MINUTES OF THE SECOND MEETING OF DIRECTORS OF HAEMOPHILIA, ASSOCIATE HAEMOPHILIA AND BLOOD TRANSFUSION CENTRES IN RHAs 04, 05 & 06, HELD AT THE ROYAL FREE HOSPITAL on Friday, 23rd September 1977

Present

Dr. D.G. Chalmers	Addenbrooke's Hospital, Cambridge	(04)
Dr. J. Leslie	Norfolk & Norwich Hospital	
Dr. S. Ardeman	Edgware General Hospital	(05)
Dr. S. Bateman (for Dr. Crawford)	Hammersmith Hospital	
Dr. M. Boots (for Dr. Mitchell)	Charing Cross Hospital	
Dr. T. Davies (for Dr. Cleghorn)	North London B.T.C.	
Dr. H. Dodsworth	St. Mary's Hospital, Paddington	
Prof. J.G. Humble	Westminster Hospital	
Dr. D. Samson	Northwick Park Hospital	
Dr. D.S. Thompson	Luton & Dunstable Hospital	
Dr. J.R.B. Williams	Lister Hospital, Stevenage	
Dr. O.H.A. Baugh	Chelmsford & Essex Hospital	(06)
Dr. D. Carmichael (Chairman)	Princess Alexandra Hospital, Harlow	
Dr. B.T. Colvin	The London Hospital	
Sister G. Davis	N.E. Thames Haemophilia Coordinator	
Dr. Katharine M. Dormandy	Royal Free Hospital	
Dr. W.J. Jenkins	N.E. Thames Regional B.T.C.	
Dr. B.A. McVerry (for Prof. Prankerd)	University College Hospital	
Dr. J.W. Nicholas	Essex County Hospital, Colchester	
Dr. J.S. Oakey	Orsett Hospital, Grays	
Dr. E. Goldman	Royal Free Hospital	
Dr. J. Voke	" " "	
Dr. R. Warwick	" " "	
Mrs. M.I. Britten	" " "	
Prof. G.I.C. Ingram	St. Thomas' Hospital	(07, 08)
Dr. W. d'A. Maycock	Lister Institute Blood Products Laboratory, Elstree	
Dr. S. Waiter	D.H.S.S.	

1. Apologies

Prof. R.M. Hardisty & Dr. C.A. Sieff	Hospital for Sick Children
Prof. G.C. Jenkins	The London Hospital
Dr. T. Cleghorn	North London B.T.C.
Dr. J. Darnborough	Cambridge Regional B.T.C.
Dr. R.C. Hallam	Bedford General Hospital
Dr. T.R. Mitchell	Charing Cross Hospital

2. Minutes of the first meeting, 15th December 1976.

Two insertions to the unconfirmed minutes, previously circulated, had been requested:

a) Prof. Hardisty: p.4, para 4 "and also because it had not yet been integrated into the reorganisation of the NHS."

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b) Dr. Gibson: p.6, item 9, para 3, after 'organisation' "Dr. Gibson pointed out that Dr. Leslie's willing acceptance of the present position regarding the Supra-Region should be looked at as representing the minority view of those concerned."

These amendments were accepted and the minutes were signed as correct.

3. Matters arising from the minutes

It was agreed to take (i), (ii) and (iii) together, region by region.

(i) Distribution of NHS factor VIII concentrates
(ii) Purchase of commercial concentrates since the previous meeting
(iii) Consumption of cryoprecipitate

EAST ANGLIA

Dr. Chalmers, for Dr. Darnborough: Their allowance of NHS conc. was now 110 bottles/month - 75 to Addenbrooke's, 25 to Norfolk & Norwich, 10 to emergency store. 50,000 u commercial conc. had been purchased by the BTC to be held as store and replaced as used. The consumption of cryo. had fallen considerably.

Dr. Chalmers, as Director of the Cambridge Haemophilia Centre: Cryo. was used in the hospital and NHS and commercial conc. for home treatment (HT). Commercial conc. was used for HT only to make up for the shortfall in NHS conc. There were 2 HT patients on commercial conc. and 2 more trained. 50,000 u commercial conc. had been obtained from the BTC for these 2 HT patients (approx. 6,000 u) and for 2 surgical cases.

Dr. Leslie: The Norfolk & Norwich used its NHS conc. for HT; so far the supply had been adequate. No commercial conc. had been used.

N.E.THAMES

Dr. Jenkins: The current allocation of NHS conc. was 370 bottles/month - 149 to The London, 161 to RFH, 60 to emergency store. Some HT patients were still on cryo. and the region was considerably short of its requirements of NHS conc. The region's consumption of cryo. had not decreased despite the increased allocation of NHS conc.

Dr. Dormandy (RFH): Most HT patients, and all who were allergic to cryo., were on NHS conc. 25 HT patients were still on cryo. 264,145 u commercial conc. had been purchased by RFH for its NHS patients in N.E. and N.W. Thames during the last 9 months (i.e. since the previous meeting). Most of this had been used for patients with inhibitors. Two private patients used commercial conc. for HT for which they or their sponsors paid.

