

THIRD MEETING OF DIRECTORS OF HAEMOPHILIA, ASSOCIATE HAEMOPHILIA  
AND BLOOD TRANSFUSION CENTRES

from RHAs 04 (East Anglia), 05 (N.W. Thames) and 06 (N.E. Thames)

Friday, 1st September, 1978, at 2.30 p.m. in the Seminar Room of the  
HAEMOPHILIA CENTRE, ROYAL FREE HOSPITAL (Ground Floor back)

A G E N D A

1. Apologies
2. Minutes of the second meeting, 23rd September, 1977
3. Matters arising from the minutes other than those appearing as separate items on the agenda:
  - (a) Functions of Associate Haemophilia Centres - decisions of the Haemophilia Reference Centre Directors on 27th January, 1978 (Item 4)
  - (b) Dr. Dormandy's questionnaire on the facilities available at Haemophilia and Associate Haemophilia Centres (Item 5)
  - (c) The Haemophilia Centre Handbook (Item 9)
4. Distribution of NHS factor VIII concentrate (at the request of Dr. S. Ardeman)
5. Possible problems of blood donations from family members of patients on home treatment (Drs. P. Kernoff and E. Tuddenham)
6. The value of Supra-Regional Meetings (questioned by Dr. D.G. Chalmers)
7. Any other business

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MINUTES OF THE THIRD MEETING OF DIRECTORS OF HAEMOPHILIA,  
ASSOCIATE HAEMOPHILIA AND BLOOD TRANSFUSION CENTRES IN RHAs  
04, 05 & 06, HELD AT THE ROYAL FREE HOSPITAL on Friday,  
1st September 1978

P R E S E N T

Dr. S. Ardeman	Edgware General Hospital	(05)
Dr. D.S. Thompson	Luton & Dunstable Hospital	
Dr. A. Rankin (for Prof. Hardisty)	Hospital for Sick Children, Great Ormond Street	
Dr. D. McCarthy (for Dr. P. Hilgard)	Hammersmith Hospital	
Dr. T.R. Mitchell.	Charing Cross Hospital	
Dr. S.J. Machin (for Prof. Stewart)	The Middlesex Hospital	
Dr. R.C. Hallam	Bedford General Hospital	
Dr. C. de Silva	Northwick Park Hospital	
Dr. T. Cleghorn	North London B.T.C.	

Dr. D. Carmichael (Chairman)	Princess Alexandra Hospital, Harlow (06)
Dr. B. T. Colvin	The London Hospital
Dr. D.H.A. Baugh	Chelmsford & Essex Hospital
Dr. J. Richards	University College Hospital
Dr. J.S. Oakey	Orsett Hospital, Grays
Sister Gill Davis	N.E.T. Regional Coordinator for Haemophilia
Dr. P.B.A. Kernoff	Royal Free Hospital
Dr. E.G.D. Tuddenham	" " "
Dr. Eleanor Goldman	" " "
Mrs. Peggy Britten	" " "

Professor G.I.C. Ingram	St. Thomas' Hospital	(07, 08)
Dr. R. S. Lane	Blood Products Laboratory, Elstree	

Opening the meeting, the Chairman Dr. Carmichael spoke a few words about the late Dr. Katharine Dormandy and her work in the field of haemophilia. It was agreed that all present stand for a few seconds in silence as a tribute to her.

Dr. Carmichael then introduced the two new Co-Directors of the Royal Free Hospital Haemophilia Centre, Drs. P.B.A. Kernoff and E.G.D. Tuddenham.

1. Apologies

Dr. D.G. Chalmers	Addenbrooke's Hospital, Cambridge
Dr. J. Leslie	Norfolk & Norwich Hospital, Norwich
Dr. J. Darnborough	Cambridge Blood Transfusion Centre
Dr. P. Hilgard	Hammersmith Hospital
Professor J.W. Stewart	The Middlesex Hospital
Dr. T. Davies	North London Blood Transfusion Centre, Edgware
Dr. J.R.B. Williams	Lister Hospital, Stevenage
Dr. R.P. Britt	Hillingdon Hospital
Professor G.C. Jenkins	The London Hospital
Professor R.M. Hardisty	Hospital for Sick Children
Dr. W.J. Jenkins	NET Regional Blood Transfusion Centre
Sir William Maycock	Blood Products Laboratory, Elstree
Dr. D. Ellis	" " " "
Dr. Sheila Waiter	DHSS

2. Minutes of the Second Meeting - 23rd September 1977:

These were signed as a correct record.

