

West Midlands Regional Health Authority

WORKING PARTY ON THE TREATMENT OF HAEMOPHILIACS

Notes of a meeting held on Monday, 21st November
1977 at 10.30 a.m.

PRESENT:

Dr. N.K. Shinton (in the chair)
Dr. W.S.A. Allen
Dr. F.G. Hill
Dr. R.M. Ibbotson
Dr. R.W. Payne
Dr. E.G. Rees
Dr. J. Stuart
Dr. J.C. Stewart
Dr. R. Moore (by invitation)
Mr. G. Dodwell (in attendance)

Apologies for Absence

77/19

Apologies for absence were received from Sir Melville Arnott, Dr. G.W.G. Bird and Dr. S.R.F. Whittaker.

Minutes of the Previous Meeting

77/20

The minutes of the meeting held on 23rd May 1977, having been circulated, were confirmed and signed as a correct record, subject to the following amendment:-

Minute No. 77/7 "Funding of Technical Staff to provide a Regional
Diagnostic Service":

Delete the second sentence "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" and substitute "Dr. J. Stuart said that all other Regions had technicians specially allocated for this work, but there were no such specific allocations in this Region".

Dr. Stuart pointed out that the Region was spending £100,000 per annum on the purchase of freeze dried Factor VIII concentrates, and a saving of 10% might be achieved by instituting a system of central purchasing.

Annual Meeting of Directors of Haemophilia Centres

77/21

Dr. Stuart said that at the annual meeting of Directors of Haemophilia Centres held on 24th October 1977, three major items had been considered.

First, it had been reported that the Lister Institute were capable of processing all the plasma which they received and could deal with more. Dr. Shinton, referring to Enclosure 1 to the agenda, said that the target figure of fresh plasma sent to the Lister Institute from this Region for 1977 was 1,820,000 units but it had been anticipated that only 1,200,000 units would be returned and he thought that such a marked short-fall required an explanation. However, it was proposed that in 1978 the BTS should have more technical staff for this work which would then permit 2,352,000 units to be sent to Lister and by 1980, subject again

to technical staffing, it was hoped to be able to send 3,800,000 units per annum to Lister, which would cover all the requirements of the Region in respect of Factor VIII concentrate if all the processed units were returned. The Working Party were agreed that a return of two-thirds might be reasonable because of the loss in processing. Dr. Stewart said that he had been informed that the Lister Institute could not process more material than the target figure for 1978 and it would not, therefore, be possible to justify extra technicians for the BTS on those grounds, but two extra part-time technicians had already been approved.

Referring to the second item discussed at the Annual Meeting, Dr. Stuart said that the home treatment packs produced by different commercial firms were different in composition and price. He queried where the extra packs needed were to come from if the Lister Institute provided all the Factor VIII required in the Region. He said that the DHSS were looking into this particular problem because of the differing views expressed in the Regions. Certainly, the problem of producing home treatment packs was one of some magnitude in the Central District of Birmingham; the thirty-five patients under treatment would need the services of almost a whole-time person to prepare such packs if they were not obtained from commercial sources.

Finally, Dr. Stuart referred to the third item of discussion; the treatment of patients with Factor VIII inhibitors. In 14 out of 19 cases, treatment with "ETBA" had proved effective, but there was a new product "Auto 9" in course of preparation.

Availability of Cryoprecipitate and Freeze Dried Factor VIII Concentrate
(Previous Minute No. 76/11, 76/12 and 77/3)

77/22

Members of the Working Party had before them a table showing the availability of cryoprecipitate and freeze dried Factor VIII concentrates during 1977 (Enclosure 1 in minute book).

Dr. Shinton referred to Enclosure 1 of the previous meeting and said that it had been calculated that the annual Regional requirements of cryoprecipitate and Factor VIII would be 3,500,000 units; in 1976 cryoprecipitate had accounted for 2,000,000 units, the Lister Institute 668,000 units of Factor VIII, and commercial sources had provided another 722,000 units of Factor VIII. Dr. Shinton said that the demand in Coventry was increasing and he asked whether 3,500,000 units would be sufficient for 1978. Dr. Stuart said that the demand in the Central District of Birmingham was fairly steady, but it was agreed that the demand was bound to rise because of improved diagnosis and the treatment of inhibitors. Dr. Shinton went on to point out that the production of cryoprecipitate by the BTS had dropped from 2,000,000 units in 1976 to 1,500,000 in 1977 and was expected to fall to 1,000,000 in 1978; the reduction was due to the transfer of material to the Lister Institute for conversion to Factor VIII. It was anticipated that the return from the Lister would be in the order of 1,500,000 units, leaving 1,000,000 units to be obtained from commercial sources in 1978, with a consequent increase in cost. Dr. Stewart said that the DHSS and the RHA had made available funds to cover additional blood collection as well as the laboratory work involved in making available material for the Lister Institute; extra staff who already had been appointed, and with the further staff that had now been approved he hoped that the need for commercial Factor VIII could be minimised.

Dr. Stuart said that this emphasised the need for central funding. Dr. Hill said that the transfer of materials to Lister resulted in a shortage of by-products such as purified protein fraction. Dr. Stuart said that the production of blood products was a primary function of the BTS and Dr. Shinton

said that there was a case for asking the RHA to give special support to the BTS for this essential work.

Dr. Stewart referred to the possibility of negotiating a central contract for purchase and asked whether it was necessary for this to be done through the BTS; Dr. Hill said that the problem of transport would indicate the BTS as an efficient distribution centre. Dr. Stuart queried whether the BTS had sufficient refrigerator space to act as a central depot and Dr. Shinton said that he would look into this question. Dr. Stuart said that this would bring in the problem of home treatment packs, whilst Dr. Stewart was concerned as to whether the Areas would be prepared to commit themselves in advance to the costs involved for the material supplied for the treatment of patients in their Areas. Dr. Stuart said that it would be advisable to arrange supplies from two firms in order to avoid a monopoly situation.

