

WEST MIDLANDS REGIONAL HEALTH AUTHORITYTreatment of Haemophiliacs

Notes of a meeting held on Thursday, 18th December, 1975 at 10.30 a.m.

Present:

Dr. N.K. Shinton (in the Chair)  
Dr. W.S.A. Allan  
Dr. G.W. Bird  
Dr. C. Giles  
Dr. J.R. Mann  
Dr. M. O'Shea  
Dr. E.G. Rees  
Dr. J. Stuart  
Prof. Sir Melville Arnott  
Dr. J.C. Stewart  
Miss J.E. Jelf - in attendance

Apologies for absence Apologies for absence were received from  
Dr. R.W. Payne and Dr. J.J. Kramer.

Minutes of the previous meeting The minutes of the previous meeting held  
on 14th May, 1975 were confirmed as a correct record (Circulated with agenda).

Terms of Reference Dr. Shinton explained that this meeting had been  
called by the Regional Scientific Committee to discuss a number of matters.  
The decision of this Committee would be communicated by him to the Regional  
Scientific Committee at its meeting on the 8th January, 1976.

Details of patients treated during 1974 Members received a list giving  
details of patients treated in the recognised Centres during 1974 (Appendix A  
in minute file). Dr. Shinton gave further detailed information with regard  
to Coventry, Dr. Stewart read out information from Dr. Payne in respect of  
Worcester Royal Infirmary and from Dr. Kramer in respect of the County  
Hospital, Hereford all of which had been received too late to include in the  
list. (Appendix B in minute file). It was agreed that these details should  
be circulated to members with the minutes of the meeting.

Availability of Cryoprecipitate and freeze-dried Factor VIII Dr. Bird explained  
that the DHSS were expecting this Region's donation of fresh frozen plasma  
to the Lister Institute to reach the annual rate of 26,000 donations by  
31st March, 1977. He estimated that the number of issues of cryoprecipitate  
for this Region alone for 1975 would be about 40,000 and at the present rate  
of demand it would be impossible to meet the West Midlands Region's need  
and also supply to the Lister Institute with the amount of fresh plasma  
they require.

Financial allocations had been made by DHSS to meet the cost of supplying  
the additional amount of plasma but these will not be sufficient and the  
Regional Health Authority have agreed to increase the blood donor teams  
and to give high priority to the necessary capital building work at the BTC.

Members considered a table prepared by Dr. Bird showing the cryoprecipitate  
supplied to hospitals throughout the Region (Appendix C). This showed that  
over 60% was supplied to the Queen Elizabeth and Children's Hospitals.  
Dr. Bird said that the requirement of the Queen Elizabeth Hospital was  
rising and he stressed that if the present demand continued the supply of  
cryoprecipitate would soon be exhausted; there would not be enough for the  
Region, let alone the Lister Institute. He raised the question of centres  
buying commercially prepared freeze-dried Factor VIII, and members then  
considered a paper by Dr. Stuart on the availability of freeze-dried Factor  
VIII concentrate from the Lister Institute (Appendix D in minute file).



Dr. Stuart made the point that as the BTC was unable to meet all his requirements of cryoprecipitate it was necessary for him to purchase commercially manufactured concentrate. The Working Party had previously agreed that an emergency supply should be kept at the Queen Elizabeth Hospital, but with this increase and the estimated cost would be around £30,000 per year. The Central District, Birmingham carried two and a half times the patient load of other centres and therefore would have the greater financial burden. Dr. Stuart felt that special recognition of this should be made in the allocation of revenue. He agreed to compile a list of the patients from outside the Birmingham Area who were treated at the Queen Elizabeth and Dr. Mann, a list of those treated at the Birmingham Children's Hospital. It was pointed out that if cryoprecipitate were not available from the BTC the cost of commercial Factor VIII might be of the order of £350,000 annually in the Region.

Following discussion it was agreed:-

- (i) to draw the attention of the Regional Medical Officer to the possibility of an acute shortage of cryoprecipitate over the next few weeks.
- (ii) to draw the attention of the Regional Scientific Committee to the problem of the supply of cryoprecipitate and the cost consequences of buying commercial Factor VIII concentrate.
- (iii) to recommend to the Regional Scientific Committee that all Directors of Associated Haemophilic Centres be allowed to purchase commercially prepared concentrate should the necessity arise. The recommended Factor VIII concentrate was Kryobulin.

#### Treatment of Haemophiliacs in hospitals other than recognised Centres

Members considered a paper by Dr. Stuart on this matter (Appendix E in minute file). Dr. Bird made the point that hospitals other than those designated as Haemophilia Centres were treating haemophiliacs and while issues of cryoprecipitate to these hospitals could not be denied there was a need for some sort of formal control over the patients treated.

