

FILE: 8 VOLUME: TITLE:

File Ref	Doc No./ref.	DOCUMENT NAME	DOCUMENT TYPE	DATE	ORIGINAL	COMMENT ON HANDLING
		Minutes of the Seventeenth Meeting of the UK Regional Haemophilia Centre Directors Committee held on 5 September 1994	Minutes	5/09/94		
		UK Haemophilia Centre Directors Organisation Comprehensive Care Centre Status	Note of a meeting	05/09/94		
		UKHCDO Applications for Centre Designation	List	Undated		
		Minutes of 16 Meeting of UK Regional Haemophilia Centre Directors Committee Held on 14 March 94	Minutes	14/03/94		
		Minutes of the 15 Meeting of the UK Regional Haemophilia Centre Directors Committee held on 10 December 93	Minutes	10/12/93		
		Minutes of the 25 <sup>th</sup> meeting of the UKHCD held on Friday 1/10/93	Minutes	1/10/93		
		Minutes of the 14 <sup>th</sup> Meeting of the UK Regional Haemophilia Centre Directors Committee held on 10/09/93	Minutes	10/09/93		
		Minutes of the 13 meeting of the regional Haemophilia Centre Directors' Committee held on 8/02/93	Minutes	08/02/93		
		Minutes of the 12 Meeting of UK Haemophilia Centre Directors Regional representatives held on 10/12/92	Minutes	10/12/92		



**Minutes of the Seventeenth Meeting of the UK Regional  
Haemophilia Centre Directors Committee held at the Lansdowne  
Club, London on Monday 5th September, 1994.**

**PRESENT:**

1. **Apologies**

2. **Minutes of the Sixteenth Meeting**

The Minutes were approved and signed.

3. **Matters arising from the Minutes**

invited Directors to raise matters additional to the items already on the Agenda.

- i) enquired what the situation was regarding hepatitis C litigation. said that a number of suits were being filed and he had been asked through the Royal College of Pathologists to look at some cases. It was understood that it would be very difficult for cases to succeed. asked if Centres should ask for informed signed consent to treatment with blood products and suggested that perhaps signed consent should be obtained when the type of material changed. After discussion it was agreed that informed consent should be discussed in more detail at the

next Regional Centre Directors' Committee Meeting.

ii) Audit of Regional Centres

said that this was not yet complete.

4. Chairman's Business and Annual Report

The Chairman's Annual Report had been pre-circulated (Appendix i).  
outlined the content of the Report and suggested that the document should go to all Directors with the AGM agenda. This was agreed.  
queried the auditing of new Comprehensive Care Centres.  
said that he understood that they would be provisionally approved and then audited.  
said he would prefer the new Comprehensive Care Centres to be audited before any announcement or approval.  
asked who now represented the South West and noted that no one had attended recent meetings.

a) Constitution and Charitable Status

A document had been pre-circulated to the meeting (Appendix ii).  
said that this was a statement for approval at the AGM which was necessary for the organisation to be granted charitable status.

b) Comprehensive Care Centre Designation

A paper was tabled (Appendix iii) The Minutes of a meeting held at Edinburgh on 21st July were discussed in detail. Concern was expressed about the South West of England which did not at present appear to have a representative on the Haemophilia Centre Directors' Committee or a Comprehensive Care Centre. The financing of the Comprehensive Care Centres was considered and would be discussed later.  
drew attention to the document HSG93/30 and said that new Haemophilia Centres would need to let purchasers know if there are any requirements that they could not meet.  
asked if the Genetics Working Party had a feel regarding the level of ante-natal diagnosis. He was concerned that there might be lack of expertise at some of the Centres.  
pointed out that although Comprehensive Care Centres were audited there was no requirement that the audit should be satisfactory. This was discussed and it was noted that there was no procedure to strike off Centres that had unsatisfactory audits.  
said that it would be very difficult to publish a list now and change it later.  
said that the list would not be

issued to purchasers until after the audit process had been completed. suggested that it would be better to leave Comprehensive Care Centres not yet audited off the list for the AGM. said that the auditors should stick closely to HSG93/30 when visiting Centres. It was suggested that more than one auditor should visit those Centres which had been selected. After further discussion it was agreed that:

1. A list of audited Comprehensive Care Centres should go to the AGM.
2. Non-audited Comprehensive Care Centres should not be named.
3. Centres not recommended as possible Comprehensive Care Centres should not be audited.

agreed to:

**ACTION: BC**

- i) Prepare a revised document for the AGM.
- ii) State at the AGM that further Centres were to be audited.
- iii) Explain the situation to all the applicants for Comprehensive Care Centre status.
- iv) Write to as soon as possible for his views.
- v) Draw up a list of Haemophilia Treatment Centres.

c) **Article**

said that he had replied to article on Viral Contamination of Blood Products on behalf of the Haemophilia Centre Directors. The correspondence had been published in July in the Lancet. was also concerned that had been the first named author on a publication regarding clinical studies. This was discussed and not everybody agreed with 's view that this was undesirable. thought that this topic should be considered under the item on declaration of interest.

d) **Press Statements**

had written to about press statements which could be misleading. He suggested that those communicating with the Press should be sent pre-press release

copies of statements but it was recognised that this would be very difficult to arrange.                      said that all the Directors should do their best to inform the press accurately but not be surprised if press releases were not correct.

e) International HIV Register

                    had received a request for data from NIH regarding Oxford Haemophilia Centre patients and                      had also received a similar letter.                      said that he had written to NIH and                      had spoken to                      when she visited NIH.                      suggested that the data supplied to                      should be on a UK basis. After brief discussion it was agreed that                      would refer the document to the HIV Working Party.

