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Date: 7 April 1993

cc: Dr Rejman HC(M)2

File - HIM 1

## QUALITY GROUP'S BOOKLET ON HAEMOPHILIA

I have discussed with Dr Rejman HC(M)2 and we have the following comments and suggested amendments to your draft sections for the Quality Group's booklet on haemophilia.

### SECTION 1

#### Background

Antepenultimate line - "Van Willeband's" should read "Von Willebrand's".

Amend second paragraph to read - "Haemophilia usually affects only males, and their daughters are carriers who can pass the condition on."

Third paragraph, end of line 4 - "suffers" should read "sufferers" or "patients".

#### Diagnosis

Line 3 "diagnosis" should read "diagnoses".

Antepenultimate line - suggest insert " or may present at childbirth" after "early age".

#### Treatment

Amend first sentence to read - "The immediate need is that each bleeding episode be promptly treated by an intravenous infusion of a concentrate of the missing clotting factor or in some cases with a synthetic compound DDAVP".

The last sentence on page 1 is incomplete. Presumably you intended to refer to the increasing availability of treatment at home or at work as patients become trained in self treatment methods.

First paragraph on page 2, last line - The guidance is scheduled for issue in 1993.

## Complications

Inhibitors - amend to read:

"About 5-10% of people with haemophilia develop antibodies or "inhibitors" to factor VIII so that when the normal amount of factor VIII concentrate is given for a bleed there is no clinical response, and extra factor VIII or a different form needs to be used."

Liver disease - add a second sentence:

"Donors are tested for hepatitis B and C and the manufacture of Factor VIII destroys most if not all these viruses."

HIV and AIDS - amend to read:

"Approximately 1220 people were infected with HIV as a result of contaminated blood products. All blood products used are now tested for HIV, which is destroyed by the manufacturing procedure"

There were a small number of women amongst those infected with HIV through contaminated blood products. You should leave out the reference to contaminated blood products "principally imported from the USA". Since the introduction of the manufacturing processes currently in use there has been no new infection reported through blood products. Therefore we can say that the manufacturing procedure destroys HIV, but we should not say that there is no risk.

## SECTION 2

Our general comments are that there are too many quotes and we wonder whether the general tone is too critical. We do not know how these particular quotes have been selected, and are a little surprised not to see more demands for self referral to the treatment centre of choice.


Fourth quote on page 2 penultimate line - delete "as".

Penultimate quote on page 3 line 1 delete "as".

## SECTION 3

Amend third paragraph first sentence to read - "At present there is no cure for haemophilia but it can be managed."

Fourth paragraph - we are not sure what is meant by the sentence "As a result people with haemophilia become experts in their own condition."



## Comprehensive Care

The sentence

"These services need to be coordinated and under the overall responsibility of the haemophilia consultant."

should be replaced by

"The haemophilia consultant should arrange for the appropriate provision of these services."

Second indent - amend the last three lines to read "..... and knowing that they will receive continuity of care by a haematologist who has a particular interest and expertise in haemophilia, but not necessarily seeing him on each occasion."

## Replacement therapy

Amend second indent to read:-

"\* immediate assessment and if necessary treatment on arrival - delay aggravates any bleeding and the associated pain"

Penultimate indent last line replace "that" with "they".

We suggest that you delete the final indent about prophylactic treatment for children from as early an age as possible. This is a contentious point and no change has yet been decided.

## Information, guidance and support

6th indent - Does "external agencies" mean agencies outside the NHS? Could you clarify what you mean by external agencies.

9th indent - replace "usually run by the Haemophilia Society" with "such as those run by the Haemophilia Society"

last indent penultimate line - replace "many" with "some"

## Choice of Centre

It may be necessary for some patients to go to a comprehensive care centre for all of their treatment. In other cases eg mild cases where there is little clinical need, it may not be necessary for the patient to be treated at a comprehensive care centre at all; if these patients were to be treated unnecessarily at the comprehensive care centres, they would become cluttered up. There is also the question of who is to provide and pay for the transport.

### Choice of blood product

The consultant is responsible for prescribing the blood product, and relative costs of different treatments may also be a factor. Your draft should be amended to reflect that haemophilia patients have some input into the decision on which blood products are prescribed.

### Choice of treatment programme

The final sentence of this paragraph "Parents should be given the opportunity....." should be deleted. Please see my earlier comment. No decision has yet been made on this change.

### Facilities

First indent - How much is sufficient car parking space, and do we mean sufficient only for the ones who need it?

Second indent - suggest "wheelchair access and lifts rather than stairs where possible"

### Issues

You also asked about issues that may confront purchasers over the next 2-3 years. In our view the major ones with considerable cost implications will be

- move towards prophylactic treatment
- introduction of recombinant products
- pressure for interferon treatment for haemophiliacs who are HCV positive

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DEPARTMENT OF HEALTH

FAX MESSAGE

TO

Sharon Creber, CF-ME 520A Han Hse

FAX NUMBER

GRO-C

NUMBER OF PAGES (Excluding this cover)

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MESSAGE

Attached minute of 7/4/93 on  
Quality Group's Booklet on Haemophilia -  
as promised

FROM

GRO-C: Monica C

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GRO-C

14/4/93

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