAEMOPHILIA CENTRE DIRECTOR

Fax: GRO-C

Subject: Recombinant Factor VIII

Sender: PAULA BOLTON-MAGGS

YOU SHOULD RECEIVE 2 PAGE(S), 5 including this one. INCLUDING THIS COVER SHEET. IF YOU DO NOT RECEIVE ALL THE PAGES, PLEASE CALL 0151 252-5073

Dear Christopher

Are you happy if I ask Rosemarie Spooner to circulate these two documents? I can not remember whether I told you that Frank Hill was somewhat reluctant that we should publish the data in a journal about the recombinant Factor VIII usage on the basis that 'state of the art' would indicate that it is ok not to prescribe recombinant Factor VIII. I am not sure that I agree with him. I think it is difficult to have done this work and then not do anything with the results. I feel it is important to give the contributors some kind of rapid but confidential feedback, not least because it might be helpful to them in their own causes. Perhaps we could discuss what we do with the information at the next Executive Committee in February.

Tues - Fri please reply to fax GRO-C

With best wishes, Paula.

Enc.

Haematology Treatment Centre
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PBM/BC

1 December 1997

Dear Colleague

Re: Survey of implementation of the UKHCDO Guidelines - October 1997

Many thanks indeed for your prompt response to our questionnaire. The numerical information and the comments were extremely helpful in getting the picture of the difficulties experienced by people across the country. It is quite clear from your comments that completely different philosophies are being adopted in different districts. The overall figures are given below together with some quotes from the replies I received. Please treat all this information as confidential for the present time.

Total number of Haemophilia Centres circulated	Number of Haemophilia Centres responding	Total number of children up to the age of 16 surveyed	Number receiving recombinant Factor VIII	Number not receiving recombinant Factor VIII	Number of children where purchasers have not reached a decision
95	62	667	336	331	128

Notable Quotes

'The current view of the Health Authority was that the theoretical risk differential did not justify the very high additional cost, especially when set alongside all the competing demands for resources.....it was agreed that the policy of not funding recombinant Factor VIII (is supported) until and unless this becomes available at the same price as plasma derived Factor VIII'.

The local Haemophilia Centre Director felt that the subject had at least been considered in detail with a sensible and comprehensive briefing paper.

'The Public Health Consultants looked to us to prevent a uniform policy' .....'four months ago there was agreement that we will use recombinant Factor VIII for PUPs and probably all virally naieve patients'.

The Purchasers Prescribing Forum agreed the UKHCDO guidelines for all patients except HIV positives but funding has not been agreed in this area. '

'In practice I will treat PUPs with recombinant Factor VIII but can not treat others',

The family of one of the patients aged seven, **'have sought support from every conceivable source including their MP, without success. They have been quite hostile at times'.**

Currently recombinant Factor VIII is not approved for any group of patients in the West Midlands. In the North West region the Public Health Directors took a stance very early on that the funding of recombinant Factor VIII was not justified on public health grounds. Despite this a couple of districts have agreed to fund recombinant Factor VIII for children or 'special circumstances'. In contrast in South Wales the Directors of Public Health specifically disagreed with the policy of prioritisation of recombinant Factor VIII on the basis that all patients had the right to receive the best available treatment.

The nine health districts centred around Newcastle have not agreed recombinant Factor VIII for any patients and have been reluctant to enter into any discussion with the Haemophilia Centre Director.

As you know, the intention was to classify the prescribing or not prescribing of recombinant Factor VIII by postcode but this has proved very difficult to do in practice, and the data has not yet been analysed in this way. However, we thought it would be helpful to see the fruits of your rapid response to our questionnaire. If you want any further information please telephone me.

With best wishes

Yours sincerely

PAULA BOLTON-MAGGS
CONSULTANT PAEDIATRIC HAEMATOLOGIST