5. Financial Matters

a) Treasurer's Report

A report (Appendix ix) was tabled by                      The British Society for Haemostasis and Thrombosis had made a grant of £5,000 to the Organisation for use in Oxford for updating the computing facilities. It has not been possible for the Treasurer to collect all the subscriptions.

b) Annual Contribution Towards Cost of Secretariat in Oxford

                    said that Oxford had received one donation of £900. Nine hundred pounds per annum would amount to less than 2% of the annual expenditure of Oxford Haemophilia Centre in running the Secretariat. He would prefer a payment from the Haemophilia Centre Directors' Organisation not to be linked to the membership fees. After discussion

                    said that Oxford would not ask the Organisation to provide an annual subscription towards the running of the Secretariat.                      raised the question of the format of the Report on Annual Returns and it was agreed that this would be discussed at the next Regional Centre Directors' Meeting.

c) Charges for Attending RCD and Working Party Meetings

                    requested that representatives should send apologies to                      or                      before the date of meetings so that the costs of lunches, etc. at the meetings could be reduced. There had been some problems with recent meetings when apologies were not received and the numbers attending were rather low.

d) Payment of HCDO Membership Fees

suggested that Comprehensive Care Centres should pay more than other Centres. said that he thought that it would be appropriate to consider requesting a higher fee from Comprehensive Care Centres but the Directors would need to have some idea of how the money would be used.

suggested that the matter should be discussed at the AGM. said that Working Party needs should be taken into account. said that the meeting should support Oxford continuing with the work that they were doing on behalf of the HCDO. After further discussion it was agreed that -

- i) No funds would be sent to Oxford Haemophilia Centre this year.
- ii) The Treasurer would continue to collect fees from Haemophilia Centres and from Commercial firms for copies of the Annual Report.
- iii) The Regional Representatives should consider a higher charge for Comprehensive Care Centres.
- iv) would prepare a document for the next RCD meeting on plans for the future on the reports on the Annual Returns. It was agreed that it would be a good idea for the Directors to try to publish reports on the Annual Returns in "Haemophilia" in the future.

6. a) Annual Returns for 1993

said that he was confident that a report would be ready in time for tabling at the AGM.

b) Letter from (Appendix v)

After brief discussion it was agreed that the Directors should continue to collect data by calendar year for the time being.

said that he would be in favour of changing to the financial year in due course.

c) Review of Methods for Data Collection

said that he had received a copy of letter to and reply. He thanked for his contribution. outlined the present system used in Oxford and the proposed

new system which would be going ahead as soon as possible.

7. Arrangements for the 1994 AGM

outlined the programme and said that final details would be circulated to Directors within the next few days. The AGM agenda was discussed in detail. outlined the background to item in the Agenda. wondered whether the arrangements for the meeting should be revamped referring to the meeting held three years ago to discuss contracts and to whether a similar meeting should be held again. There was a brief discussion on the type of contracts that the Directors held with purchasers. Some changes were made in the format of the 1994 AGM.

8. Declaration of Interests (Appendix vi)

was invited to speak on this item. She said that Declaration of Interests was required by the Constitution. The document gave the framework for the Declaration of Interests and was based on a document used by the CSM. suggested that he should write to all Regional Representatives asking for a Declaration of Interests and this was agreed. During the discussions the presence of the DOH representative at meetings was raised. said that it was agreed some time ago that the DOH representative should only be invited to part of each meeting.

9. Working Party Reports and Related Topics

a) Genetics

gave a resumé of the proceedings at two meetings which the Working Party had held recently. had been invited to join the Working Party.

b) Paediatrics

said that the Paediatric Working Party's proposals would go to the AGM and a series of tasks had been set by the Working Party. A document would be pre-circulated to Directors before the AGM.

c) von Willebrand's Disease

said that the Working Party had held two meetings. Diagnostic and treatment criteria had been drawn up and these would hopefully be ready for presentation at the



AGM. Regarding 8Y and Haemate P,                      would leave  
copies of her correspondence with                      with

The data was not yet adequate for publication and it  
was doubtful whether sufficient data for this purpose could be  
collected.

d) Adverse Events

After discussion it was agreed that the Adverse Events  
Working Party should be reconvened and that  
                    should be Chairman.

e) HIV

                    said that the Working Party had drawn up two  
documents, HIV 94/1 which was a modified AIDS reporting  
form and would be mailed out soon and HIV 94/2 which would  
ask Directors to give information about the current situation  
with all their HIV+ patients. The Directors would also be  
receiving guidelines regarding advice to be given to HIV+  
patients who wish to have children and a questionnaire  
regarding the partners of HIV+ haemophiliacs. An MRC grant  
application had been made for funding to support Nurses to  
visit Centres to help with the completion of data forms which  
were currently being drawn up by the Working Party for use  
next year.

f) Inhibitors

The Inhibitor Working Party had held two meetings and  
another one would be held this week. NEQAS's Inhibitor  
exercise was discussed and recommendations on investigation  
and treatment were being drawn up.

                    and                      had been co-opted to the  
Working Party with a view to studying the genetics and  
immunology of inhibitor development.                      confirmed  
that a short report on inhibitor development in the UK from  
1990-93 had been submitted to the British Journal of  
Haematology.

10. Date of Next Meeting of Regional Directors' Committee

Monday 30th January, 1995 at the Lansdowne Club.

11. Date of 1995 Meeting

                    said that he was moving to Manchester and the meeting

could be held there instead of in Liverpool. He would find dates as soon as possible and let the Chairman and Secretariat know. After discussion it was decided that the 1996 meeting would not be held in Dublin and the decision of the venue was deferred.

12. Any Other Business

No other business was discussed.

The meeting closed at 3.10 p.m.

11.11.94