

APPENDIX A

Annual Returns for 1978

To date (1.11.79) 103 Centres have sent in their 1978 Annual Returns. A provisional report on the information provided in these returns is attached (Tables 1-7). We hope it will be possible for us to prepare a more detailed report early next year, covering the 1976-78 treatment years.

To assist us with the analysis of the data which we have received from the U.K. Haemophilia Centres, we are using the Oxford Regional Health Authority's computer with the help of the Regional Computer Unit's staff. Tables 8 and 9 give a provisional analysis of the 1977 data to show the age and severity groupings of Haemophilia A and Haemophilia B patients. These tables will be up-dated when the late returns which have come in from Centres have been processed.

Figs. 1 and 2 show the amount of materials used by U.K. Haemophilia Centres from 1969-1978. It is interesting to note that although there is still an increase in the total amount of factor VIII used, the increase is less for 1978 than in the previous 2-3 years. The average amount of material used per patient in 1978 remains the same, however, at 22,000 units. The total amount of factor IX used for Haemophilia B (Christmas disease) patients decreased in 1978,

as did the average amount used per patient (from 23,000 units per patient to 21,000 units per patient).

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1st November, 1979

Table 1
Factor VIII Units Used by Haemophilia Centres During 1978

Type of Patient	Total No.* of Patients treated	Plasma	Cryo	NHS F.VIII Conc.	Commercial F.VIII Conc.	Total	% Total	average amount used per patient
Haemophilia A**	2,078	5,000	10,932,000	14,768,000	19,353,000	45,058,000	96.80	22,000
Carriers of Haem. A	30	3,000	141,000	25,000	27,000	196,000	0.42	7,000
Von Willebrand's	240	16,000	1,030,000	171,000	79,000	1,296,000	2.78	6,000
TOTAL	2,348	24,000	12,103,000	14,964,000	19,459,000	46,550,000	100.00	20,000

* Provisionally adjusted for duplications on the basis of the percentage duplication in previous years' returns

** Additional materials used for Haemophilia A patients with F.VIII Antibodies.

NHS F.IX Conc.	124,000 units
PROPLEX	149,000 units
PROTHROMPLEX	12,000 units
FEIBA	1,928,000 units
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	2,281,000 units
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Table 2
Factor IX Units Used by Haemophilia Centres in 1978

Type of Patient	Total No.* of Patients treated	Plasma	NHS IX	Commercial IX	Total	Average amount used per patient
Haemophilia B	330	28,000	6,789,000	11,000	6,827,000	21,000
Carriers of Haem. B	7	3,000	10,000	-	13,000	2,000
TOTAL	337	31,000	6,799,000	11,000	6,840,000	21,000

* Provisionally adjusted for duplicates on the basis of the percentage duplication in previous years.

Table 3

Materials Used by Haemophilia Centres in 1978 to treat
135* Haemophilia A patients who had F.VIII Antibodies

	Factor VIII Units		Total
	Used at Hosp.	Supplied for HT	
Cryo	137,000	Nil	137,000
NHS F.VIII Conc.	400,000	71,000	471,000
Commercial F.VIII Conc.	2,255,000	386,000	2,641,000
TOTAL	2,792,000	457,000	3,249,000

Other Materials:

NHS F.IX Conc.	124,000 units
PROPLEX	149,000 units
PROTHROMPLEX	12,000 units
FEIBA	1,928,000 units
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	2,281,000 units
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* adjusted for duplicates

Table 4

Material used by Haemophilia Centres in 1978 to treat 2
Haemophilia B (Christmas disease) patients who had F.IX
antibodies.

NHS F.IX Conc. : 33,810 F.IX units.

Table 5

The number of patients known to Haemophilia Centre Directors on 30.10.79 and the occurrence of Factor VIII and Factor IX antibodies. Patients known to have died before 1.1.79 have been excluded.

