Minutes of the Twenty-ninth Meeting of Haemophilia Reference Centre Directors held at the **ROYAL FREE HOSPITAL** on **Monday 1st FEBRUARY, 1988**

Present:
Dr. C.R. Rizza (Chairman)
Dr. A. Aronstam
Prof. A.L. Bloom
Dr. M. Greaves
Dr. P. Jones
Dr. P.B.A. Kernoff
Dr. C. Lee
Dr. G.D.O. Lowe
Dr. C.A. Ludlam
Dr. E.E. Mayne
Prof. F.E. Preston
Dr. G. Savidge
Miss R.J.D. Spooner
Dr. I. Temperley (Observer)
Dr. J. Craske
Dr. I.D. Walker (rep. Dr. G. McDonald)

1. Apologies for absence were received from:-

Dr. P. Hamilton.

2. Minutes of the Twenty-eighth Meeting were approved and signed by the Chairman.

3. Matters arising from the Minutes

a) Trust Fund to help haemophiliacs infected with HIV

Dr. Rizza said that the Haemophilia Society were proceeding slowly with setting up the Trust Fund. Dr. Jones said that on average it takes ten months to set up a Trust Fund but the Society hoped to do it within 4-5 months. Dr. Kernoff moved a vote of thanks to Dr. Jones for all the work he had done in helping the Society to get the funds from the Department of Health.

b) Appointment of Secretary

The matter of the Secretaryship of the Group was raised again. Dr. Kernoff said that it would be difficult for anyone outside Oxford to take on the role of Secretary because of the need for the Secretary to be near to the data collection centres. He suggested a re-definition of the role of Secretary. Miss Spooner had been Administrative Secretary for many years and he suggested that Miss Spooner should be officially appointed as Administrative Secretary to the Haemophilia Centre Directors and that a Vice Chairman or Deputy Chairman should be appointed. **It was agreed** that Miss Spooner should be appointed as Administrative Secretary to the Haemophilia Centre Directors' Organisation and that a postal ballot for the post of Vice Chairman would be taken from the Reference Centre Directors'. The discussion on the subject highlighted the need for a constitution to be drawn up to

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define the roles of the various officers. The Chairman reminded the members that Dr. Savidge was Chairman of a Working Party with the brief to draw up a Constitution for the Haemophilia Centre Directors' Organisation. Dr. Savidge said that it would take time to have the constitution drawn up and it had to be approved by the Colleges, the Department of Health and other organisations. Several members felt there was no need for the Directors' constitution to be approved by other bodies.

c) Constitution of the Haemophilia Centre Directors' Organisation

Dr. Savidge said that a meeting would be held in 2-3 weeks time when he hoped to have a draft constitution ready for discussion. He hoped to get a new version of HC76(4) for discussion within the next 2-3 weeks. After discussion **it was agreed** that the constitution of the Haemophilia Centre Directors' Organisation needed to be drawn up before the re-organisation of Haemophilia Centres could be undertaken.

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d) Up-dating of official DHSS booklet listing Centres

Dr. Savidge said that the two-tier system of Centres had been agreed and that Centres treating more than 10 severely affected haemophiliac patients would be regarded as Centres and those treating less than 10 severely affected haemophiliac patients in any one year would be called 'Haemophilia treatment units' although this latter title was still under discussion. Oxford had produced a list which had gone to the Department of Health of Haemophilia Centres and Treatment Units but no reply had been received. Dr. Savidge hoped to have a discussion with Dr. Smithies in the near future. Dr. Rizza asked how often the yellow booklet should be updated and who would pay for it. Dr. Savidge said that there was a proposal that the new lists would be printed on A4 sheets for distribution to Haemophilia Centres but Dr. Kernoff said that he did not like this idea and he would prefer a proper booklet and suggested that the Haemophilia Society might help with the cost of producing the booklet if the Department of Health was unwilling to meet the cost.

e) Haemophilia Cards in Scotland

Dr. Lowe reported that the new Haemophilia Card had been distributed in Scotland.

4. Haemophilia Centres Directors Annual Returns

Dr. Rizza presented Appendix A, a Report on the Annual Returns for 1986. The response had been excellent and was probably the best ever. Dr. Jones asked if the Reference Centre Directors should be told which Centres were non co-operative. Miss Spooner said that these were only Centres with small numbers of patients and after further discussion **it was agreed** that the identity of those Centres should not be disclosed. The question of removing from the 'inhibitor register' patients whose

inhibitors had disappeared was raised but **it was agreed** that this should not be done. Dr. Savidge was concerned that the prevalence of antibody might be biased because of the way in which it was expressed as a percentage of all haemophiliacs. It was suggested that in future reports the severity of haemophilia of the patients who subsequently developed inhibitors would be

