THE ROYAL INFIRMARY OF EDINBURGH

COPY OF DOCTORS LETTER

NUMBER

NAME

M15

DEPARTMENT OF HAEMATOLOGY

Consultants
Dr C A Ludlam
Direct No: GRO-C

Dr P R E Johnson
Direct No: GRO-C

Fax: GRO-C

Service Manager
Mrs F Turner
Direct No: GRO-C

Laboratory Enquiries
Tel: 0131 536 2373

Clinic Appointments
Tel: 0131 536 2136

CAL/AT

6th August 1997

Dr N Cooper
Health Services Management Centre
Park House
40 Edgbaston Park Road
BIRMINGHAM
B15 2RT

Dear Nigel

Thank you for letting me see a further draft of the document you are compiling for the DOH. I am sorry that we were not able to discuss its contents prior to you sending a final version to the Department. Might I make the following observation:

1. You indicate that there are 3,400 haemophiliacs in England. The total number of haemophiliacs registered in the UK is 5,400 of which perhaps 4,500 live in England. In 1994 in the UK 2,432 were treated and thus for England the number is perhaps in the region of 1,800.

2. I would be interested in your estimate of the current cost of factor VIII concentrates. As you will be aware the cost of intermediate purity has increased markedly and recombinant has fallen very sharply.

3. Those with severe haemophilia have less than 2% normal factor VIII level (not 5% as in para 2, line 3).

4. It states that ".....factor VIII concentrates as higher doses ..... presumed long term disability" (para 2, line 10). I think it fair to say that factor VIII therapy does reduce joint bleeds and long term disability when it is used prophylactically. I do not think there is any doubt about this. In the following sentence it states that there is "possible early death" without factor VIII treatment. I think it would be reasonable to say that there would be early death. Prior to the introduction to cryoprecipitate the average life expectancy was 18 years in an individual with severe haemophilia.

5. In para 3, second sentence, I think it might be more correct to state that "By the early 1980's many haemophilic subjects .....". It is unclear in the following sentence what 45% of the total population are infected with - is this HIV, HCV or another virus?

6. In para 4 you enquire about virus transmission since 1985. These episodes are given in the Therapeutic Guidelines. No mention is made of the fact that there is very little protection against non lipid coated viruses as these are resistant to solvent/detergent and heat. As you know parvovirus is still probably transmitted by all plasma derived factor VIII concentrates and if another similar virus were to contaminate the starting plasma it might well infect large numbers of haemophiliacs.

7. In para 6 I think there may be a misunderstanding in terminology. Previously untreated patients (PUPs) are the approximate 30 individuals born each year with haemophilia. The remain PUPs until they receive treatment with factor VIII concentrate. For the majority of those with severe haemophilia A this will be within the first two years of life. There are a further group of individuals, mostly children up to the age of about 12 years who have only received virally attenuated concentrates and are free of infection with HIV and particularly HCV. As you rightly indicate the 3rd principal group are those with HCV alone or HIV and HCV. The latter group, particularly, have clearly an increased mortality. Furthermore such individuals tend to be large users of factor VIII and many will have been treated with monoclonally purified concentrate. There are thus relatively expensive to treat and each death results in the release of a considerable financial resource which is potentially available to treat small children who on a per capita basis will clearly use much less factor VIII concentrate.

8. I am interested in the figure but have some difficulty in understanding the graphs, perhaps because of some terminology's.

I hope these comments are helpful. If you are able to let me see the version that was sent to the DOH I would find this most useful.

I look forward to hearing from you.

With kind regards
Yours sincerely

Christopher A Ludlam
Consultant Haematologist