Dr. McVerry: UCH needed 40-45 bottles NHS conc./month as they now had 3 more patients on HT. They were currently purchasing 20-25 bottles (4,400-5,500 u) Hemofil/month to make good this shortfall. They wanted 20-25 extra bottles of NHS conc./month. Dr. Dormandy pointed out that the addresses of the patients should be taken into account in deciding whether Brentwood or Edgware should supply the extra needed.

Dr. Sieff (letter from HSC read by Dr. Dormandy): Despite their allocation of 30 bottles NHS conc./month they had needed to buy more commercial conc. from January to August 1977 (235,000 u) than over the same period in 1976 (185,000 u).

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Dr. Colvin (The London): So far, in 1977, they had used 1,536 bottles (347,112 u) of NHS conc., 22 bottles of Kryobulin (10,724 u) and 53 bottles of Hemofil (14,360 u). A few patients were still on cryo. for HT. The Centre needed more NHS conc. if all HT patients were to go on to it.

Dr. Carmichael: Those Princess Alexandra patients who were on HT had NHS conc. supplied directly to them by the Regional Coordinator. As the patients were all registered at one of the Haemophilia Centres the hospital did not have an allocation of its own. No commercial conc. had been needed or purchased. Cryo. was used for patients who attended the hospital. He was satisfied with the arrangements.

Dr. Oakey (Orsett): the same applied and he was satisfied.

Dr. Nicholas (Essex County): the same applied but he would like more NHS conc. for his inhibitor patients. He received 4,000-5,000 u commercial conc./month from Prof. Hardisty for HT patients shared with HSC.

Dr. Baugh (Chelmsford & Essex): cryo. was used for patients treated at the hospital but, like Dr. Carmichael, she received NHS conc. from the Regional Coordinator for HT patients who were shared between her hospital and the Haemophilia Centre of the London Hospital.

N.W. THAMES

Dr. Davies: The current allocation of NHS conc. was 360 bottles/month - RFH 90, Hammersmith 40, UCH 20, HSC 30, reserve store 180. A reserve of 850 bottles had been built up.

Dr. Dormandy (RFH), Dr. Sieff (HSC) and Dr. McVerry (UCH) - See under N.E. Thames.

Prof. Stewart (The Middlesex): absent.

Prof. Humble (Westminster): NHS conc. was supplied by Dr. Rogers, South London BTC, and the allocation was satisfactory. No commercial conc. had been bought.

Dr. Bateman (Hammersmith): 40 bottles/month were enough for only 3 patients. 13,000 u/month of commercial conc. were being bought for 13 other HT patients. A large amount of commercial conc. had also been bought for in-patients so their shortfall of NHS conc. was great.

Dr. Dodsworth (St. Mary's): 1,400 bags of cryo. had been used since last September. They wanted to start 2 patients on HT so needed an allocation of NHS conc.

Dr. Hallam (Bedford General): absent.

Dr. Boots (Charing Cross): no conc. had been used and none was needed.

Dr. Ardeman (Edgware General): no conc. was needed.

Dr. Britt (Hillingdon): absent.

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Dr. Thompson (Luton & Dunstable): 1,000 bags of cryo. had been used and he had purchased 50 bottles of Hemofil (12,500 u) last year. One patient was training for HT and there were 3 more potential ones. They had no NHS conc. allocation but received 10 bottles/month from RFH and could use more.

Dr. Williams (The Lister Hospital): only cryo. was used and no NHS conc. was needed.

Dr. Ardeman reported that he had circularised everyone in N.W. Thames, asking what NHS conc. each needed. The figures added up to 427 bottles/month against a supply of 360. He and Dr.Davies had revised the allocations to fit in with the increased supply and also to reduce the reserve stock. Even so, there would still be a shortfall of 67 bottles/month.

Dr. Maycock said the Blood Products Laboratory of the Lister Institute was on target with production but alterations to the Manchester and Liverpool BTCs had not been completed. When they were, there would be an increased production of NHS conc. of about 20 percent. After that there would be no capacity at the Lister Institute for a further increase of plasma, even if it were produced. Current production of NHS conc. was about 50,000 bottles/year.

Dr. Jenkins asked if the units/bottle could be standardised.

Dr. Ellis replied that they were trying to do this and aimed to stabilise at 220/230 units per vial.

Dr. Ardeman asked how rigid the expiry dates were.

Dr. Ellis replied that the potency starts to fall off slowly from the beginning, but there is no acceleration after a year. Expiry dates might be extended.

Dr. Maycock stressed the necessity for the material to be used up rapidly and for reserves to be carefully managed.

Dr. Waiter reported that, in the ten months to 31st August, 1977, 10 million units of commercial conc. had been bought for £1 million. By far the most purchased was Hemofil (5 million units), followed by 2 million from Immuno and the same from Armour; Abbott was far behind and she had no record of purchases from Speywood (Koate). She wondered why Centres preferred the most expensive concs.

Prof. Ingram said it did not now seem that bulk-buying would be worth the trouble because the prices quoted for small and large quantities did not now differ greatly. One reason for choosing certain makes was that the large bottles were easier to use when covering surgery. Dr. Chalmers and Dr. Dormandy agreed.

