HP 23110 (part 1) Received in confidence from the Haemophilia Society 26.10.82 Read 1.11.82

P.3 Annual Reports

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REPORT ON THE 13th MEETING OF THE U.K. HAEMOPHILIA CENTRE DIRECTORS, held in Manchester on 13th September 1982.

N.B. The following items are those I feel to be of particular interest, rather than a comprehensive report of everything discussed at the meeting.

1. Professor Arthur Bloom agreed to continue as chairman for three more years.

2. Report of Reference Centre Directors

(a) It was confirmed that Belfast, Edinburgh and Glasgow are now recognised as reference centres.

(b) Dr. Peter Jones, on behalf of the reference centre directors, presented a re-draft of the DHSS circular defining arrangements under which hospitals are designated as haemophilia centres (see Annex 1 to this report).
Changes were felt necessary because of the widespread availability of home treatment, and because of the increasing number of centres (now about 150).
The major changes proposed are:-

(i) The circular refers to arrangements for care of people with haemophilia etc. and their families.

(ii) The distinction between haemophilia centres and associate centres is to be removed.

(iii) It is no longer thought appropriate to recognise as centres hospitals providing only local treatment facilities for only a few patients (2 or 3 in some instances).

(iv) The functions of reference centres are to include those newly specified in paragraphs 2(iii), (iv) and (vii) of Annex 1, and the requirement of paragraph 2 (v) is more specifically stated.

(v) Specific recommendations on situation and staffing of reference centres are given - see paragraphs 3 and 4 of Annex 1.

(vi) The definitions of the respective responsibilities of reference centres and haemophilia centres imply increased control over the latter by the former.

In response to a request by Professor Bloom, I undertook on behalf of the Society to submit our comments to the reference centre directors. In conversation with Professor Bloom and Dr. Jones at lunch they confirmed that the general intention is to exert more control over the haemophilia centres and in consequence to raise the general quality of service. I offered my view that the changes were to be welcomed, but that the Society would probably want to ensure that arrangements made by individuals for local treatment are safeguarded.

3. Annual Returns for 1981

The returns for 1981 were presented, and these are given as Annex 2 to this report. The major features of these are:-

(a) Total usage of Factor VIII rose to 65.7 million units (compared with 57.7 million units in 1980). The increase over several years shows no sign of falling off, and the predictions of a total requirement of 85 million units by 1985, and of 100 million units by the end of the decade, still seem valid.

(b) All the increase in Factor VIII usage was accomodated by increased N.H.S. production (from 14 million to 22.5 million Units), there being no increase in usage of commercial products (see also Paragraph 4 below).

(c) It was noted that demand for Cryo had stabilised at about 8 million units, and was expected to show some increase in future in view of its value for treatment of mild and moderately affected patients (because of its lower hepatitis risk) - see also paragraph 5 below.

(d) In discussion it was suggested that more information on treatment of severe haemophiliacs is needed. In addition, unreliability of diagnosis of severity was suspected from anomalies in the figures. The information on cause of death was felt to be inadequate, and in particular it was asked that an assessment of liver damage should be made at autopsy whenever possible.

4. Blood Products Laboratory, Elstree

Dr. Richard Lane reviewed progress at the Laboratory. Most of his review we had already covered by conversation with Mr. Godfrey of DHSS, but the main points are that BPL reached its production target in 1981 (19 million units) and should reach its 1982 target of 30 million units. The re-built plant is still hoped to be in commission in 1985-6, but a major problem is expected to be plasma supply. In conversation, Dr. Lane told me that he possibly could buy unprocessed plasma from the U.S.A., but that obviously there would be political problems in that course. In addition, he was of the view that at least some of the commercial companies would stop selling Factor VIII in the U.K. before very long.

5. Hepatitis Working Party

Dr. Craske produced statistics on the incidence of hepatitis which I found largely incomprehensible. However, it appears from a study at Oxford, that the risk of contracting hepatitis from large-pool N.H.S. concentrates is unexpectedly high. Dr. Craske reported that a trial of Hepatitis B vaccine is being undertaken in the U.K., and speculated on the value of such vaccine to mild or moderate haemophiliacs.

6. Home treatment Working Party

Dr. Jones reported that 44% of severe haemophiliacs were now on home treatment. Given that this percentage represents 84% of those eligible, he felt that this working party had fulfilled its objective, and it was agreed that the working party should be wound up.

7. Inhibitor patients Working Party

Dr. Prentice reported that a trial to compare Autoplex with high dose Factor VIII therapy was being undertaken.

8. In addition to the conversations referred to above, I had conversations of particular interest with:-

(a) Dr. Daly (Bristol), who was representing Dr. Scott. She stated that special arrangements had been made to supply Cryo to three patients who particularly requested it, but that it might not be possible to continue the arrangement indefinitely.

(b) Dr. Aronstam (L.M.T.H.), who was continuing to find difficulty in financing treatment of his inhibitor patients.

(c) Dr. Savidge (St. Thomas'), who raised the problem of financing treatment of patients at hospitals outside their own regions.

K.E. Milne
10 October 1982