

Mr Draper

cc Dr Beddard
Dr Raison
Dr Maycock ✓
Dr Waiter
Dr Smithies

Mr Glyn John
Mr Cleasby

THE TREATMENT OF HAEMOPHILIA

1. At a meeting held at the end of January 1976 the Minister of State emphasised -

- (a) that there should be maximum co-operation between all concerned in England and Scotland with the production at Elstree and Liberton of AHG;
- (b) that the qualities and presentation of NBTS products must be such that they are equally as acceptable to clinicians as are the (imported) commercial products - particularly Hemofil as being the product most firmly established. (In this connection there was a discussion at the meeting on points such as relative volumes and solubility which required to be examined).

The Minister of State asked for a further report within a few weeks.

2. Since the meeting Med DS4 has been undertaking field work primarily intended to familiarise the Department with the range of commercial products available for the treatment of haemophilia, their relative merits and their advantages and disadvantages compared with the NBTS AHG concentrates. HS2B has been considering the bodies from which the Department might seek the advice they will need if they are to ensure that the NBTS products are equally as acceptable to clinicians as the commercial preparations. The findings which have emerged from the Med DS4 field work will be embodied in a paper or papers which will form the basis of the discussions between the experts who will advise the Department on this subject. The remainder of this minute considers the bodies from which it would be appropriate to seek advice, the arrangement for obtaining it and the topics to be considered.

3. The relative positions of the Expert Group on the Treatment of Haemophilia and the Joint Steering Committee on Blood Products Production are examined in an HS2B memorandum of 9 February (copy attached) where the conclusion was reached that the terms of reference of the Joint Steering Committee were wide enough to cover all the matters which now needed examination. Since then, Departmental opinion has swung in favour of focussing consideration initially on the range of products available to clinicians from NBTS and commercial sources and the distribution arrangements of the AHG concentrate produced by Elstree and Oxford. It is anticipated that an important part of the discussions will be concerned with clinical preferences for particular products and the circumstances of treatment, and it is generally felt that the Expert Group on the Treatment of Haemophilia would be the body best equipped to advise on these subjects. It could, at the same time, advise on the target for AHG production which the Department should be aiming at if, as appears possible, trends in treatment make it necessary to regard the present production target as an interim one. If, subsequently, the Joint Steering Committee on Blood Products Production is reconvened it will have available the best assessments of the clinicians' needs. The Expert Group on the Treatment of Haemophilia has one member from SHHD already (Dr I S Macdonald) and it is suggested that membership

might be extended to include an administrator from SHHD, possibly Mr R N Roberts (Principal). The Welsh Office might also be asked to confirm that they are content to leave matters to England and Scotland or to send possibly a medical member. There is a considerable overlap of membership between the Expert Group and the Joint Steering Committee which should facilitate the process, if consideration has to be handed over at any stage from one body to another. Med DS4 have suggested that Mr Watt (Director of the PFC at Liberton) should be invited to attend depending on the contents of the agenda, but since it might not always be possible to explain satisfactorily why he is invited to some meetings and not to others, and in view of the Minister of State's concern that there should be close liaison with those with parallel responsibilities in Scotland, it might be preferable to include Mr Watt as a member of the Group from the outset.

4. Dr Maycock has proposed that in addition to Dr Stratton who is already a member of the Group, two other RTDs should be invited to attend if the Expert Group discusses the distribution of AHG in England and Wales. He has suggested Dr Jenkins and Dr Gunson. Since the distribution of the AHG currently available may arise at the first meeting of the Group it would be advisable to include the two additional RTDs from the outset.

5. On this basis the Expert Group with associated officials would consist of -

Dr Raison (Chairman)
 Dr Rosemary Biggs
 Professor E K Blackburn
 Professor A S Douglas
 Dr Maycock
 Dr Katherine Dormandy (Royal Free)
 Professor G I C Ingram (St Thomas')
 Dr I W Delamore (Manchester Royal Infirmary)
 Dr P Jones (Newcastle Royal Victoria Infirmary)
 Major General H C Jeffrey
 Dr C Rizza
 Professor J Scott
 Dr F Stratton (RTD)
 Dr H H Gunson (RTD)
 Dr W J Jenkins (RTD)
 Mr J Watt (Liberton PF Laboratory)

All but 3 of the above - Drs Gunson and Jenkins, and Mr Watt attended the last meeting of the Expert Group on 11 October 1974.

DHSS : Dr Sheila Waiter
 Mr G John (Supply)
 Mr M W Draper
 Mr T E Dutton

SHHD : Dr I S Macdonald
 Mr McLean or Mr R N Roberts

Welsh Office : A representative

6. The Terms of Reference which were framed for the Group when it first met in 1973 were:

"To advise the Department on trends in methods of treatment of haemophilia and allied conditions; and to consider possible future requirements for the treatment of the condition and the consequences for the supply of therapeutic agents."

In general the terms of reference are wide enough to cover all the topics which have to be considered but in view of the Minister of State's wish that there should be close co-operation with DHSS, it is for consideration whether the Group should be advising all three Departments, possibly with some strengthening of the Scottish expertise.

7. I should be glad to have the agreement of recipients of this minute to:-

- (a) the reconvening at the earliest date possible of the Expert Group expanded as indicated above. It seems unlikely that this will be possible before early April. The invitation to members, which we would aim to send out early next week, would simply enclose a copy of the Terms of Reference, refer briefly to earlier meetings of the Group and say that it was considered that a further meeting was desirable in view of developments since the meeting in 1974. The invitation might also invite papers from members and promise an agenda in due course;
- (b) the continued use of the Terms of Reference above or suggestions for change;
- (c) copying this minute to SHHD and the Welsh Office.

GRO-C

T E Dutton

HS2B

Room 1208 HANH X **GRO-C**

25 February 1976