DECISION noted. **This was agreed.** Dr. Kernoff suggested that it was important to know the numbers of patients whose inhibitors had disappeared. Dr. Ludlam wanted to know if inhibitor patients were tested each year and suggested that this question was added to the Annual Returns. This was discussed but no decision was taken. Dr. Savidge asked if data on the type of inhibitor test was collected. Miss Spooner said that this information was only collected when patient's inhibitors first appeared. Concern was expressed that there were still many patients in the National Register whose factor VIII levels and dates of birth were not known by the Haemophilia Centre Directors especially since some of these patients were apparently receiving home therapy. Professor Bloom wondered whether the identity of the 'poor performance centres' should be disclosed to the Reference Centre Directors so that the Reference Centre Directors could chase up the information. Dr. Kernoff was worried about the HIV status of the missing people but it was felt that if these people had not attended a Haemophilia Centre over the last five years or more they were probably not receiving treatment at any hospital in the

ACTION RS United Kingdom. After discussion **it was agreed** that Miss Spooner should write to Directors about the missing people. Regarding the von Willebrand's disease patients, Professor Bloom asked why the VIIIc data was given and not the von Willebrand factor. It was pointed out that the other information was being collected and analysed by the von Willebrand's Working Party and would be presented separately. Dr. Jones asked about Regional statistics and if it would be possible for Regional statistics to be prepared for the Reference Centre Directors again as had happened

ACTION RS, CR in previous years. **It was agreed** that Miss Spooner and Dr. Rizza would prepare Regional statistics for the Reference Centre Directors as soon as possible. Dr. Kernoff asked if a limited survey among the Reference Centre Directors could be undertaken on the amounts of material used in the various severity groups. Professor Preston said he would also be interested in having more detailed statistics. It would be interesting to know the reasons for the increased amounts of material used and which groups of

ACTION RS, CR patients were the greatest users. After discussion **it was agreed** that a limited survey as proposed by Dr. Kernoff would be undertaken. Dr. Jones said that his MP and his Regional Medical Officer were asking how the figures for the Northern Region compared with other Regions and had asked Dr. Jones for data concerning factor VIII usage during the past 10 years in the different Regions. Members were very concerned about passing on

DECISION ACTION PJ such information and after much discussion of the different possible courses of action **it was agreed** that Dr. Jones should give information based only on National statistics without breaking it down into Regions.

ACTION ALL Dr. Rizza asked the members to let him have their comments

on the 1986 Annual Returns Report within the next two weeks so that the Report could be sent to all Haemophilia Centre Directors with the Minutes of the AGM.

5. Reports from Working Party Chairmen:

a) Hepatitis

Dr. Craske said that after the last Hepatitis Working Party meeting he had put forward recommendations about future surveillance of the usage of materials. He felt that if the Hepatitis Working Party continued at all it would depend on the decision about the paper presented as Appendix C, Item 6. There had been a drop in the numbers of cases of hepatitis reported since 1984 (see Appendix B).

Item 6 Dr. Craske had prepared a document (Appendix C) in which he suggested that there should be more intensive surveillance of the safety of blood products and that the Directors should work more closely with other outside bodies (such as the CSM and BPL) in this regard. He had discussed the matter with the Director of the Public Health Laboratory Service and had drawn up Appendix C on the basis of these discussions. During discussion all the Directors supported the principles set out in Dr. Craske's document and felt that all blood products should undergo the same stringent monitoring as other new drugs. The way in which this should be done would require careful thought. In the current climate it was important to be able to advise the U.K. Directors as to which was the safest product to use to treat haemophilic patients. Dr. Mayne agreed with Dr. Craske and suggested that two years of trying a reporting system similar to the one used by CSM ("yellow card") should be undertaken in the first instance. Dr. Lowe said that there should be provision for 'not previously encountered' complications to be reported. Dr. Rizza suggested the Reference Centre Directors send in writing to him their comments on Appendix C within the next ten days and send a copy of their
ACTION ALL comments to Dr. Craske. **This was agreed.** In view of the urgency of the matter Dr. Jones proposed that Dr. Kernoff should Chair a Working Party to enquire into the products which were currently being used by Haemophilia Centre Directors and to come up with a recommendation regarding the safest products. Dr. Rizza suggested, and **it was agreed,** that the matter would be discussed during the AIDS Working Party meeting during the afternoon.
ACTION JC, IT, EM During further discussion about adverse reactions Dr. Craske and Dr. Temperley agreed to let the Reference Centre Directors have information about patients who had developed hepatitis following use of Koate and Dr. Mayne said she would give information about a case of hepatitis in a patient who had been treated with the Scottish NHS Factor VIII concentrate.

b) von Willebrand's disease

Dr. Savidge said that he had now received data from Miss Spooner and the Working Party would meet within two weeks time to

decide what to do with it.

c) Inherited Platelet Disorders

Professor Preston said that the Working Party would be meeting very soon. The document on Platelet Disorders had been expanded to 32 pages and would be published for the BSH/BSHT meeting. BSH would fund it.

d) Data Collection

Dr. Rizza reported that the Data Working Party had not met for two years but would be having a meeting very soon.