3.a) Functions of Associate Haemophilia Centres:

There was a debate at the last meeting about whether or not Associate Haemophilia Centres should issue Special Medical Cards. The Reference Centre Directors later decided that Associate Centres might do so if they wished. In order that each Reference Centre Director would know of all patients in his Supra-Region, Miss Spooner from the Oxford Centre would notify him of new patients reported in the annual returns of other centres in his area. Dr. Carmichael asked for the views of those present on this.

Dr. Baugh expressed the view that she would prefer to refer her patients to a Haemophilia Centre.

Dr. Machin said that Professor Stewart felt quite strongly about this. Although the Middlesex Hospital was now an Associate Centre, he would continue to issue Medical Cards and would refer patients only if he felt it necessary, and not overseas patients passing through London.

Dr. Colvin felt that the solution to the problem depended on local factors. In the North East Thames Region it was generally agreed that patients would be registered at a Haemophilia Centre. This enabled the Regional Register to be efficiently maintained and provided useful contact and mutual quality control between the various centres.

Dr. Carmichael asked members whether they felt it a reasonable suggestion that, when patients were registered with Associate Centres, Haemophilia Centres should be notified.

Dr. Kernoff felt that the information, when available from Oxford, would be more complete.

Dr. Oakey felt it would simplify matters if the returns from Oxford reported with accuracy the types of therapeutic material used.

Dr. Tuddenham wondered whether, when Oxford was informed of the patients registered at an Associate Centre, a copy could be sent to the Haemophilia Centre it liaised with as well as to the Reference Centre.

Dr. Ardeman suggested that Dr. Machin's point about overseas patients be noted, but what about the patients registered who required continuing care under the Supra-Region?

Professor Ingram had two comments to make, one about registering and the other about notifying Oxford. He felt that temporary visitors who were treated should not be registered; Oxford should, however, be notified because visitors represented a drain on resources which should be taken into account when allocations of therapeutic materials were made.

Mrs. Britten said she had discussed with Miss Spooner of Oxford the question of notifying Oxford of new patients. Oxford wanted forms only for new, long-term patients, not for temporary visitors treated. Their names appear in the annual returns, with details of treatments received.

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AGREED that Associate Haemophilia Centres would notify a Haemophilia Centre of each new patient registered.

b) Dr. Carmichael informed those present that two Haemophilia Centres and six Associate Centres had failed to return Dr. Dormandy's questionnaire on the facilities available at their Centres. He felt that the details from the questionnaires should be circulated to all haematologists, with the name of the person responsible at each Centre. He asked for the views of those present on this.

Dr. Kernoff felt that the main emphasis should be put on diagnostic tests available, rather than on other facilities.

Dr. Carmichael said he was thinking on the lines of sending the analyses to all haematologists in the Supra-Region, not only to those present.

Professor Ingram said that most haematologists in 07 and 08 were aware of the tests available, as it was discussed at their Regional haematology meetings.

It was AGREED that the individual regions should take this up as they thought fit.

c) Dr. Carmichael reported that circulation of a draft of the Haemophilia Centre Handbook had not been possible as Dr. Dormandy was working on it until just before her death. Dr. Voke hoped to have it published shortly at a price of £1.50. Immuno would publish it free and the profits from sales were to go to the Katharine Dormandy Trust for Haemophilia and Allied Disorders.

#### 4. Distribution of NHS factor VIII concentrate:

Dr. Ardeman had two matters he wanted to raise: The first one was parochial, involving North West Thames, and he apologised to those who were not concerned. In April 1978, Dr. Dormandy, Dr. Tuddenham, Dr. Ardeman, Dr. Davies and Mrs. Britten met to try and sort out the distribution of the 360 bottles per month of NHS concentrate allowed to North West Thames, bearing in mind that the requirements of the region were much more than this. He wanted to air the conclusions arrived at to see whether it was a fair arrangement, and if any suggestions could be made. The arrangement was that the 360 bottles should be allocated to Centres for patients on home therapy, pro rata on the basis of the returns for those patients treated in 1977. This meant that certain hospitals now received less than they were receiving prior to the meeting. He wanted to know whether the Meeting felt this was a reasonable suggestion or not. The decision had been implemented since the April meeting.

Dr. Carmichael said that these sorts of matters were usually settled at the North East Thames Regional meetings of the Haemophilia Working Party.

Professor Ingram commented that South East and South West Thames also did this at their haematology meetings and had come to the conclusion that allocation of concentrate on the basis of home treatment requirements was a fair and practicable method of distribution. An additional advantage of the method was that it might be easier for Centre Directors to negotiate with their pharmacists for the purchase of commercial concentrates as drugs when used for operations, rather than for long-standing commitments like home treatment.