From the ensuing discussion the following points were agreed:-

- (i) that all haemophiliacs should be treated in Haemophilia Centres except in emergency, when they should be treated at the local hospital in consultation with the nearest Centre.
- (ii) if the local hospital treating a haemophiliac emergency could not co-ordinate with a Haemophilia centre, they should inform the nearest Centre retrospectively of the treatment given in order that this might be included in the Annual Return.
- (iii) the above points (i) and (ii) should be put to the Regional Scientific Committee with the suggestion that a suitable circular be sent to Area Health Authorities enclosing a list of Haemophilia Centres with which each local hospital should collaborate.

#### Home Treatment

Members reported that the number of haemophiliacs on home treatment was steadily increasing. It was agreed that this was the preferable form of treatment but there was discussion concerning the possible increased requirement of cryoprecipitate/Factor VIII concentrate in order to offer this more widely. Dr. Stuart said that papers had been published to show that in the long term there was no difference but other members of the Working Party suggested that an increase should be expected during the early period of transfer.

Dr. Stuart said that he had written to all Haemophiliacs registered in the Region asking for their views on home treatment. He emphasised that it was his opinion that haemophiliacs should preferably be treated locally, so that the training in home treatment would place a heavier initial load on the Associated Centres.

The Working Party agreed that home treatment should be instituted in suitable patients where possible.

The Working Party considered papers by Dr. Stuart on record keeping and advice sheets for home treatment of haemophilia patients (Appendices F, G, H and I). It was agreed that this type of documentation should be used for home-treatment patients.

Members felt that an annual return giving details of home treatment patients would be most useful and centres should be asked to provide the following information annually for consideration by the Working Party:-

- (i) The number of patients on home treatment
- (ii) The type of treatment
- (iii) The amount of material patients were using annually for self-treatment.

Dr. Mann suggested that a nursing sister should be attached to each centre to assist in training patients for home treatment. She said that the most urgent need was at the Children's Hospital and the Queen Elizabeth Hospital.

This nursing requirement at Haemophiliac Centres was supported.

#### Availability of freeze-dried Factor IX from Oxford

On Dr. Stuart's suggestion, it was agreed that it would be preferable for the BTC to receive the Factor IX in future, particularly as it had the necessary transport to distribute it to Centres. Dr. Stuart undertook to inform the Oxford Reference Centre of this change.

#### Attendance of Directors of Associate Centres at Annual meetings of U.K. Directors

Members agreed with Dr. Stuart that Associate Directors should be invited to attend Annual meetings of U.K. Directors. Dr. Shinton undertook to communicate this to Dr. Biggs at Oxford, at the same time giving details of names, addresses, designations of Directors, together with any impending changes.

#### Designation of Queen Elizabeth Hospital as Haemophilia "Referenced" Centre

The Working Party had before them a draft HSC (IS) letter from the Department dated November 1974, setting out the criteria for designation of Haemophilia Centres, Associate Centres and Reference Centres (Appendix J in minute file). Dr. Stuart pointed out that there was no Reference Centre in the Region and while Birmingham AHA (T) had agreed that the Queen Elizabeth, Childrens and General Hospitals should be designated, no application had been made to the DHSS.

Dr. Stuart said that the facilities at the Childrens and Queen Elizabeth Hospitals did not come up to the standard required for recognition as a Reference Centre.



It was agreed that the matter should be passed to the Regional Scientific Committee for consideration, with the suggestion that they should determine the deficiencies at the Queen Elizabeth and Childrens Hospitals in this respect and what facilities would be necessary to bring the two hospitals jointly to the standard of a Reference Centre, and that the matter should be reviewed by the Working Party in one year's time. In the meantime the Reference Centre for the West Midland Region would be Oxford.

#### Records

(a) Registration Cards Dr. Stuart raised the question of the completion of the green registration cards. He asked if Associate Centres would fill these in themselves and send photocopies of the information on the index card to him at the Queen Elizabeth Hospital instead of sending him the Registration Card to fill in and send back. Members agreed to do this and also to send photocopies to Dr. Mann at the Children's Hospital, if the patient was a child.

(b) Card Index Dr. Stuart drew attention to a Card Index he had designed and said that it would facilitate record keeping if all centres used the same card. He said he would have some cards printed and send them to Centres upon request.

(c) Clinical Returns It was agreed that Annual Returns of patients treated should be forwarded by each Centre and Associate Centre to Oxford but in addition a copy should be sent to Dr. Stuart to enable him to complete an annual report for the Working Party.