	<u>Haemophilia A</u>	<u>Haemophilia B</u>
Cumulative total number of patients known at Centres	4,085	722
Cumulative total number with factor VIII or IX antibodies	217	6
% with factor VIII or IX antibodies	5.31	0.83

Table 6

Cause of death in Haemophilia A and Haemophilia B Patients
During 1977 and 1978

Cause of Death	Number of Deaths	
	1977	1978
Intracranial bleeding	2	4
Intracranial bleeding after accident	-	2
Intra-abdominal bleeding	1	2
Intrathoracic bleeding	2	-
Pulmonary haemorrhage	1	-
Post-operative complications	1	1
Pulmonary embolism	1	-
Cerebral Vascular Accident	-	3
Renal failure	1	1
Cancer	2	1
Acute Myeloid Leukaemia	-	1
Ischaemic Heart Disease	-	2
Diabetic Coma	-	1
Viral Encephalitis	-	1
Bronchopneumonia	-	1
Asthma	-	1
Suicide	1	1
Non-haemorrhagic but details N/K	2	-
N/K	-	1
TOTAL	14	23

Table 7

Severity of Coagulation Defect and Age at Death of
Haemophilia A and Haemophilia B Patients known to
have Died during 1977 and 1978

Age at Death (years)	Number of Deaths			
	Factor VIII/IX Level %			TOTAL
	<2*	2-10	>10	
<10	1(1)	-	-	1(1)
10 - 19	1	-	-	1
20 - 29	4(3)	-	-	4(3)
30 - 39	7(5)	1	-	8(5)
40 - 49	4	1	-	5
50 - 59	4(1)	1	-	5(1)
60 - 69	2	3	3	8
70+	3(1)	2	-	5(1)
TOTAL	26(11)	8	3	37(11)

* Figures in brackets () = Haemophilia A
patients with F.VIII antibodies.

Table 8

Haemophilia A Patients Known at Haemophilia Centres on 31.12.77, showing the number of patients treated during 1977, with the Severity of the Coagulation Defect and Age

	Number of Patients														
	Factor VIII Level (% Average Normal)												Total		
	<2% A.N.			2-10% A.N.			>10% A.N.			Not Known					
Age (Yrs)	In Reg	Trtd	On HT	In Reg	Trtd	On HT	In Reg	Trtd	On HT	In Reg	Trtd	On HT	In Reg	Trtd	On HT
<5	105	78	2	60	34	0	19	5	0	3	0	0	187	117	2
5 - 9	166	140	55	101	52	7	51	14	0	14	4	1	332	210	63
10 - 19	458	379	202	246	134	23	134	52	1	58	7	1	896	572	227
20 - 29	382	295	141	168	73	6	115	33	1	35	4	0	700	405	148
30 - 39	260	208	84	148	52	4	58	18	0	41	3	0	507	281	88
40 - 49	145	108	38	102	36	4	65	18	0	30	3	0	342	165	42
50 - 59	89	64	12	80	37	5	48	13	0	27	6	0	244	120	17
60 - 69	43	20	3	42	13	0	43	14	0	17	0	0	145	47	3
70+	19	10	1	28	5	0	22	6	0	6	1	0	75	22	1
Not Known	25	7	0	20	2	0	12	1	0	166	19	0	223	29	0
Total	1692	1309	538	995	438	49	567	174	2	397	47	2	3651	1968	591