7. a) HNA Report on their Blood Product Reaction Survey 1985-87

Dr. Rizza said that the Report from the HNA had been pre-circulated to the Haemophilia Reference Centre Directors. He had received two letters from Sister Sharp. One had arrived the day before the Directors AGM so there was not time to circulate it or the report to the Directors at their AGM. The second letter had arrived recently. In summary there were three items which the HNA would like the Haemophilia Reference Centre Directors to consider:-

1. Would the Reference Centre Directors continue to support the HNA in continuing to survey reactions in patients receiving treatment from Haemophilia Centres?

2. Would the Reference Centre Directors agree to the HIV status of patients being collected by the HNA to enable them to analyse their data on reactions?

3. Would the Reference Centre Directors agree to the Secretariat giving to the HNA information regarding the amounts of materials used at individual Haemophilia Centres in the United Kingdom?

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During discussion some members said that the HNA study was too loose and they did not think that it should continue in its present form. After discussion **this was agreed. It was also agreed** that Dr. Rizza would write to Sister Sharp to thank her for the interesting report, and informing her that the Reference Centre Directors felt they could not provide the HNA with information regarding the HIV status of the patients included in the Survey or the amounts of materials used at individual Centres. Sister Sharp would also be informed that the Reference Centre Directors felt that the study on reactions in patients would be included in the remit of the proposed new group which would undertake surveillance of blood products.

8. 8Y Study - Progress Report

Dr. Kernoff presented the Reference Centre Directors with a form (Form A) which was to be used for the formal prospective

study of BPL Factor VIII concentrate 8Y. Dr. Kernoff said that this form had been discussed and all parties involved in the study had approved it. Elstree (BPL) would fund a Roving Nurse/Co-ordinator based in Oxford to help the participating
ACTION CP Centres with the collection of the data. After discussion **it was agreed** that the forms would be sent out from Oxford to the contributing Centres.

9. NEQAS

Professor Preston said that Dr. Poller had stepped down as organizer of the scheme and that Dr. Kernoff was now the Organizer. The results of the latest survey were outlined by Professor Preston. There was a marked improvement in the performance of Haemophilia Centres from the results of earlier surveys. Dr. Kernoff reported that progress was being made in shifting the organization of NEQAS from Manchester to the Royal Free but that it would take time.

10. Arrangements for the 1988 meeting of all Haemophilia Centre Directors

Dr. Mayne said that the provisional programme had been prepared and distributed copies of the programme to the members. Professor Temperley said that he would shortly be sending to Oxford information for distribution to all Haemophilia Centre Directors about travel and hotel accommodation.

11. Date and place of next meeting of Reference Centre Directors

It was agreed that the next meeting would be held at St. Thomas' Hospital on Monday 5th September at 10.30 a.m.

12. A.O.B.

1. Dr. Jones said that his Region had asked him to ask another Haemophilia Centre to pay for the use of FEIBA in Newcastle for the treatment of a patient who was usually under the care of the other Centre. He did not think that this was a good idea and he was strongly resisting pressure from his Region to send bills to other Centres in this way. He asked if the Reference Centre
DECISION Directors would support his stance and after discussion **it was agreed** that the Reference Centre Directors would not support any move for Regions to cross charge for the treatment of patients who moved around the United Kingdom.

2. Dr. Kernoff said that he was now encountering a problem regarding the funding of lunches for the Reference Centre Directors' meeting. He wondered if it would be reasonable for the Reference Centre Directors to be asked to contribute a small amount, i.e. £5 towards the cost of lunches when the host Centre
DECISION was encountering difficulties. After discussion **it was agreed** in

principle that it was not unreasonable for the Reference Centre Directors to pay £5 to the host Centre should the host Centre need this money.

The Reference Centre Directors meeting ended at 1.30 p.m.