#### Date and time of next meeting

It was agreed that the next meeting of the Working Party should be held on Thursday, 13th May, 1976 at 10.30 a.m.

The meeting ended at 12.40 p.m.

GD/JRH  
31/12/75

WEST MIDLANDS REGIONAL HEALTH AUTHORITY.

Treatment of Haemophiliacs

Summary of work load, 1974

Queen Elizabeth Hospital

Number of patients registered 491  
Number attending for treatment 103  
(Haemophilia 80, Christmas disease 15, Von Willebrands 8)  
Average number of patients attending each day 5.3

Facilities

- (i) 24 hour telephone advisory service. (not always consultant)
- (ii) Specialist consultant service for surgical, dental, physiotherapy, and social care.
- (iii) Home therapy programme instituted.
- (iv) Reference Laboratory service for factor assays, inhibitor titres etc.
- (v) Educational facilities for patients, medical and para-medical staff.
- (vi) Available factor concentrates: cryoprecipitate, freeze-dried factor VIII and freeze-dried factor IX.

Children's Hospital

Number of patients registered 120  
Number attending for treatment 60  
(Haemophilia 50, Christmas disease 10)  
7,909 units of cryoprecipitate and 231 bottles of factor IX (Oxford) were administered. Two patients were newly diagnosed as having factor VIII anti-bodies. Six children are receiving home care at the moment and several more have applied.

Facilities

- (i) 24 hour telephone advisory service. (not always consultant)
- (ii) Specialist consultant service for surgical, dental, physiotherapy and social care.
- (iii) Home therapy programme instituted.
- (iv) Reference Laboratory service for factor assays, inhibitor titres etc.
- (v) Educational facilities for patients, medical and para-medical staff.
- (vi) Available factor concentrates: cryoprecipitate, freeze-dried factor VIII and freeze-dried factor IX

Coventry Hospitals

Number of patients registered 60  
Number attending for treatment 30  
(Haemophilia 23, Christmas disease 2, Von Willebrands 5)

Facilities

- (i) 24 hour telephone advisory service. (not always consultant)
- (ii) Specialist consultant service for surgical, dental, physiotherapy and social care
- (iii) Home therapy for 4 students at Hereward College.
- (iv) Reference Laboratory service for factor assays, inhibitor titres etc.
- (v) Education facilities for patients, medical and para-medical staff.
- (vi) Available factor concentrates: cryoprecipitates, freeze-dried factor VIII and freeze-dried factor IX



### Hereford County

Number of patients registered 8  
Number of patients treated (haemophiliacs) 3

#### Facilities

- (i) 24 hour telephone advisory service (not always consultant)
- (ii) Laboratory service for factor assays, inhibitor titres.
- (iii) Available factor concentrates: cryoprecipitate.

### North Staffs.

Number of patients registered 71  
Number of patients treated 22.  
(Haemophilia 15, Christmas disease 3, Von Willebrands 3, Hypofibrinogenasia 1)

#### Facilities

- (i) 24 hour telephone advisory service
- (ii) Specialist consultant service for surgical, dental, physiotherapy and social care.
- (iii) Reference Laboratory service for factor assays, inhibitor titres etc.
- (iv) Educational facilities for patients, medical and para-medical staff.
- (v) Available factor concentrates: cryoprecipitate, freeze-dried factor VIII, and freeze-dried factor IX.

### Shrewsbury

Number of patients registered 5  
Number of patients treated 5  
(Haemophilia 4, Christmas disease 1)

#### Facilities

- (i) 24 hour telephone advisory service. (not always consultant)
- (ii) Home therapy programme instituted
- (iii) Reference Laboratory service for Factor assays, inhibitor titres etc.
- (iv) Educational facilities for patients, medical and para-medical staff.
- (v) Available factor concentrates: cryoprecipitate, freeze-dried factor VIII and freeze-dried factor IX.

### Wolverhampton

Number of patients registered 5  
Number of patients treated (haemophilia) 5

#### Facilities

- (i) 24 hour telephone advisory service.
- (ii) Laboratory service for factor assays and inhibitor titres.
- (iii) Educational facilities for patients, medical and para-medical staff.
- (iv) Available factor concentrates: cryoprecipitate.

### Worcester

Number of patients registered 14  
Number of patients treated (haemophilia) 3

#### Facilities

- (i) 24 hour telephone advisory service.
- (ii) Laboratory service for factor assays and inhibitor titres.
- (iii) Home therapy instituted
- (iv) Educational facilities for patients, medical and para-medical staff.
- (v) Available factor concentrates: cryoprecipitate;