

West Midlands Regional Health Authority

WORKING PARTY ON THE TREATMENT OF HAEMOPHILIACS

Notes of a Meeting held on Monday, 23rd May 1977, at 10.30 a.m.

PRESENT: Dr. S.R.F. Whittaker (in the Chair)
Dr. W.S.A. Allen
Sir Melville W. Arnott
Dr. G.W.G. Bird
Dr. F.G.H. Hill
Dr. R.M. Ibbtson
Dr. J.R. Mann
Dr. N.K. Shinton
Dr. J. Stuart
Dr. J.C. Stewart
Mr. G. Dodwell (in attendance)

Apologies for absence

77/1

Apologies for absence were received from Dr. R.W. Payne and Dr. E. Rees.

Minutes of the previous meeting

77/2

The minutes of the meeting held on 22nd November 1976, having been circulated, were confirmed and signed.

Availability of Cryoprecipitate and Freeze Dried Factor VIII Concentrate

77/3

(Previous minute No. 76/11 and 76/12)

Dr. J.C. Stewart said that the Regional Team of Officers had called for a joint report from the Treasurer and the Regional Scientific Officer concerning expenditure on Freeze Dried Factor VIII Concentrate; in the last financial year, the expenditure had been in the order of £80,000, and Dr. Stewart said that he had been informed that the R.T.O. was prepared to allocate up to £100,000 during the current financial year but he would seek assurances first that the proposed method of distribution was the right one and second, that all the possible variations of supply of Factor VIII Concentrate from commercial sources, as opposed to the supply from the Lister Institute had been considered. Dr. Stewart confirmed that the joint report of the Treasurer and Regional Scientific Officer would be discussed with Dr. Bird for ratification before submission to the Regional Team of Officers. The Working Party reiterated their view that the purchase of Factor VIII Concentrate should be centrally funded and organised. Dr. J. Stuart said that, in his view all orders for Factor VIII concentrate should be placed through the BTS, but at the end of each financial year, Haemophilic Directors should have power to order supplies against Area budgets (assuming funds were available) if central sources of supply dried up.

Dr. Bird said that the DHSS were pressing for an increase in the use of packed red cells, in the West Midlands Region, only 31% of issues were in this form instead of the 50-60% advocated by the DHSS. Dr. Bird asked those present to encourage their clinical colleagues to make greater use of packed red cells. Dr. Shinton said that he would bring this matter up at a future meeting of the Haematology Group.

Dr. J. Stuart said that the Queen Elizabeth Hospital used 25% of packed red cells and said that at Edinburgh Royal Infirmary, the first two packs used were always packed red cells regardless of the order placed by the clinician and he thought that there was a case for the introduction of a standardised system of this sort. Dr. Bird said that he would consider this possibility. Dr. J. Stuart went on to say that surgeons in general preferred to use whole blood; clearly there was a need for education in this respect as fluid could be added to packed red cells in any event and the first litre was not normally significant in respect of blood volume. Dr. Shinton said that he would ask for this matter to be raised at a future meeting of the Regional Medical Committee. Sir Melville Arnott said that whole blood should only be supplied in the first instance at the specific request of a consultant or senior registrar. It was suggested by the Chairman, and agreed, that Dr. J. Stuart, Dr. Shinton and Dr. Bird should draft a memorandum on this subject which could be circulated throughout the Region, after approval by the Working Party.

Dr. Bird said that The Blood Transfusion Centre's stocks of Factor VIII concentrates had been used up; the concentrate supplied by the Lister Institute was not being used at the rate which had been predicted, and the demand for cryoprecipitate was going down. He pointed out that there was no policy for the allocation of this material. Referring to Enclosure 1 to the Agenda, Dr. Shinton pointed out that there was no allocation of Lister Factor VIII to Coventry and he felt that there should be a specific allocation; it was largely a question of payment and he queried why the Coventry Area should be expected to pay for all their concentrate when Stoke and Birmingham had an allocation of free concentrate from Lister. Dr. J. Stuart said that the figures in the enclosure had been based on the old allocation system for dealing with emergencies, etc., and he said that, in his opinion, Dr. Bird must still have the final say with regard to the allocation of this material, subject to the priorities agreed by the Working Party. He went on to point out that much of the Factor VIII used by the Queen Elizabeth was supplied direct by the Lister Institute.

Haemophilia Statistics

(Previous Minute Nos. 76/3 and 76/13)

77/4

The members of the Working Party received statistics compiled by Dr. J. Stuart (Enclosure 1 in minute file).

