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NOTE OF MEETING OF SNBTS DIRECTORS AND HAEMOPHILIA DIRECTORS HELD IN ST ANDREW'S HOUSE ON 8 MAY 1975

Present:

Dr G A Scott (Chairman)

Dr C Cameron Dr J D Cash Dr I A Cook

Professor S H Davies

Dr A A Dawson

Professor R H Girdwood Major-General H C Jeffrey

Dr H B M Lewis Dr G A Macdonald Dr C R M Prentice

Dr D Shaw Dr J K Smith Dr J Wallace

In Attendance:

Dr A D McIntyre )
Mr G N Munro ) SHH

Mr R N Roberts
Mr J Docherty

Secretariat

# Apologies for Absence.

1. Apologies for absence were intimated on behalf of Professor Douglas, Dr Tudhope and Mr Watt. The Chairman welcomed Dr Shaw who was attending in place of Dr Tudhope.

# Introduction

- 2. The Chairman in opening the meeting said that this was the second of what he hoped would be a series of meetings with SNETS Directors and Haemophilia Directors. The first meeting in November 1973 had by general consensus been most useful and it was felt that this second meeting had perhaps been delayed too long.
- 3. The Department was increasingly aware that in the information provided for Ministers to enable them to answer questions in Parliament about the supply of Factor VIII for the treatment of haemophiliacs, constant reference was being made to the fact that when the PFC was fully commissioned long term supplies of Factor VIII concentrate would be assured; it was however still not clear what the time-table was for cryoprecipitate being replaced by concentrate. It was important that all concerned should be kept up-to-date with any changes in the programme and this was one of the main reasons for the meeting.
- 4. It was agreed that the paper "The Supply of Factor VIII", copies of which had been circulated previously to members, should serve as an informal agenda and any points not covered in discussions of the paper could be brought up later.

#### The Supply of Factor VIII

5. In introducing the paper Major-General Jeffrey said that it had been prepared

in collaboration with the Scientific Director of the PFC and they had found it difficult to come to any firm forecast figure on the yield of Factor VIII from a given quantity of plasma. Processing of plasma including separation, freezing, storing and thawing resulted in a variable loss of activity. Assay before fractionation showed an average of 600 units Factor VIII activity/litre, but the range was wide. The process of fractionation causes further loss and the ultimate yield may be as low as 250 units/litre rather than the 400 units previously hoped for. The freeze dried preparation now issued has activity of 200 units/vial being reconstituted to 15 mls.

6. It was proposed to have soon a first meeting of Regional Transfusion Directors to consider the whole question of the processing of plasma; Haemophilia Directors might be invited to attend meetings at a later stage. The programme at the PFC to commence processing 400 litres of plasma per week for Factor VIII had started on 5 May.

# Factor VIII/Cryoprecipitate

7. It was estimated that it cost approximately \$\frac{1}{100}\$ per year using cryoprecipitate to look after one severe haemophiliac compared to \$1,800\$ using comparable commercial Factor VIII preparations. If concentrate prepared at PFC was used the cost was likely to be about £1,000. The decision which needed to be taken was whether to back cryoprecipitate in the short term or switch resources to concentrate; the Department's view until now had been that the aim should be towards increasing production of concentrate. Less plasma was required to produce a given amount of anti haemophiliac activity as cryoprecipitate than as Factor VIII. If it could be assumed that the use of plasma for other purposes had now reached a plateau then any increase in supply could be used for the production of Factor VIII. There is no clear indication however that this plateau has been reached and it was not therefore possible to make accurate predictions about supplies in the near future. Much would also depend on the yield obtained on factionation.

# Use of Factor VIII

- 8. Maemophilia Directors were asked if they could give PFC an indication of the most convenient size of dose for use in the various clinical situations. From the discussion it emerged that two dose sizes were required, one of about 250 units and the other around 600 units; intermediate and larger doses would be obtained by suitable combinations of these packages. The situation would be kept under review.
- 9. During discussion on whether the replacement of cryoprecipitate by Factor VIII should be complete or only partial and what the estimated timescale would be, Directors agreed that the aim should be eventually to replace cryoprecipitate completely by concentrate. It was however stressed that the latter would have to be available in sufficient quantity before this could be achieved. At the moment only cryoprecipitate and commercial products were available in quantity. PFC would have to prove that concentrate could be supplied in quantity before any

, programme of phasing out cryoprecipitate could be started. It was suggested that cryoprecipitate could be obsolete in 5 years but some Directors preferred to wait another six months to see how the production at the PFC was going to be before coming to any conclusion about the time scale.

- 10. It was considered to be essential to have a good stock in reserve before starting a programme of cryoprecipitate replacement and the PFC were aiming for a processed stock of about 1,000,000 units by the end of September. Some disappointment was expressed at the September deadline and the need for 1,000,000 unit stock was questioned. General Jeffrey agreed to look again at the possibility of releasing material to Haemophilia Centres in August before the 1,000,000 units target was achieved.
- 11. There was general agreement that as supplies became available the home treatment programme should be given the first priority; a very small pilot scheme had shown that home treatment need not necessarily lead to any significant increase in demand. It was hoped that it might be possible to start with a few cases in September/October; many patients had been awaiting this development for a considerable time and a start, even on a small scale, would do much to raise morale.
- 12. On the question of medical supervision of home treatment for haemophiliacs it was noted that patients would obtain their supplies from their haemophilia centre and in this way a check would be available on the amounts used. Dr Dawson expressed considerable anxiety at the position in Orkney and Shetland where there were undoubtedly haemophiliacs who were undetected and therefore undertreated. Dr Cook agreed and mentioned the apparent reluctance of GPs to put haemophiliacs under consultant supervision. GPs in remote areas needed to be educated in this respect and if the true number of haemophiliacs was discovered the demand for Factor VIII would undoubtedly increase.

#### Requirements

- 13. Discussion underlined the difficulty at arriving at any precise total requirement for the future in terms of Factor VIII. Major-General Jeffrey agreed to prepare a questionnaire for completion by the Haemophilia Directors giving information about the number of known haemophiliacs, the number who from the treatment point of view are mild, moderate or severe, and other related data.
- 11. All Directors were endeavouring to encourage an increase in use of concentrated red cells and a usage of around 40% had now been attained generally; in the SE recently a rate of up to 65% had been reached. Such a campaign was however difficult to sustain because clinicians found it difficult to see the benefit if there was no corresponding increase in the availability of other blood products. This raised the question of whether the use of concentrated red cells was seen to be a treatment of choice or a means of providing additional plasma for fractionation.

# Date of Next Meeting

15. It was agreed that the meeting had provided a forum for a useful exchange of information and that a further meeting should be held at 2.15 pm on Friday, 14 November.