Dr. Colvin was strongly in favour of this method of distribution.

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Dr. Richards reported on a patient of his who had severe reactions to cryoprecipitate. They were having to spend about £400 per month on commercial concentrates for him because they were short of NHS concentrate. The burden was on the Haematology Department which was trying to find the funds.

Dr. Lane felt he didn't have much to say on this matter except that more was being spent on commercial factor VIII by the DHSS than was spent on the entire budget for the NHS fractionation programme. They were in a position to process more fresh frozen plasma than they were receiving. If they could get more finance from the Department of Health, to double the production of factor VIII in the next few years, it would go a long way towards alleviating the present problems. However, the financial difficulties of the Blood Transfusion Service and the Department of Health could not be discussed at this meeting.

Dr. Rankin commented that their allocation had been reduced from 100 to 65 bottles. This was enough to treat only half their patients on home therapy, hence they had started transferring their patients to other Centres at a much younger age, e.g. to Professor Ingram and the Royal Free Hospital. She also made the point that, as the children were growing, their concentrate requirements increased steadily.

Dr. Kernoff felt that this did not solve the problem - it merely passed it to someone else; it increased the Royal Free's use of concentrates and they were already overrunning their budget. The problem needed to be dealt with at a regional, supra-regional and national levels. Only 20% of the Royal Free's requirements were being met with NHS concentrate at present. Despite this, and in accordance with the Reference Centre Directors' recommendations, it was the intention to switch home treatment patients from cryoprecipitate to concentrate. Half the home treatment patients at the Royal Free were still using cryoprecipitate and this was felt to be an unacceptable state of affairs. If NHS concentrate was not available then commercial concentrate would have to be bought. In fact, the extra cost might not be very great since the cost of cryo to the Royal Free was not inconsiderable and, taking into account the unitage, it worked out at almost the same price as commercial concentrates.

Dr. Carmichael felt that distribution problems should be solved at regional level.

He then read a letter from Dr. Williams in which he strongly supported the cross-checking of patients of Associate Centres by their Reference Centre. He was worried that the change of distribution of NHS factor VIII had been arranged without discussion of the financial implications at Area and District levels.

Dr. Carmichael wondered if it might not be a good idea to invite Regional/District/Area medical officers to future Supra-Regional meetings. He suggested that Drs. Kernoff and Tuddenham should write to the medical officers.

Dr. Cleghorn reiterated that all the problems seemed to be connected with finance.

Dr. Kernoff pointed out that although the Royal Free was in the North East Thames Region, the Haemophilia Centre had more patients from North West Thames. This complicated arrangements with supply of factor VIII, and was one good reason for continued and increased collaboration between North East and North West Thames.

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Professor Ingram said that the Pharmacist at St. Thomas' Hospital considered factor VIII to be a drug, so the cost was borne by the hospital. It was very important to try to forecast the future shortfall of factor VIII and to present this estimate to the Finance Officer so that he could make a bid for further money. To strengthen one's case it was necessary to produce hard facts for the administrators.

Dr. Carmichael thought it might be worth trying this out in North East Thames.

Dr. Cleghorn stressed that the most important thing was to see how more money could be obtained to produce more concentrate at Elstree.

Dr. Ardeman's second point was about the decision that the sub-committee had made that all the 360 bottles received by North West Thames should be distributed each month, so the Blood Transfusion Centre had no reserve stock. He understood that some regions had concentrate left over and stockpiled it.

Dr. Lane said that factor VIII concentrate was distributed to Regional Transfusion Centres on the basis of haemophiliacs reported to Oxford as being under treatment. This method of allocation was adopted after it had been discussed and agreed with the DHSS ad hoc Advisory Group on Haemophilia, the Haemophilia Centre Directors meeting and the Regional Transfusion Directors meeting. He was not willing to be drawn into any discussion on this issue, as it wasn't the only way of solving the problem. One of the things that could be done was the provision of incentives to Blood Transfusion Centres to provide more plasma for fractionation. Hence it was necessary that hospitals should not hide facts about the increase in purchases of commercial concentrate. This needed to be thought out in detail.

Dr. Colvin said that the North East Thames kept a reserve. The stockpile was continually turning over.

Dr. Cleghorn said he was very disturbed that Dr. Ardeman and the sub-committee had distributed the stockpile from the Blood Transfusion Centre. He thought the Blood Transfusion Centre should have had some say in the matter.

