0002
file Haemophilia directors meeting

MEETING OF DIRECTORS OF THE SCOTTISH NATIONAL BLOOD TRANSFUSION SERVICE AND HAEMOPHILIA DIRECTORS IN ST ANDREW'S HOUSE, FRIDAY 30 JANUARY 1981 4/23/1

PRESENT:

Dr A E Bell (Chairman)
Dr B Bennet
Dr C Cameron
Dr J D Cash
Dr I A Cook
Miss M Corrie
Dr C D Forbes
Dr P Foster
Professor R H Girdwood
Dr H M B Lewis
Dr C A Ludlam
Dr R Mitchell
Dr D B L McClelland
Dr G A McDonald
Dr A Pettigrew (Vice Dr Willoughby)
Dr C R M Prentice
Dr G R Tudhope
Mr J C Watt

IN ATTENDANCE:

Dr A D McIntyre (SHHD)
Mr J H F Finnie (SHHD)
Mrs M J Learmonth (Secretariat)

21 AUG 1981

APOLOGIES FOR ABSENCE

1. Apologies for absence were intimated from Dr Wilson, Dr Dawson and Dr Willoughby.

CHAIRMAN'S INTRODUCTION

2. In welcoming members Dr Bell explained that for a number of reasons the Department thought that the time was ripe to reconvene the group, which had not met since 1977. It would not be possible to reach positive decisions on all the agenda items in a single meeting of this nature, but it was important to have fully participative discussions that would lead to more detailed studies.

TRENDS IN PLASMA PROCUREMENT AND PRODUCTION OF FACTORS VIII AND IX CONCENTRATE (paper 81/1)

3. (a) At the chairman's invitation Dr Cash introduced the paper he had provided to assist discussion of SNBTS planning for the future availability of Factor VIII and IX concentrates within the NHS.

(b) Supply and demand

Section 1 of the paper dealt with the supply/demand position from 1975-1980 and gave details of:- (i) Total fresh frozen plasma processed, (ii) total cryoprecipitate issued from the regional centres and (iii) total PFC issues of intermediate VIII. The data for the latter years gave an accurate picture of the position.

(c) Commercial purchases of factor VIII

The data provided for 1979 and 1980 showed that a significant and apparently increasing quantity of commercially produced factor VIII was being used, and the

reasons for this were discussed. It was stated by haemophilia directors that sometimes only a commercial product was available; there were also occasions when, for clinical reasons, a high purity product was required. Some haemophilia directors said that the slower solubility of the PFC intermediate VIII was a disadvantage, and also that some patients experienced more side effects than with the commercial products. In acknowledging the solubility problem Mr Watt said that he hoped to have a PFC product available soon which met the solubility characteristics of the commercial products. Mr Watt also invited members to discuss with him the question of a high purity product so that the PFC might meet this requirement.

(d) Home Therapy and Future Demand

The trend towards home therapy and the demand for factor VIII which it created was discussed. Of the several centres for which figures (annual requirement per patient) were available it was agreed that the Oxford figure of 20,000 was typical for the UK as a whole, but that the Newcastle figure of 50,000 was more realistic for forward planning purposes. It was accepted that, taking into account other therapeutic requirements for VIII, the overall figure of 2.75×10^6 iu/10^6 pop/year suggested in the paper was a suitable basis for further consideration.

(e) PFC Factor VIII yields

Dr Cash acknowledged the work done by Dr Foster in producing substantive and reliable information on yields of factor VIII at the PFC from 1975 to 1980. In 1980 the number of international units of factor VIII per litre of FFP processed was 250 and it was anticipated that, on the basis of the further improvement in yields during the last 3 months of 1980, 300 units per litre could be achieved in 1981.

(f) Cryoprecipitate yields and use

In introducing this part of the paper Dr Cash emphasised the important part cryoprecipitate could play in haemophilia treatment. The increase in home therapy would place such a strain on resources that all options had to be studied, including serious consideration of the use of cryoprecipitate for this form of treatment. Haemophilia directors were generally not in favour of using cryoprecipitate in this way, as in their view the risks of side effects were too great. They were however prepared to use cryoprecipitate in hospitals. Having regard to the difficulties in meeting increasing demands, the chairman emphasised that the therapeutic needs of haemophilia patients could only be matched with an optimum range of products which took into account resource constraints.

(g) Factor IX

While because of lower demand factor IX did not present problems similar to those of factor VIII, there were a number of issues which would have to be resolved. There was general agreement with Dr Cash's proposals.

4. The chairman thanked Dr Cash for his comprehensive paper which had set the scene for a very useful discussion. The many issues raised would require further investigation and discussion, and he proposed that the best way to proceed should be considered later in the meeting.

DEVELOPMENT OF A NEW APPROACH TO REGIONAL ISSUES OF FACTOR VIII CONCENTRATE FROM PFC

5. Mr Watt invited members to consider a proposal that each region should get back quantities of blood products in proportion to the amount of plasma sent to the PFC for processing, rather than by the present method whereby factor VIII was distributed on the basis of population.