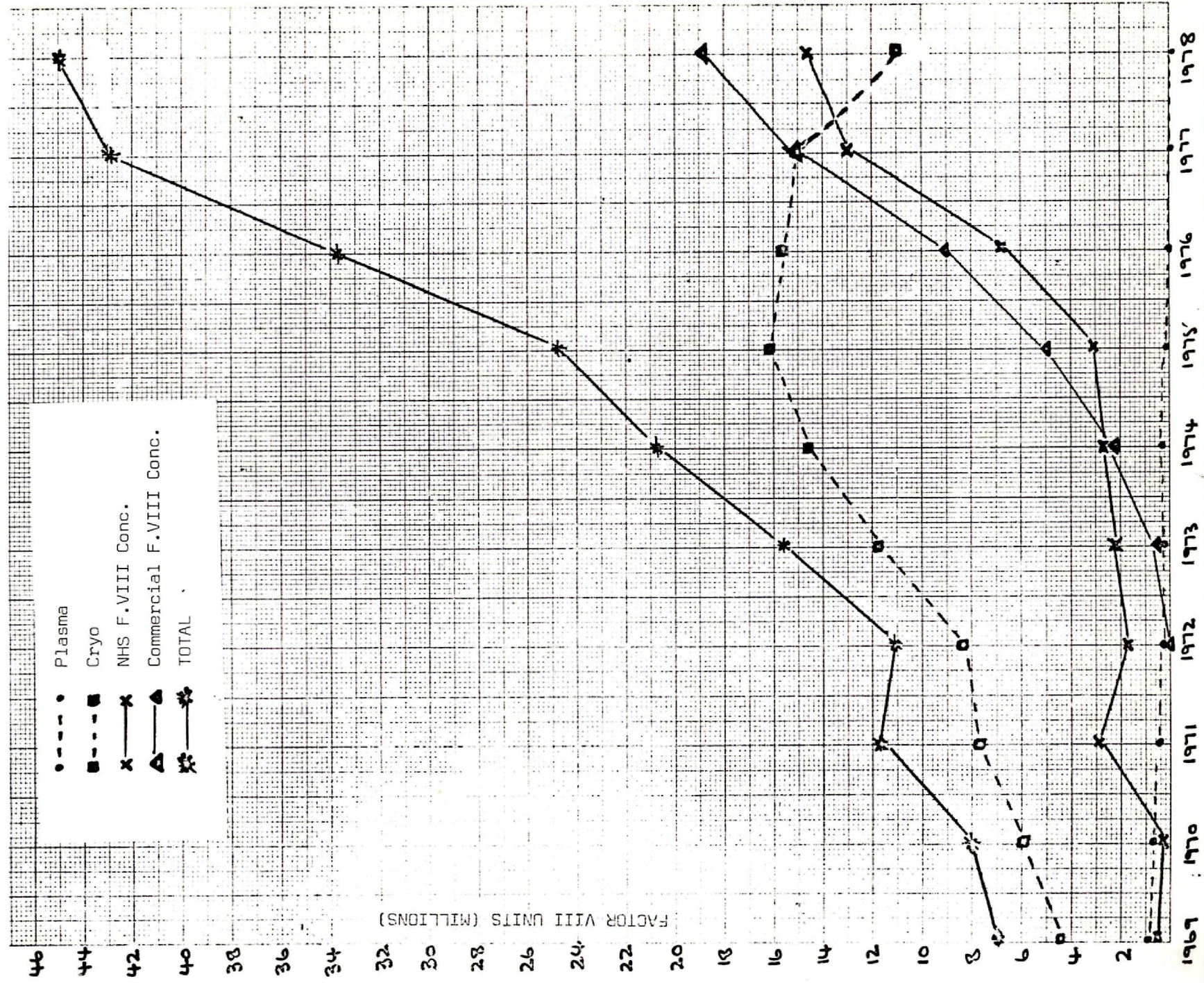
Table 9

Haemophilia B Patients known at Haemophilia Centres on 31.12.77, showing the number of patients treated during 1977, with the Severity of the Coagulation Defect and Age

	Number of Patients														
	Factor IX Level (% Average Normal)												Total		
	<2% A.N.			2-10% A.N.			>10% A.N.			Not Known					
Age (Yrs)	In Reg	Trtd	On HT	In Reg	Trtd	On HT	In Reg	Trtd	On HT	In Reg	Trtd	On HT	In Reg	Trtd	On HT
<5	16	12	1	10	7	0	3	1	0	2	0	0	31	20	1
5 - 9	28	24	7	28	21	0	9	6	0	0	0	0	65	51	7
10 - 19	66	58	20	55	29	5	23	7	0	11	3	0	155	97	25
20 - 29	49	41	18	43	19	1	25	6	0	6	0	0	123	66	19
30 - 39	33	25	16	20	7	2	11	4	0	10	3	0	74	39	18
40 - 49	17	13	2	28	14	2	2	1	0	9	2	0	56	30	4
50 - 59	12	8	1	13	3	0	9	3	0	4	2	0	38	16	1
60 - 69	6	4	1	10	5	0	7	0	0	6	2	0	29	11	1
70+	4	3	1	5	2	0	2	0	0	7	0	0	18	5	1
Not Known	4	1	0	5	2	0	3	1	0	33	1	0	45	5	0
TOTAL	235	189	67	217	109	10	94	29	0	88	13	0	634	340	77

Fig.1

Amount of Material Used to Treated Haemophilia A Patients



Amount of Material Used to Treat Christmas Disease Patients

Fig. 2

