

11/10/74

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MINUTES OF THE MEETING OF THE EXPERT GROUP ON THE TREATMENT OF HAEMOPHILIA HELD ON FRIDAY 11 OCTOBER 1974 AT ALEXANDER FLEMING HOUSE

PRESENT:

Chairman

1140

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DHSS

1. APOLOGIES FOR ABSENCE

An apology for absence was received from [unclear] of the Welsh Office.

2. REORGANISATION OF HAEMOPHILIA CENTRES

Draft HSC(1S) - Paper I.

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The following amendments were agreed:-

- (a) Para 2 line 4 - "and therapeutic" to be inserted after "diagnostic".
- (b) line 8 - "preventive medicine and dentistry" to be inserted after "fields of" and "and social medicine" to be added after "Genetic counselling".
- (c) Para 3 - New heading "Associate Centres" and text to read:- "Centres which were designated in 1968 but which do not fully meet the new criteria may nevertheless, to avoid inconvenience to patients already registered with them who live or work nearby, continue to be recognised for the purpose of giving emergency treatment. These Centres will be known as Associate Centres. Each will be linked with a convenient designated Haemophilia Centre so that together they will be in a position to offer patients attending a full therapeutic, diagnostic and advisory service".
- (d) Para 4 - new heading "Reference Centres".
- (e) line 9 - omit "major".
- (f) Para 5 - to be rewritten by the Department so as to reflect the decision that Authorities should be asked to review, in consultation with the appropriate Reference Centre, the current list of Haemophilia Diagnostic and Treatment Centres and to inform the Department which are to be designated as Haemophilia Centres and which are to be known as Associate Centres.
- (g) Para 6 - to be omitted and Para 7 renumbered Para 6.

Draft Memorandum - PAPER I

- (h) Para 2 sub section (i) (c) should read "in collaboration with the appropriate Reference Centre to investigate relatives of patients with haemophilia or related conditions".
- (i) Para 2 sub section (iii) - should be omitted and the following substituted - "an advisory service to patients (and, in the case of child patients, to their parents) on matters of concern to them such as preventive medicine and dentistry, education, employment, genetic counselling and social medicine. Advice should also

be given to general practitioners about the emergency treatment of haemophilic patients on their list and the procedure for securing these patients' admission to hospital when required, including what the patient should do to obtain ambulance transport in an emergency".

- (j) Para 3 lines 4 & 9 add "and telephone number" after "address".
- (k) Para 4 remove "Major" from title.
- (l) Para 5 line 5 insert "currently so designated" after "the centres".
- (m) The list of Reference Centres to be revised as follows:-

St Thomas' Hospital)	London, the South East and East Anglia.
The Royal Free Hospital)	
The Churchill Hospital, Oxford)	Oxford, Wessex, the South West The Midlands & NI
The Royal Infirmary, Manchester)	The North West, North Wales Trent and Yorkshire
The Royal Infirmary, Sheffield with)	
the Children's Hospital)	
The Royal Victoria Infirmary)	The North of England
Newcastle)	
University Hospital of Wales)	South Wales
Cardiff)	

- (n) Para 6 sub section (i) should read - "to co-ordinate the allocation of available therapeutic materials to Haemophilia Centres and Associate Centres".
- (o) sub section (ii) should be renumbered (ix) and all other sub sections renumbered accordingly.

3. OPTIMUM USE OF FACTOR VIII PREPARATIONS

The C/M asked I _____ and I _____ to
speak briefly to their respective papers.

PAPER II

major recommendation was that any money which could be made available should be spent on home therapy. He also pointed out that at the present time the commercial preparations of factor VIII were only available to recognised Haemophilia Centres and not on prescription from GPs. This was appropriate as the commercial preparations were too expensive for indiscriminate use. Unfortunately until the preparations were easily available through the NHS money would have to be spent on commercial products. In Newcastle this would amount to about £90,000 per year, within 3 years.

PAPER III

main recommendation was that in the London area a central committee to co-ordinate the use of factor VIII be set up. This Committee would include representatives of all interested parties with a small committee appointed by the central committee to deal with emergencies in supply or organisation. The chairman would be independent, neither a Regional Transfusion Director nor a Haemophilia Centre Director.

PAPER V

spoke briefly to her paper on home treatment with cryoprecipitate. 530,000 packs each containing 60-100 units were used last year for home treatment by haemophiliacs normally treated at the Royal Free Hospital. The Chairman asked the meeting if a study carried out to show the difference in cost between home therapy and treatment at a Haemophilia Centre was feasible and whether it would provide data which would be useful when planning future requirements for factor VIII. Members were of the opinion that many of the advantages of home treatment could not be quantified, for example, the reduction in number of children crippled or the improvement in the quality of life for patients on home treatment. It was decided that a costing study would be of little benefit at the present time.

PAPER IV

spoke to his paper which looked at the problem from an economic standpoint. He found it difficult to obtain accurate figures on the demand for haemophilic materials as different sources of information gave different figures.

felt that any money available for the supply of blood products principally freeze-dried factor VIII, should be used to increase production within the NHS. It was felt that an effort should be made to increase the supply of plasma to the Fractionation Centres, thereby increasing the amounts of blood products available from NHS sources.

4. ANY OTHER BUSINESS

asked for guidance from the Group on a problem arising from the current limited production of factor VIII.

There were indications that Regional Authorities in a position to supply plasma for fractionation to BPL, Elstree were expecting to receive in return factor VIII concentrate in proportion to the amount of plasma supplied.

If such requests were met the consequence would be that Regions who could produce only small volumes of plasma for fractionation would receive little or no NHS factor VIII concentrate, even though their needs might be very great.