Dr. Ardeman asked what a reasonable amount for the Blood Transfusion Centre to hold would be.

Sister Davis said that Brentwood stockpiled 60 bottles per month for emergencies and so that she could have some stock to give to patients going on holiday.

Dr. Kernoff pointed out that stockpiling meant you had to replace from another source, so why stockpile? If there were no stockpile and there were an emergency, commercial concentrates could be used.

Dr. Richards said deliveries of commercial concentrates were slow and mentioned that he had had to pay an extra £70 for an urgent delivery.

Dr. Carmichael thought it was necessary for hospitals which did not keep a stock to be able to approach the Blood Transfusion Centre if they needed concentrate urgently.

Dr. Cleghorn again reiterated his great concern about the lack of a stockpile at the Blood Transfusion Centre.

Dr. Ardeman then commented that arrangements were going to have to be altered again.

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Dr. Tuddenham mentioned that, even though the stockpile had been distributed, it was the intention of the Royal Free Hospital to keep a certain reserve of commercial concentrate to supply other haemophilia centres if any emergencies arose.

Dr. Colvin said there should be a stockpile of some kind.

Dr. Carmichael said that individual arrangements were possible.

The question was who should maintain the stockpile. North West Thames might wish the Royal Free Hospital to keep it, but the North East Thames preferred the Blood Transfusion Centre to hold it.

Professor Ingram said that their requirements of concentrate for patients on home treatment had gradually increased. They were having to buy commercial concentrates and other Centres could borrow from St. Thomas' in an emergency. Regions 07 and 08 had used up most of their reserves and had no stockpile of NHS material.

Dr. Ardeman asked whether Dr. Cleghorn wished him to change the amount of National Health Service concentrate allocated per month to rebuild the stockpile.

Dr. Cleghorn said that, since the stockpile had already been dissipated, that would be difficult. It would be better to approach the Region for finance to build up a reserve of commercial concentrates.

Dr. Tuddenham agreed that it was necessary to maintain a stockpile. Dr. Ardeman said the Royal Free Hospital could use and replace commercial concentrates. The Blood Transfusion Centre could not. Should it hold both commercial and NHS concentrates?

It was AGREED that Dr. Cleghorn should maintain a stockpile at the Blood Transfusion Centre.

5. Possible problems of blood donations from family members of patients on home treatment:

Dr. Kernoff mentioned an incident that had taken place at the Royal Free Hospital where the mother of a patient on home treatment pricked herself and subsequently developed hepatitis. Before becoming ill, she had donated blood which had apparently been administered to a patient on the Liver Unit in the Royal Free Hospital. The boy himself was positive to hepatitis B antigen though remained asymptomatic. Dr. Kernoff pointed out that family members of patients on home treatment should be considered high risks for transmission of hepatitis and should not be allowed to donate blood.

Dr. Colvin mentioned that he used to be a blood donor but had given up donating blood when he started working in a haemophilia centre.

Dr. Carmichael suggested that the Haemophilia Society might publish a warning in its bulletin.

Dr. Kernoff requested that Dr. Cleghorn take up the issue at the next meeting of the Blood Transfusion Centre Directors.

Dr. Cleghorn did not foresee much co-operation from donors, especially since members of affected families were usually keen to donate blood.

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6. The value of Supra-Regional Meetings:

Dr. Carmichael read out a letter received from Dr. D. G. Chalmers, Consultant Haematologist at Addenbrooke's Hospital, Cambridge, who questioned the value of Supra-Regional meetings as he felt that most problems were discussed and dealt with at the National Meeting of Directors.

Dr. Carmichael requested the views of those present. He himself valued the meetings, though thought it might be a good idea to involve Regional Medical Officers.

Dr. Colvin felt that these meetings were important as a means of liaison between the North West and North East Thames.

It was AGREED to continue holding Supra-Regional Meetings annually and that the Directors of Centres in East Anglia be invited as before, but it was entirely up to individual Directors to decide if they wanted to attend.

7. Any other business:

Dr. Carmichael mentioned that he had taken the Chair at the previous two meetings as Dr. Dormandy was not well. He offered his resignation and asked whether Dr. Kernoff and Dr. Tuddenham might not be asked to take the Chair at the next meeting.

Dr. Carmichael's resignation was accepted and it was AGREED that Drs. Kernoff and Tuddenham would arrange who would be Chairman of the next Supra-Regional Meeting.

Dr. Ardeman proposed a vote of thanks to Dr. Carmichael for his excellent chairmanship during the last two years and the meeting was then declared closed.