

WEST MIDLANDS REGIONAL HEALTH AUTHORITY

WORKING PARTY ON THE TREATMENT OF HAEMOPHILIACS

Notes of a meeting held on Monday, 15th May 1978 at 10.30 a.m.

PRESENT: Dr. N.K. Shinton (in the Chair)  
Dr. W.S.A. Allan  
Dr. G.W.G. Bird  
Dr. F.G.H. Hill  
Dr. R.M. Ibbotson  
Dr. M.J. O'Shea  
Dr. R.W. Payne  
Dr. J. Stuart  
Dr. J.C. Stewart

Miss J.E. Jelf - in attendance

Apologies

78/1

Apologies for absence were received from Sir Melville Arnott, Dr. J.R. Mann, Dr. E.G. Rees and Dr. S.R.F. Whittaker.

Minutes of the previous meeting

78/2

The minutes of the last meeting of the Working Party held on 21st November, 1977 were confirmed as a correct record and signed, subject to the following amendments :-

- (i) Include Dr. M. O'Shea in the list of those present
- (ii) Minute 77/21, last paragraph, 3rd line amend "FEBA" to read "FEIBA".

Matters Arising from the previous minutes

78/3

- (a) Home Treatment Packs  
(Previous Minute No. 77/21)

Dr. Stuart had nothing further to report on this matter, but undertook to raise it for discussion at the Supra-Regional Haemophilia meeting in Oxford in June 1978.

The question of home treatment packs should be given further consideration at the next meeting.

- (b) Appointment of Haemophilia Sister  
(Previous Minute No. 77/25)

Dr. Stuart reported that there had been no further progress in the appointment of a Haemophilia Sister. He had enquired of Central Birmingham Health District if unallocated revenue could be reallocated for this purpose, but had been told that this was not possible. The appointment of a haemophilia sister was however high on the priority list.

It was agreed to consider this matter again at the next meeting.



(c) Determination of Variants of von Willebrand's Disease  
(Previous Minute No. 77/28)

Dr. Shinton reported that the facilities at Coventry for testing for this disease had been developed and it was no longer necessary for all of this work to be centralised at the Childrens Hospital, Birmingham.

Availability of cryoprecipitate and freeze dried Factor VIII concentrate  
(Previous Minute No. 77/22)

78/4

Members received and considered in detail a summary showing the availability of cryoprecipitate and freeze dried Factor VIII concentrate, from October 1977 - February 1978 (Enclosure 1 in minute file).

Dr. Bird referred to DHSS calculations, based on overall albumin requirement, that indicated a need to increase the number of blood donations dramatically - by 185,000 a year in this Region. If this were done, the amount of Factor VIII potentially available would be doubled, but expansion of the BTS to that extent was unlikely in the current financial climate (even if the DHSS calculations were accepted).

Dr. Shinton indicated that the BTS had passed its target figure of 3.8 mil. and was now sending 4.1 million units to the Lister Institute, but Lister was returning to this Region only 1.4 million units of Factor VIII. This meant that the Region was getting back only 1/3rd of the units sent, whereas the return expected was between 2.8 - 3.4 million units. Dr. Bird did not think that this loss was peculiar to this Region, part of the loss could be accounted for by natural wastage and part by subsidising other Regions.

Dr. Shinton and Dr. Stuart agreed to raise the question of this loss at the Supra Regional Haemophilia meeting at Oxford on 19th June 1978, and report back to the next meeting of this Working Party.

Members then considered a paper by Dr. Stuart, showing the "Actual and Estimated Consumptions of Factor VIII in 1977", which was laid on the table (Enclosure 2 in minute file). Dr. Stuart pointed out that it had been estimated that in 1977, 2,022,500 units of Factor VIII would be used and the actual number used was 2,197,827, and 2,157,900 units of Cryoprecipitate VIII would be used and the actual number was 1,557,750. Dr. Stuart said that it was also interesting to note that the number of units of Cryoprecipitate or Freeze dried Factor VIII used per patient had dropped from 18,916 in 1976, to 15,718 in 1977.

A further paper by Dr. Stuart showing the number of patients treated and the Units of coagulation factor activity used in 1976 and 1977 was laid on the table (Enclosure 3 in minute file). Dr. Stuart explained that the amount of Cryoprecipitate used in the Region had dropped from 2,020,480 in 1976 to 1,557,750 in 1977, while the amount of Commercial Factor VIII used had doubled; that produced by Lister had remained the same.