Dr. Jenkins thought Armour met the requirements of patients on HT the best (below 7.8p/unit with syringes, etc. supplied free). He thought it might be necessary to deal with 2 firms, e.g. Armour for HT and another firm for surgery.

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Dr. Colvin thought that home treatment should have priority for NHS conc. and that it might not be necessary to buy commercial conc. for this. He had found Travenol the most cooperative firm.

Dr. Carmichael said that N.E. Thames had just agreed to bulk-buying by Brentwood BTC to obtain the cheapest rate.

Dr. Chalmers suggested that BTCs should combine for centralised bulk-buying as their region, for example, would not be buying enough to get the cheapest rate. He felt it would be unnecessary to use 2 firms as a good firm would produce different sizes of bottles for all requirements.

Prof. Ingram said that St. Thomas' had purchased 10,000 u from Speywood. There had been an unduly high titre of anti-A and anti-B antibodies and the patient had developed haemolytic anaemia. St. Thomas' normally bought from Travenol and Immuno, simply because they knew them best. He asked how the accounting for bulk-buying would be done. Would the BTC bill the hospital eventually?

Dr. Jenkins thought not; the bill should be paid from the regional budget which already paid the hospitals' pharmacy bills. He would like to be able to see the whole picture of the use of cryo., NHS and commercial concs.

iv. Quality Control

Prof. Ingram said he and Dr. Dormandy had hoped to run a quality-control scheme but:-

(a) many hospitals had joined Dr. Poller's PTTK quality-control scheme so did not wish to take part in a second.

(b) Oxford had carried out a big exercise on factor-VIII assays which had shown that the main cause for discrepancy was in the reagents, particularly phospholipids. It would be wise to wait until Oxford had clarified the problems with phospholipids. This might also explain the differences between the 1-stage and 2-stage assays between concentrate and plasma samples.

(c) St. Thomas' is looking at the sensitivity to the defect in mild haemophilia of various commercial reagents by comparison with Dr. Poller's reagents, for a joint WFH/ICTH working party of which he is chairman. It might be wise to wait to see which reagents were best.

The N.E. Thames Regional Study, for which Dr. Jenkins proposed to plasmapherese a haemophilic patient and distribute frozen samples in the region, was discussed briefly.

Dr. Carmichael said national schemes were cumbersome, mainly because results were not sufficiently immediate - by the time they had been worked out the participants tended to have lost interest.

Dr. Colvin said small schemes had the disadvantage of not having enough people involved.

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Prof. Ingram said it would be difficult to interpret the results with a small scheme, especially if reagents and methods were not standardised.

AGREED to keep Quality Control on the agenda for future meetings.

4. Associate Haemophilia Centres - Functions (DHSS circular HC(76)4)

Dr. Carmichael said it had been agreed that Associate Centres should treat patients on an emergency basis and supervise those on HT, but it had not been agreed whether or not they should issue special medical cards.

The advantages and disadvantages of having Associate Centres issue special medical cards, versus restricting this to Haemophilia Centres, were discussed. As no agreement was reached, and as it was felt that a uniform policy would be desirable, it was decided to put the matter forward for discussion at a meeting of the Haemophilia Centre Directors.

5. DHSS letter - Services available at Haemophilia and Associate Haemophilia Centres

Dr. Dormandy said that, in some regions, Associate Centres were being established without consultation with the relevant Reference Centre Directors. It had now been agreed that the new DHSS list would not be sent out until the Reference Centre Directors had confirmed that the necessary facilities were available at the Haemophilia and Associate Centres in their regions. For this reason she had drawn up a questionnaire which she would be grateful to have filled in so that she could make her decision when the time came.

Everyone agreed to fill in the questionnaire.

6. Suggested topics for the meeting of Directors of Centres to be held in Oxford on 24th October, 1977

Dr. Dormandy said it had been planned to hold this meeting of the Supra-Region one month before the Oxford meeting of Haemophilia Centre Directors so that items could be raised there, if necessary. It was now clear that one month before the larger meeting was not long enough as the agenda had already been drawn up.

Prof. Ingram suggested that a letter be written to Dr. Rizza asking that a space be left on the agendas of Haemophilia Centre Directors' meetings for items from the regions. AGREED.

7. Appointment of a new Co-Director at the Royal Free Hospital Haemophilia Centre

Dr. Dormandy explained that this was a new NHS Consultant appointment which had been established because her post was a University appointment whereas the running of the Haemophilia Centre was a service commitment.

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8. Date of next Supra-Regional Meeting

There was some discussion as to whether the next meeting should be at RFH and whether members wished to nominate a new chairman for it.

It was AGREED to keep the same chairman for two years, and that the next meeting should be held in about 8 or 9 months' time. That would give ample time for getting items on to the agenda of the Haemophilia Centre Directors' next autumn meeting. The date and place of the next Supra-Regional meeting would be announced nearer the time.

9. Any Other Business

Dr. Dormandy said Dr. Voke and she were preparing a handbook, a draft of which would be sent for comment to those present, if they would be interested. It was intended for SHOs, Registrars, Sisters,etc.

It was AGREED that all would like to see it.

The Chairman then declared the meeting closed.