Dr. J. Stuart said the figures submitted did not include all the cases on the register - only those cases who had needed treatment during the year under review. He stressed that the statistics showed that the Central District was still carrying the major load in respect of the treatment of haemophiliacs. He quoted as an example the fact that, of the 35 major cases on home treatment, only 16 came from the Birmingham Area and of those only 6 came from the Central District.

Appointment of Haemophilia Sister

(Previous Minute Nos. 76/7 and 76/14)

77/5

Dr. J. C. Stewart said that he had spoken to the Regional Nursing Officer, and to Nursing Officers of Birmingham Area and the Central Birmingham District, and he had been assured that funds were simply not available

for this appointment. It was agreed that the matter should be submitted to the Birmingham Area Medical Committee. Dr. Mann said that the view in Birmingham was that there were more pressing nursing needs, and the Area were not happy that staff intended to provide a Regional service should be paid exclusively from Area funds. Dr. J. Stuart said that he had written to Dr. J.C. Stewart giving figures of the nursing staff employed in other Regions where the Haemophilia Centres were comparable in size to those at the Queen Elizabeth and it was clearly apparent that this Region suffered badly by comparison. Dr. Stuart went on to say that the Haemophilia Society had brought pressure to bear but without avail; Dr. Whittaker suggested that the Society should be asked to write direct to the Chairman of the AHA; and proposed that the number of treatments should be quoted rather than the number of patients treated.

Dr. J. Stuart said that the work load of emergency treatment at hospitals had been reduced by an increase in home treatment, but this method of treatment underlined the very real need for a Sister to supervise and advise the patient in his or her home. The members of the Working Party were unanimously agreed that a Haemophilia Sister would provide a Regional service, and should be funded at Regional level. The Chairman suggested that perhaps Dr. Bird would help by requesting the appointment of a Regional Nursing Sister, and Dr. J. Stuart said that he would discuss this proposal with Dr. Bird. Dr. Hill said that the Haemophilia Sister at the Royal Free Hospital was appointed to the BTS and was seconded to the Hospital.

Dr. Shinton placed on record the fact that, in his view, the first essential was to ensure adequate central funding for the supply of commercial Factor VIII Concentrate for issue by the BTS in the first instance and that the appointment of a Haemophilia Sister should take second place to that.

Organisation of Haemophilia Centres
(Previous Minute Nos. 76/5 and 76/16)

77/6

Dr. J.C. Stewart, in Dr. Payne's absence, said that Dr. Payne had discussed with Dr. Lewis the establishment of a joint centre at Worcester, Kidderminster and Bromsgrove, and Dr. Lewis had expressed a preference to be recognised as an independent Centre. The Chairman instructed Dr. J.C. Stewart to inform Dr. Lewis that there was no likelihood of this being done.

Dr. Ibbotson then said that there was no problem at Stafford; he assumed that the cases from there went to Birmingham. There were two haemophiliacs in Burton, one of whom attended Derby for treatment and one who went to Birmingham; both had expressed a wish to continue these arrangements. After discussion, it was agreed that the provision of a service to Burton presented a problem, but linking with the Centre at Stoke was not the answer. Dr. J. Stuart suggested that concentrates should not be sent to Burton, but Dr. Bird said that he could only advise and not direct in this situation. Dr. Shinton agreed to undertake to discuss the problem with the clinician at Burton.

Funding of Technical Staff to provide a Regional Diagnostic Service.
(Previous Minute No. 76/17)

77/7

It was reported that Dr. Hill and Dr. J. Stuart had seen Dr. Nicol on this subject without success. Dr. J. Stuart said that all other Centres had four, five or six technicians, whereas Dr. Hill and Dr. Ibbotson had one-half a technician each. Dr. J.C. Stewart said that he hoped that this position would be remedied when RAWP was refined, and Dr. Shinton pointed out that haemophilia was not included in RAWP at national level. The Chairman undertook to discuss the matter with the Regional Medical Officer.

Metal Seals on Concentrates from Lister Institute.

77/8

Dr. Bird said that he had received reports that one type of the metal seals used by the Lister Institute was faulty, so that if the centre flap was pulled back, the whole cap tended to come off, and this presented a risk in home treatment. He said that pending rectification of the fault, it was preferable for the centre flap to be folded back rather than pulled.

Date of next meeting

It was agreed to hold the next meeting of the Working Party at the offices of the Authority on Monday 21st November 1977, at 10.30 a.m.

GD/NHC
5.8.77