Dr. Stewart said that distribution was a major factor in the Q.E; 500,000 units of Factor VIII purchased from commercial sources had been used for home treatment during 1976; all the Factor VIII obtained from the Lister Institute had been used for the treatment of hospital cases, including dental patients, etc. He queried the use to which the material from Lister should be put; surgery was already adequately covered and he asked whether consideration might not now be given to its use for home treatment. Dr. Shinton said that this problem concerned the Queen Elizabeth Hospital and Walsgrave only at the present time and he suggested that Dr. Bird might be asked to distribute the Lister material on the basis of the amount used, so that all Centres received an allocation. He said he was quite prepared to leave the mechanics of the distribution to Dr. Bird. Dr. Stuart said that he would prefer to have all the supplies from one source; either Lister, or purchased commercially so that he could pinpoint the source of supply immediately in the event of untoward happenings. He said that he had in mind discontinuing home treatment with cryoprecipitate and said that he would prefer to use Factor VIII from Lister for all home treatment. Dr. Stewart said that providing Areas were prepared to meet the costs involved, they were at liberty to make their own arrangements.

Dr. Shinton pointed out that a distribution based on usage would only justify sufficient material to treat, say, one patient in a small Centre like Shrewsbury, but both Dr. Rees and Dr. O'Shea felt that this would be worthwhile for the experience gained. Dr. O'Shea said that it was essential as a first step, to agree the mechanics of a centralised purchase system; the problems of distribution could be sorted out afterwards.

Dr. Shinton agreed that the present system of distribution could, with advantage, be continued at least for the time being but he hoped that the figures for 1977 would be available for the next meeting of the Working Party, and also perhaps the decision of the RTO as to the funding of the service.

DHSS Central Contracts 1977/78

77/23

Dr. Stuart said that contract prices for the supply of Factor VIII from commercial sources ranged from 8p to 16p per unit as from 1st November 1977. It was more than likely that prices might change in the future, but there was still room to negotiate. The DHSS had advocated purchasing from four designated suppliers. Dr. Stuart said that he intended approaching all four to obtain quotations.

Use of Red Cell Concentrate

77/24

The members of the Working Party had before them a copy of a letter sent by the Chairman of the Regional Medical Committee to all users of blood products (Enclosure 2 in Minute Book). Dr. Shinton said that the BTS had found difficulty in meeting all the demands now being made on it for red cell concentrates, but it was hoped that extra staff now approved would be appointed in the near future and would be able to deal with the total demand.

Appointment of Haemophilia Sister

77/25

Dr. Stuart said that he had discussed the proposed appointment of a haemophilia Sister at Area and District level but so far without result. One of the regrettable consequences was that he was compelled to purchase expensive commercial packs rather than having them made up in the hospital. Dr. Stewart said that this was a matter for the Area concerned but he pointed out that at the last meeting of the Working Party Dr. Whittaker had suggested that a Regional appointment be made to the BTS. The RTO had been unable to agree to this proposal but had agreed to look at the problem again in February 1978 when next year's revenue allocations were known.

Organisation of Haemophilia Centres

77/26

(Previous Minute Nos. 76/5, 76/16 and 77/6)

Dr. Shinton said that he had made enquiries regarding the treatment of haemophiliacs in Burton-on-Trent; the numbers concerned were very small, and the patients had each formed attachments to a particular centre to which they had been transferred and to which they wished to continue to be referred. Dr. Shinton said that he would be writing to the Chairman of the Area Medical Committee on this subject.

Funding Technical Staff to Provide a Regional Diagnostic Service

77/27

(Previous Minute Nos. 76/17 and 77/7)

Dr. Shinton said that it was not possible to lay down firm rulings on this subject; when Centres were established the question as to the level of provision of staff was a matter for the Area concerned, and it was only possible for the Working Party to submit recommendations as to desirable level.

Dr. Hill then referred to the problem concerning his application for an additional technician to work in the Children's Hospital, Birmingham (Enclosure 3 in Minute Book).

Dr. Hill said that the workload in that hospital was steadily increasing, and problems were arising because of the lack of staff for a coagulation service. He had had no success in his approaches to the AHA(T) and his patients were suffering in consequence. He appreciated that the Region were unable to take action in this matter, and asked whether it would not be possible to make a direct approach to the DHSS.

Dr. Shinton said that there was a need for Dr. Hill to support his case by figures and salaries, etc. Dr. Stewart said that the Reference Centre had recommended an establishment of one Chief Technician and two Technicians for each 80-120 patients treated and he asked whether the members of the Working Party would be prepared to draw up similar recommendations which he (Dr. Stewart) would be prepared to take on to the RTO in February.

After further discussion, the members of the Working Party agreed that, in the first instance, Dr. Hill should make an approach to his District Management Team for the staff which he required, but on Dr. Stuart's suggestion it was agreed to minute the support of the Working Party for Dr. Hill's case.

Determination of Variants of von Willebrand's Disease

77/28

Dr. Shinton asked whether this work should be concentrated, and Dr. Stuart agreed that it should be centralised, as was already done in other Regions. He went on to point out that Dr. Hill had already done a great deal of work of this nature at the Children's Hospital in Birmingham, and had established reliable techniques.

Date of Next Meeting

77/29

It was agreed that the next meeting of the Working Party should be held at the offices of the RHA on Monday, 15th May 1978 at 10.20 a.m.

Dr. Stuart said that he would try to draw up a summary of the 1977 consumption figures for that meeting, and he particularly requested Haematologists to send in their annual returns early to Oxford, with a copy to him in order that he could proceed with the production of a paper in time for the meeting.