Dr. Stuart expressed his concern at the failure to increase output from Lister. Only 1/3rd of the Factor VIII used at the Queen Elizabeth Hospital was from Lister, the other 2/3 was purchased commercially, this meant that the cost of Factor VIII to that Centre had increased from £50,000 in 1976 to £80,000 in 1977. Coventry obtained 34% of its Factor VIII from Lister and Stoke-on-Trent 67%, and small amounts were now being

made available to the Childrens' Hospital also. Dr. Hill made the point that it would be more economical if Lister produced some of the Factor VIII in smaller numbers of units per vial.

DHSS Central Contracts 1977/78  
(Previous Minute No. 77/23)

78/5

Dr. Stuart said that the Queen Elizabeth Hospital obtained its Commercial Factor VIII from two firms only. These firms had been changed in September 1977. Previous to this patients on home treatment were given a bottle of 320 units of Factor VIII costing £32 and they were now given bottles of 240 units costing £24 which had proved quite adequate. Members gave details of the costs of commercial Factor VIII from firms which they dealt with and agreed that it was a good principle to buy Factor VIII within the Region from at least two commercial firms.

Dr. Stewart explained that there would be no saving with a Regional Contract, as the amounts being purchased would not increase the discount. Since there was no financial gain in having a Regional Contract, he had not submitted this proposal to the RTO. He went on to say that a Working Party was at present considering the funding of Regional Services and it was expected to report in Autumn 1978. It was anticipated that the Working Party would recommend an improvement in the resource allocation formulae rather than direct Regional Funding.

It was agreed to give further consideration to this at the next meeting.

Organisation of Haemophilia Centres  
(Previous Minute No. 77/26)

78/6

Dr. Shinton said that he had had discussions with the persons concerned at Burton-on-Trent and it appeared that the patients with haemophilia who were concerned were so used to travelling to Birmingham that they were reluctant to change. It was suggested, however, that new patients could be referred to Stoke-on-Trent and Dr. Shinton undertook to write to the Chairman of the Staffordshire Area Medical Committee suggesting this as a matter of principle.

Diagnostic facilities in relation to Haemophilia and Haemoglobinopathies 78/7

Members received an extract from the notes of a meeting of the Working Party to Review Diagnostic Facilities for Genetically - determined Diseases and Congenital Abnormalities. (Enclosure 4 in minute file).

Dr. Stewart explained that the Working Party had been set up by the Regional Medical Committee, and it had in its turn set up four Sub-Groups:-

- (1) Sub-Group on Ultrasound and Amniocentesis
- (2) Sub-Group on Cytogenetics
- (3) Sub-Group on Inherited Metabolic Disorders and Abnormal Haemoglobins.
- (4) Sub-Group on Neural Tube Defects.

In addition, this Working Party had been asked to provide by the end of June 1978, a report on Haemophilia and Haemoglobinopathies. This should include existing facilities in the Region, inadequacies in the service, recommendations for future developments and trends of diagnosis.



Members discussed the inadequacies of the service and it appeared that there was a need for more laboratory staff support at the Children's Hospital. The need was also agreed for a Regional Diagnostic Unit for Haemorrhagic disorders where difficult cases could be referred. It was agreed to comment on necessary facilities of diagnosis of red cell enzyme defects.

The Working Party agreed to adhere to its current policy of Haemophilia and Associate Centres providing diagnostic facilities and treatment (both paediatric and adult); other hospitals should be encouraged to use these facilities. The Centres should be adequately funded, with sufficient equipment, technical support and ancillary staff.

Dr. Hill and Dr. Shinton undertook to write a paper including the points agreed above and send this to Dr. Stewart for submission to the Working Party to Review the Diagnostic facilities for Genetically - determined Diseases and Congenital Abnormalities.

Future of the Working Party

78/8

Dr. Shinton explained that the Regional Medical Committee had now agreed to the establishment of a Regional Blood Transfusion Service Advisory Committee. It had been suggested that when established, this Working Party should be disbanded and all its business taken over by the new Committee. He asked members for their comments.

Members felt that the work of this Working Party did not fall within the remit of the Blood Transfusion Service Advisory Committee and it was agreed that the Working Party's minutes should be exchanged with those of the Blood Transfusion Service Advisory Committee.

Dr. Shinton undertook to submit this proposal to the next meeting of the Regional Scientific Committee.

Time and Date of next meeting

78/9

It was agreed that the next meeting of the Working Party should be held on Monday, 4th December, 1978 at 10.30 a.m.

Dr. S.R.F. Whittaker

78/10

It was noted that Dr. S.R.F. Whittaker would be resigning from the Regional Health Authority during the summer and it was agreed that the first item on the agenda for the next meeting should be "Appointment of Chairman".

The meeting ended at 11.50 a.m.

JJ/JB/MJ  
27th June, 1978.