

West Midlands Regional Health Authority

WORKING PARTY ON THE TREATMENT OF HAEMOPHILIACS

Notes of a meeting held on Monday, 22nd November 1976 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. Ibbotsan
Dr. M. O'Shea
Dr. R. W. Payne
Dr. N. K. Shinton
Dr. J. Stuart
Dr. J. C. Stewart

Mr. G. Dodwell (in attendance)

Apologies for absence

76/9

Apologies for absence were received from Dr. J. Mann and
Dr. E. G. Rees.

Minutes of the previous meeting

76/10

The minutes of the meeting held on 13th May 1976, having been circulated, were confirmed and signed as a correct record, subject to the following amendment:-

Minute 76/3 "Availability of cryoprecipitate and freeze dried Factor VIII concentrate"; paragraph 3, line 5 for "40,000 units" read "40,000 packs".

Availability of cryoprecipitate and freeze dried Factor VIII concentrate
(Previous Minute No. 76/3)

76/11

The members of the Committee received a copy of Circular RHA(M)76/16 dated 10th August 1976 "Arrangements for the care of persons suffering from haemophilia and related conditions". (Enclosure 1 in minute book)

The members of the Committee had before them details of the total estimated Regional requirements of freeze dried Factor VIII concentrate (Enclosure 2 in minute book). Dr. Stuart said that five firms had now contracted to supply freeze dried Factor VIII concentrate, all at about 8p per unit, and it was open to users to negotiate such details as to the contents of home kits - syringes, water, etc. Dr. Stewart said that no action had been taken as yet with regard to supra-regional contracts.

It was agreed that it would be advisable to split the regional contract between two firms at least, in order to safeguard against a possible breakdown in supply, and to avoid the consequences arising from a monopoly position. Dr. Stuart said that many decisions could not be made until it was known whether it was the intention of the RHA to fund the service regionally.

Dr. Bird said that whilst the provisional allocation of freeze dried Factor VIII concentrate from The Lister Institute was 200 bottles per month, it was possible that this figure might be reduced; further, it was necessary to agree the division of this allocation within the Region. The production of cryoprecipitate continued at the level of 40,000 packs per year.

Dr. Stuart suggested that all the Lister Allocation of freeze dried Factor VIII concentrate might be allocated to the Queen Elizabeth Hospital, leaving other Centres to use cryoprecipitate or commercial Factor VIII; he based this proposal on the fact that the Queen Elizabeth now used considerably more freeze dried Factor VIII concentrate than any other Centre and it was inequitable to expect the Central District to pay for commercial supplies of concentrate used to provide a Regional service. He pointed out that the Lister had in the past supplied Factor VIII concentrate for major operations; if the supply ceased, the cost of Factor VIII for a hip replacement might be £2000.

Dr. Whittaker referred to the current economic crisis in the Health Service which necessitated a careful re-calculation of priorities, and Sir Melville Arnott said that in assessing priorities precedence must of necessity be given to life-saving procedures - a consideration which did not apply to many orthopaedic operations.

Dr. O'Shea made the point that patients frequently exchanged notes on their treatment, and those on home treatment receiving freeze dried Factor VIII concentrate tended to disaffect those patients who were still receiving hospital treatment on cryoprecipitate.

Summing up, Dr. Whittaker said that it was essential to contain supplies of freeze dried Factor VIII concentrate from commercial sources within reasonable limits, in order not to bring about considerable financial cuts elsewhere in the Health Service; he pointed out that the continued replacement of x-ray and scientific equipment was vital in order to maintain a continuing service to considerable numbers of patients.

Dr. Hill referred to the hepatitis risk in respect of freeze dried Factor VIII concentrate obtained from commercial sources, and with this in mind he asked whether it might not be advantageous to reserve the supplies of concentrate obtained from the Lister Institute for children, leaving the concentrate obtained from commercial sources, largely of foreign origin, for adults. Dr. Stuart agreed with Dr. Hill as to the hepatitis risk, and said that in case of doubt he would prefer to use cryoprecipitate for children rather than commercially obtained freeze dried Factor VIII concentrate.

Establishment of separate budget for purchase of freeze dried Factor VIII concentrate

76/12

Dr. Hill asked the views of the Working Party as to the desirability of raising a separate budget for the purchase of commercial concentrate. It was generally agreed that the establishment of a separate budget was desirable, and Dr. Whittaker said that whilst the RHA would probably be prepared to agree to the establishment of a separate budget, on the lines of the budget for renal dialysis, there had to be a limit to the amount that could be spent. Dr. Stewart said that he would put this proposal to the Regional Team of Officers.

