WEST MIDLANDS REGIONAL HEALTH AUTHORITY

WORKING PARTY ON THE TREATMENT OF HAEMOPHILIACS

Notes of a meeting held Thursday 13th May 1976

Present: Dr. S. R. F. Whittaker (In the Chair)
Dr. W. S. A. Allen
Dr. G. W. G. Bird
Dr. C. Giles
Dr. J. R. Mann
Dr. R. W. Payne
Dr. N. K. Shinton
Dr. J. Stuart
Dr. Rosemary Biggs (By invitation)
Dr. J. C. Stewart
Mr. G. Dodwell (In attendance)

Apologies for absence 76/1

Apologies for absence were received from Sir Melville Arnott, Dr. J. J. Kramer and Dr. M. O'Shea.

Minutes of the previous meeting 76/2

The minutes of the meeting held 18th December 1975, having been circulated, were confirmed as a correct record, subject to the following amendment:-

Page 2, under "Availability of Cryoprecipitate and freeze-dried Factor VIII", para. (iii) Amend the last sentence to read "One of the recommended Factor VIII concentrates was Kryobulin".

Availability of cryoprecipitate and freeze dried Factor VIII concentrate 76/3

On behalf of the Working Party the Chairman welcomed Dr. Rosemary Biggs, of the Haemophilia Reference Centre, Oxford, who was present by invitation for discussion of this and following matters.

Dr. Biggs said that it was important to have an accurate count of the number of patients treated in haemophilia centres as this would form the basis of the proportional distribution of Factor VIII, although the actual mechanics of distribution had yet to be worked out. She went on to say that NHS plasma could be produced at about one half the cost of the commercially produced product, and gave details of the material used during 1974 (Enclosure 3 in minute book).

Dr. Bird said that whilst Freeze-dried Factor VIII concentrate was the preferred method of treatment in haemophilia, lack of funds prohibited a total change over. For this reason it was not possible at this stage to cease production of cryoprecipitate: the current need in the West Midlands region was for 40,000 units packs per annum in addition to the 26,000 units required by the DHSS for the manufacture of Factor VIII concentrate. He referred to the fact that the amount of Factor VIII returned to the Region was not comparable with the 26,000 ~~units~~ packs of plasma sent to the Lister Institute. Dr. Biggs agreed that it was necessary to draw up a schedule of distribution which could be reviewed regularly, and said that a yearly meeting of directors of haemophilia centres would be helpful in this respect. She said that agreement had been reached that Factor VIII should be distributed on the basis of the number of haemophilic patients in each region, and she had sent out a letter of enquiry to try to establish the numbers concerned (Enclosure 4).

Dr. Biggs submitted a confidential paper for discussion (Enclosure 5, page 2 alternative B) and said that Factor VIII and Factor IX should be distributed through the BTS Directors. Dr. Stuart referred to the problems of the General and Dental Hospitals etc. where it was necessary to treat haemophilic patients for conditions other than haemophilia, and yet they could not all be designated haemophilia centres.

Dr. Stuart referred to the fact that at the December meeting it had been agreed that, subject to the approval of the Regional Scientific Committee, a letter should be sent to all AHAs giving details of the haemophilia centres with which local hospitals should collaborate. Dr. Stewart said that this had been held back until the DHSS had formally approved the designation of centres. It was further pointed out that the Regional Scientific Committee had referred the matter to the Regional Medical Committee as it was a clinical matter.

Dr. Shinton referred to the concentration of haemophilic patients in the Hereward College in Coventry from outside the Region, and said that his AHA were very concerned about the costs involved in treating these patients with Factor VIII.

Summing up, the Chairman asked Dr. Stewart to attend the next meeting of the Regional Medical Committee to emphasise the points made during the discussion.

The Working Party then considered copies of papers by Dr. Mann in respect of child patients treated, (Enclosure 1) and Dr. Stuart in respect of adult patients (Enclosure 2), together with a further breakdown of child patients produced by Dr. Mann (Enclosure 6). Dr. Stuart referred to the need for a strict definition of the term "treatment" when applied to haemophiliacs: did it mean occasions when patients attended for specific treatment of their haemophilia, or did it mean any form of treatment e.g. dental scaling? Dr. Mann spoke of the costs involved in the treatment of haemophiliacs and suggested that the matter might be considered by the Sub-Committee set up by the Regional Medical Committee to consider the funding of regional specialties. Dr. Stuart said that he hoped to furnish more detailed figures after the up-dating of the haemophilic register had been completed: in particular he hoped to provide details of costs of the first full working year.

Home treatment 76/4

Dr. Stuart said that of the patients attending the Queen Elizabeth, there were now 30 on home treatment, and it would be possible to pass responsibility for these cases to other centres where appropriate. Dr. Shinton said that whilst many of the cases attending the Coventry centre would prefer to go onto home treatment in fact only 9-12 were suitable for this form of treatment. Dr. Mann said that 7 patients from the Childrens Hospital were on home treatment and another 8 were suitable for home treatment but lack of a haemophilia sister was a major obstacle.

Organisation of haemophilia centres 76/5

Dr. Stewart reported for information that he had officially notified the DHSS that three centres The Queen Elizabeth and Childrens Hospitals jointly, Stoke and Coventry, had been designated Haemophilia Centres, whilst Shrewsbury, Worcester, Hereford and Wolverhampton were to be designated Associate Centres.

Records 76/6

Dr. Stuart said that he had re-designed the record cards in use at the Queen Elizabeth Hospital (Enclosure 7 in minute book), and they were available for distribution to those hospitals who might wish to make use of them. He asked all directors to ensure that copies of the annual return were sent to him in future. In this respect he thought it would be helpful if Dr. Biggs laid down a date by which time annual returns should be submitted - say the end of February in each year.

Dr. Stuart then referred to the discussion at the December meeting when it had been agreed that directors of haemophilia centres should send tc him a copy of each patient haemophilia registration card, with a further copy to Dr. Mann in the case of children. He also asked that a reminder be sent to all directors asking them to let him have copies of their annual return by the end of February in each year.

Appointment of haemophilia sister 76/7

Dr. Mann referred to her report (Enclosure 6 in minute book) concerning the appointment of a haemophilia sister at the Childrens Hospital. For the first year her salary had been paid by the Haemophilia Society who had now withdrawn this financial support, but Birmingham Central Health District were unable to accept continuing responsibility and the sister had therefore left. Dr. Stuart said that although the continuance of this appointment was supported by the Paediatric Division and the Medical Executive Committee, the Nursing Division felt that other priorities must take precedence. He went on to say that ideally there should be two part-time sisters, one at the Childrens and one at the Queen Elizabeth who should cover for each other.

Dr. Biggs expressed the view that the sister was a vital member of the haemophiliac team, and the Chairman stated that the members of the Working Party were gravely concerned at the fact that this post had been allowed to lapse. Dr. Stewart said that he would make enquiries into the matter on an informal basis initially.

Date of next meeting 76/8

It was agreed that the next meeting of the Working Party be held at the offices of the Regional Health Authority on Monday 22nd November 1976, at 10.30 a.m.

GD/CR
14th June, 1976.