January Meeting of Haemophilia Centre Directors at 9.30 a.m. on Thursday

13th January 1977 at the Middlesex Hospital Medical School

AGENDA

1.	Apologies for absence	
2.	Minutes of the last meeting	
3.	Matters arising from the minutes:	
	(a) Trial of prophylactic treatment of haemophilic patients at Alton	Dr P. Kirk
	(b) Study of hepatitis in haemophilic patients	Dr P. Kirk Dr Craske
	(c) Staffing of Haemophilia Centres and rotation of staff at Haemophilia Centres	Dr R. Biggs Prof. Blackburn Dr Dormandy
4.	Reports of Reference Centre Directors activities	
5.	Supply of factor VIII and purchase of commercial factor VIII	Dr R. Biggs Dr McDonald Dr Waiter
6.	The expectations of haemophilic patients to take part in normal activities	Mr Prothero
7.	Supply of factor IX	Dr Bidwell
8.	A handbook for haemophiliacs (HOME TREATMENT!) Inter. soc. [illegible] GRO-C: Abbott	Dr Jones Mr Prothero
9.	Transport for haemophiliacs	Mr Prothero
10.	Repair of telephones for haemophiliacs	Prof. Ingram
	LUNCH	
11.	The organisation of haemophilia care	Dr Dormandy
12.	The Institution of working parties to study problems that are important for management of haemophilic patients. EDIC: 14 members.	Dr Rizza Dr Prentice
13.	Home therapy	Dr Rizza Prof. Ingram
14.	The treatment of patients having anti-factor VIII antibodies	Dr Prentice Prof. Ingram

Morning Coffee 10.45 a.m.

Afternoon Tea 3.15 p.m.

*Guide for treat. centr. [illegible]

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JANUARY MEETING OF HAEMOPHILIA CENTRE DIRECTORS

Thursday, 13th January 1977, at Middlesex Hospital.

(Copy of Agenda attached)

Points of special interest

Item 3(a). The general conclusion from this work seems to be that prophylaxis might be considered in a small number of cases i.e. the very frequent bleeders who are liable to bleed several times per week anyway. From the figures given, this would not appear likely to lead to any large increase in the total amount of factor VIII used.

Evidence of some joint improvement was shown, and this in particular might justify a limited use of prophylactic therapy.

With the products containing higher levels of fibrinogen, the fibrinogen levels in the patients showed some rise but appeared to stabilise about 50% above normal. The regime used was between 10 and 20 iu per kg every other day.

Item 5. There was an extended discussion on possible criteria for deciding allocation, alternative to the present scheme which is based on number of patients treated per annum in each centre. In the end a vote was taken, the result being that the meeting decided to stay with the present scheme, with the exception that Von Willebrand's patients should be included.

Dr. McDonald discussed the supply of factor VIII concentrates which are used in the West of Scotland. He quoted Dr. John Watt as having said that he could fractionate up to 6,000 litres of plasma per week, given a capital investment of £20,000 - £25,000 and also a solution to staffing problems which would permit the introduction of a 24-hours shift system.

Dr. McDonald gave figures for factor VIII usage during 1976 in his region. He received 2,447 bottles of 200-250 iu of concentrate from PFC Liberton, which constituted 46% of his requirement, most of the balance being in the form of cryoprecipitate.

His total usage for the region was 1.2M iu for 180 haemophiliacs. This is 6,700 iu per patient. (He did not quote a figure for number of iu per cryoprecipitate.)

The minutes of the Sheffield meeting described John Watt as making 12-13M iu per annum. Presumably this should read as his having a capacity to produce 12-13M iu at the moment.

Dr. Waiter, who was pressed by questioners about the present UK capacity for factor VIII, said that it has been agreed in principle that plasma from North of England centres should go to Liberton and that the arrangements for these were in the process of being planned, although nothing formal had been as yet signed. She did state that there was a firm commitment to do this and that the financial arrangements were being worked out.

Comments from the floor:

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a) that on the figures available it would appear that it would involve more than just the North of England centres if 40-50M iu per annum were to be produced. (Note: I was asked in the course of discussions what the present capacity at Elstree plus Oxford was, and gave the figure 14-15M iu per annum.)

b) Would it be like North Sea oil: if the Scots were to charge us through the nose for it, we might as well buy it commercially anyway.