Haemophilia statistics
(Previous Minute No. 76/3)

76/13

The members of the Working Party had before them details of the Regional register provided by Dr. Stuart (Enclosure 3 in minute book).

Dr. Stuart emphasised that it was important for Directors of Centres to keep him informed of any changes in order that the Central Register might be kept up to date. He reminded members that at the meeting in December 1975 it had been agreed that Directors should send him copies of their annual returns to Oxford, in order that he might be in a position to check his records.

Appointment of Haemophilia Sister
(Previous Minute No. 76/7)

76/14

It was noted that a part-time Sister had now been appointed at the Children's Hospital but the Queen Elizabeth Hospital also needed help in this respect; at the present time a Senior House Officer was doing the work which should be done by a Nursing Sister. Centres in other Regions had nurses attached for this work, and the ideal arrangement would be to have one Sister at the Queen Elizabeth Hospital in addition to the Sister at the Children's, with a third Sister appointed to liaise between the two hospitals, to cover for leave and sickness, and to help out in times of peak workloads.

Dr. Stewart said that this was primarily a matter for the Birmingham Area, but he agreed to discuss the proposal with the Regional Nursing Officer, and he was assured that the Working Party supported him in his approach.

Patients treated at hospitals other than Haemophilia Centres

76/15

Dr. Stewart reminded members that the Oxford Reference Centre had asked for details of those patients treated in hospitals other than recognised centres. Dr. Stuart said that from information provided by Areas it appeared that in 1975 29 patients had attended hospitals which were not then recognised as centres. Of those 29 patients, 16 had also attended hospitals which were designated.

In 6 cases there were valid reasons for the patient not attending a Haemophilia Centre, but he was concerned to note that there were 7 patients regularly attending hospitals which were not designated Centres.

Dr. Stewart pointed out that the Circular RHA(M)76/16 (Enclosure 1 in minute book) had been sent out after 1975 and he hoped that there would be a reduction in the number of patients attending hospitals other than haemophilia centres as a result of that circular.

Organisation of Haemophilia Centres
(Previous Minute No. 76/5)

76/16

Dr. Stewart referred to a letter which he had received from Dr. Lewis, making application for Kidderminster General Hospital to be recognised as an Associate Centre for the treatment of haemophilia (Enclosure 4 in minute book).

Dr. Payne said that there were about five patients involved, under the care of different consultants. Dr. Lewis had started to bring these patients into one centre for treatment and he made the point that transport to Worcester - a distance of some 25-30 miles - was a major problem. Dr. Bird said that he was not in favour of the establishment of too many Centres, and Dr. Whittaker agreed with Dr. Bird, pointing out that it was desirable to limit the number of Centres in order to concentrate expertise. He suggested that Dr. Payne should discuss with Dr. Lewis the possibility of establishing a joint Centre at Worcester, Kidderminster and Bromsgrove, when Dr. Payne and Dr. Lewis, both of whom worked single handed at the present time, working as joint Directors and providing cover for each other. Dr. Payne agreed to institute such discussions on an informal basis in the first instance, involving the Area Medical Officer, with the object of reporting back to the next meeting of the Working Party.

Arising from the foregoing discussion, Dr. Stuart referred to the problems which arose when linking Stafford and Burton with the Centre at Stoke-on-Trent;

Dr. Ibbotson agreed to submit proposals for consideration by the Working Party at their next meeting as to the best way of dealing with this particular problem.

Funding of Technical Staff to provide a Regional Diagnostic Service

76/17

Dr. Hill referred to the advances made in the treatment of haemophiliacs and the new tests which had recently been evolved; these brought in their train new problems of re-diagnosis, new referrals and genetic counselling. At the present time one technician was fully employed on this work at the Children's Hospital, but in view of the increasing demands additional funds would become inevitable. Dr. Shinton said that the DHSS would be issuing a document in the near future, dealing with this particular problem.

Dr. Stuart supported Dr. Hill and pointed out that it was not practicable to set up a diagnostic centre in every laboratory; the Queen Elizabeth Hospital used two full-time technicians for this work and the RHA paid one half of the salary of one of those technicians for the work he did for the BTS.

Dr. Whittaker stressed that this was an AMA(T) responsibility and he suggested that Dr. Hill should discuss the matter informally with the Area Medical Officer in the first instance.

Date of next meeting

76/18

It was agreed that the next meeting of the Working Party be held at the offices of the RHA on Monday, 23rd May 1977 at 10.30 a.m.

GD/MSH

13th December, 1976