GRO-C

5 Mar 88.

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Materials used in 1986 by Haemophilia Centres in England and Wales to treat patients who have Haemophilia A, Acquired Haemophilia A or von Willebrand's Disease and Carriers of Haemophilia A, showing the number of patients treated and Factor VIII units used by Regional Health Authorities and Haemophilia Supraregions

Supraregion	Region	Number of Patients treated	Plasma	Cryoprecipitate	Factor VIII Units NHS F.VIII	Commercial F.VIII	Total	Average F.VIII units per Patient
OXFORD	Oxford	256	0	3,500	1,302,420	6,356,480	7,662,400	29,931
	S. Western	137	2,245	36,480	2,066,360	1,374,600	3,479,685	25,399
	Wessex	134	0	146,730	1,594,344	2,900,700	4,641,774	34,640
	W. Midlands	222	0	126,000	2,255,951	6,694,457	9,076,408	40,885
Total for Supraregion		712	2,245	312,710	7,219,075	17,326,237	24,860,267	34,916
MANCHESTER	N. Western	226	0	644,230	1,492,135	3,467,200	5,603,565	24,795
	Mersey	66	0	10,740	1,074,395	1,506,200	2,591,335	39,263
	N. Wales	13	0	35,350	123,235	29,680	188,265	14,482
Total for Supraregion		303	0	690,320	2,689,765	5,003,080	8,383,165	27,667
SHEFFIELD	Trent	186	0	217,630	2,674,535	2,581,719	5,473,884	29,429
	Yorkshire	169	0	63,910	2,039,183	3,613,976	5,717,069	33,829
Total for Supraregion		355	0	281,540	4,713,718	6,195,695	11,190,953	31,524
NEWCASTLE	Northern	152	8,400	319,222	660,764	5,848,749	6,837,135	44,981
ROYAL FREE	NW Thames	74	0	248,590	839,185	1,507,445	2,595,220	35,071
	NE Thames	442	720	86,570	4,287,006	6,510,417	10,884,713	24,626
	East Anglia	77	0	10,360	804,630	178,470	993,460	12,902
Total for Supraregion		587	720	345,520	5,930,821	8,196,332	14,473,393	24,657
ST. THOMAS'	SE Thames	272	0	177,800	1,973,178	8,060,648	10,211,626	37,543
	SW Thames	73	0	10,920	711,910	319,568	1,042,398	14,279
Total for Supraregion		336	0	188,720	2,685,088	8,380,216	11,254,024	33,494
CARDIFF	S. Wales	108	5,520	567,770	907,505	2,184,107	3,664,902	33,934
TOTAL FOR ENGLAND AND WALES		2,424	16,885	2,705,802	24,806,736	53,134,416	80,663,839	33,277
% Total F.VIII Units		-	0.02	3.36	30.75	65.87	100	-

Number of Patients Treated by Haemophilia Centres in England and Wales in 1986, showing Haemophilia Supraregions and Regional Health Authorities

Supraregion	Region	Number of Patients Treated				
		Haem. A	Haem. A Carriers	von Willebrands	Acquired Haem. A	Total
OXFORD	Oxford	231	4	20	1	256
	Wessex	125	1	8	-	134
	S. Western	116	2	19	-	137
	W. Midlands	202	1	19	-	222
Total for Supraregion		640	8	63	1	712
MANCHESTER	N. Western	190	4	32	-	226
	Mersey	64	-	2	-	66
	N. Wales	6	-	7	-	13
Total for Supraregion		258	4	41	-	303
SHEFFIELD	Trent	169	2	15	-	186
	Yorkshire	151	1	17	-	169
Total for Supraregion		320	3	32	-	355
NEWCASTLE	Northern	131	-	17	4	152
ROYAL FREE	NWTR	68	1	3	2	74
	NETR	370	7	62	3	442
	East Anglia	73	1	3	-	77
Total for Supraregion		505	9	68	5	587
ST. THOMAS'	SETR	244	2	25	1	272
	SWTR	63	2	6	2	73
Total for Supraregion		298	4	31	3	336
CARDIFF	S. Wales	87	2	18	1	108
TOTAL FOR ENGLAND AND WALES		2117	30	263	14	2424

C O N F I D E N T I A L

Materials used in 1986 by Haemophilia Centres in Scotland and Northern Ireland to treat patients who have Haemophilia A, Acquired Haemophilia A or von Willebrand's Disease and Carriers of Haemophilia.

Supraregion	Number of Patients Treated					Factor VIII Units				
	Haem.A	Acq. Haem.A	von W	Carriers of Haem.A	Total	Cryoprecipitate	NHS Factor VIII	Commercial Factor VIII	Total	Average Factor VIII Units per Patients
Edinburgh	101	0	10	1	112	67,000	3,194,000	0	3,261,000	29,116
Glasgow	104	0	13	0	117	215,000	1,683,000	0	1,898,000	16,222
Northern Ireland	81	0	10	2	93	265,000	2,197,000	745,000	3,207,000	34,483
Total*	282	0	33	3	318	547,000	7,074,000	745,000	8,366,000	26,308,000

* Patient number adjusted for duplicates