Other points which came up in the course of the remainder of the meeting:

a) The question of supplying vials of water was raised. I said: "We are looking into the possibility of supplying water with the product".

b) Plans for the Directors to nominate working parties to study specific problems were discussed. The Chair suggested some subjects together with chairmen of working parties for those subjects. However, Dr. Evans from the floor suggested it would be better to circulate information and make definite decisions at a later date, and it was decided to do this.

c) Under Item 8: three handbooks were the subject of discussion, the first being a handbook on home treatment being prepared by Dr. Jones, the second one primarily on social services or assistance available to haemophiliacs, being prepared by the Haemophilia Society, and the third being the Abbott guide for travelling haemophiliacs of which a second edition is shortly coming out.

d) Under Item 14: the discussion was limited to Dr. Prentice's proposed investigation and details of the protocol which he distributed at the meeting. (Copy attached)

It would appear from the discussion that at the moment the use of "activated" factor IX concentrate in the treatment of haemophiliacs with inhibitors is giving rather variable results.

c.c. Dr. Maycock
Mr. Vallet.

DE/AH.
17.1.77.

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Insert A, p.1. of Mr. Mills's report to Board of Trade

Before Ministry approval was given the technical aspects of the proposals were considered and approved by the Medical Research Council Blood Transfusion Research Committee and the overall aspects of the proposals by the M.R.C. Blood Products Laboratory and Blood Group Reference Laboratory Managing Committee.

The enlargement of the laboratory at Elstree is/ linked with the enlargement, to a similar size, of the small Plasma Fractionation Laboratory at Edinburgh which is administered by the Scottish National Blood Transfusion Association on behalf of the Scottish Home and Health Department, and which has hitherto looked after the needs of Scotland. The combined capacity of the two laboratories has been approved by the Ministry of Health in the light of the needs of the National Health Service. The enlarged Scottish laboratory will thus be responsible for part of the supplies of blood products needed by the National Health Service in England and Wales. The decision to enlarge the Edinburgh laboratory simultaneously was made because it was obviously unwise to put all the eggs in one basket (at Elstree) and because Elstree and Edinburgh would be convenient centres to which to deliver, respectively, the time-expired plasma from roughly the southern and northern halves of England and Wales.

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(Information for Mr. Hills's report (page 2, para iv) to Board of Trade)

	1964	1965	1966	1970 - 1972
DRIED PLASMA (400ml. bottles)	82,275	92,975	100,578	possibly 5000-10,000 p.a.
PLASMA FRACTIONS (released for despatch)				Approximate estimates
Fibrinogen (grams)	3,162	6,628	6,429	10,000 p.a.
Anti-haemophilic globulin (grams)	1,912	2,826	2,550	17,000 p.a.
Thrombin (units)	918,250	766,450	669,200	possibly the same
Albumin (Kg.)	107.5	131.2	120.9	180 p.a.
Normal Immunoglobulin (Kg.)	20.3	20.1	23.4	230 p.a.
Plasma protein fraction (400 ml. bottles)	Nil	ca. 300 (exper. batches)	ca. 400 (exper. batches)	80,000 - 90,000 p.a.
Litres of plasma fractionated	7,401	7,983	8,014	70,000 plus

Notes

(1) Estimates for 1971/72 assume proposed extension in operation.

(2) Dried Plasma: the capacity of the drying plant was reached in 1966.

(3) Plasma Fractions: the capacity of the fractionation laboratory was reached 3 to 4 years ago. Marginal increases have been made by by diverting to production staff and equipment etc. intended for research.

(4) Immunoglobulin: In addition to the above quantities of Human Normal Immunoglobulin, increasing amounts of specific immunoglobulins (e.g. anti-tetanus, anti-mumps, anti-chicken pox, anti-rubella and anti-D) have been made. It should be noted that all the anti-D immunoglobulin for the trials of this new treatment for preventing sensitization to the D antigen and thus preventing haemolytic disease of the newborn ("Rhesus baby") have been and are being made at B.P.L.

It is impossible to predict the amounts of these specific immunoglobulins likely to be needed in 1970-1972, except in the case of anti-D immunoglobulin for which there will exist a need for some 8 to 10 Kg. if all mothers at risk are treated.

As the starting plasma for all specific immunoglobulins can only come from suitably sensitized normal healthy human subjects its procurement is beset with easily comprehended difficulties

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