Haemophilia directors expressed reservations about this proposal, and the chairman referred to the central funding of the blood transfusion service in Scotland compared with the strong regional element in the English service. In general members agreed that Mr Watt should continue to maintain a reserved supply of factor VIII at the PFC and were of the view that while issues of VIII should be related to the amount of plasma submitted for processing it was for the transfusion service to rationalise the collection of plasma appropriately.

COUNCIL OF EUROPE RECOMMENDATION ON BLOOD PRODUCTS FOR THE TREATMENT OF HAEMOPHILIACS (Paper 81/2)

6. The Chairman introduced paper 81/2, a Council of Europe Recommendation concerning blood products for the treatment of haemophiliacs. The recommendations broadly set guidelines for the preparation and use of blood products for the treatment of haemophiliacs and urged members states to become self sufficient in these products. After consideration of the various recommendations in the paper members agreed that policy and practice in Scotland were consistent with this document, subject to further consideration of the recommendation on the setting up of a haemophilia register.

NATIONAL REGISTER OF HAEMOPHILIACS

7. The establishment of a national register had been discussed when the group met previously, and at that time had attracted only limited support. Dr Forbes said that the Oxford centre had set up a computerised record for which haemophilia directors regularly submitted information, and in return they received a list of

patients annually. He asked whether this record might fulfil the functions of the proposed Scottish register. Several members questioned the adequacy of the computerised data from Oxford insofar as they did not identify the products used or the amounts consumed by each haemophiliac. Dr Cash specifically raised the BTS interest and the lack of positive information from the Oxford scheme on which he and his colleagues could base future production of the various fractions required. It was agreed to accept the recommendation in the Council of Europe document but that there should be more specific consideration of the form of a national register and how it could be set up.

REPORTING OF UNTOWARD PATIENT REACTIONS TO PFC PRODUCTS

8. Dr Cash drew attention to the importance of reporting any untoward patient reaction to specific PFC product. He reminded members that the PFC had a statutory responsibility under the licensing arrangements to ensure that it was informed of such reactions in order that it could investigate them. Professor Girdwood reminded the meeting that the producer of any product licensed under the Medicines Act had a statutory duty to report untoward reactions to the Committee on Safety of Medicines. Mr Watt commented that he would like to know of any reaction as soon as possible in order that the remainder of the batch of that product could be removed from stock and the balance traced. It was agreed that a more efficient reporting system be devised.

PROPOSAL FOR RECOGNITION OF EDINBURGH & GLASGOW HAEMOPHILIA CENTRES AS REFERENCE CENTRES

9. The chairman reported that he had received requests from Professor Bloom, chairman of the Reference Centres Director Group, and also from Dr Forbes and Dr Ludlam, asking that the haemophilia centres in Edinburgh and Glasgow be designated as official reference centres. At the chairman's invitation Dr Forbes explained that in England and Wales the designated reference centres were charged with a responsibility for co-ordinating the functioning of the haemophilia service. Many centres in England and Wales are relatively small and look to the larger reference centres for guidance and advice. The proposal to designate the 2 largest Scottish centres as reference centres was simply to formalise the present situation whereby the Directors of the Edinburgh and Glasgow centres attended meetings of the Reference Centre Directors in the interests of UK co-ordination. Dr Forbes also explained that internationally it was important that certain centres in the UK were recognised as reference centres for training purposes. Members agreed that this link with England and Wales was important and should be maintained, and it was confirmed that the Directors of the other centres in Scotland, viz Aberdeen, Dundee and Inverness, supported the proposal that Glasgow and Edinburgh should be regarded as reference

centres. The chairman said that the Department would wish to support this recommendation in regard to the status of the Edinburgh and Glasgow directors in the UK context, but the designation of these 2 centres as reference centres would require further consideration involving the CAMOs.

ANY OTHER BUSINESS

10. The chairman reviewed progress on the agenda and referred to a number of points which had been raised and would require further discussion. He suggested that in view of the difficulties and the amount of professional time involved in bringing together the full membership, a smaller group might be more suitable for pursuing in greater depth the various points which had been raised. Members agreed that such a group should be set up to meet regularly, with a remit to report back in one year's time to the full committee. The membership of the working group was agreed as follows:-

Chairman - Dr G A McDonald

Members - Dr J D Cash
Mr J Watt
one other SNBTS nominee
one haemophilia director - Edinburgh
one haemophilia director - Glasgow

The Department would provide secretarial and medical officer support to the group.

11. It was agreed that the matters for consideration by the working group would be the specific proposals listed in paragraphs 6 and 10 of Dr Cash's paper, together with the following items:-

(i) Reporting of adverse reactions
(ii) Haemophilia register
(iii) The problem of hepatitis

12. Dr McDonald paid tribute to the excellent paper prepared by Dr Cash and expressed the hope that a similarly informative document would be available for future meetings of the main group.

DATE OF NEXT MEETING

13. It was agreed to leave over the date for the next meeting.