

Survey of Patients Treated at Haemophilia Centres in the U.K.

Annual Return for 1976

of materials used to treat patients having haemophilia or Christmas disease****

Centre: ROYAL FREE HOSPITAL

Director: Katharine M. DORMANDY, M.D.

Total number of haemophilic patients treated during the year*:

104

Number with Factor VIII antibodies:

12

Total number of Christmas disease patients treated during the year**:

18

Number with Factor IX antibodies:

0

Total amount of material used to treat these patients during the year:-

Type of Material Used	No. of bottles etc. used	Amount used (units of activity)	
		F.VIII units (for haemophilic patients)	F.IX units (for Christmas disease patients)
Plasma	Nil		
Cryoprecipitate	13985	278,250	
NHS Human Factor VIII Concentrate	1654	305930	
Abbott Factor VIII Concentrate (Profilate)	59	17759	
Armour Factor VIII Concentrate (Factorate)	28	5852	
Cutters Factor VIII Concentrate (Konte)	44	19320	
Hyland Factor VIII Concentrate (Hemofil)	937	279136	
Immuno Factor VIII Concentrate (Kryobulin)	111	40737	
Durban B.T.S., South Africa	3	not known	
Other Human Factor VIII Concentrate***		750	
Human/Porcine Factor VIII Concentrate	20	12000 (not used in the end)	
NHS Factor IX Concentrate	660		378505 396,000
Commercial Factor IX Concentrate***	Nil		
Other Materials (please specify) (FETBA (Imuno))	93	(55000)	

* Please supply details on Form A(2)

**Please supply details on Form A(3)

*** Please give name of manufacturer and/or trade name of product

**** Please do not include von Willebrand's disease patients or carriers of haemophilia or Christmas disease on this form - see Forms A(4)-A(8).

Deaths during the year:-

Name of Patient	Diagnosis	Date of Birth	Date of Death	Cause of Death
GRO-A	Haemophilia	GRO-A 45	GRO-A 76	Intrapulmonary haemorrhage
	IX-deficiency	GRO-A 102	GRO-A 1976	Not known - died in S.Africa

Survey of Patients Treated at Haemophilia Centres in the U.K.Annual Return for 1976 - von Willebrand's Disease PatientsCentre: ROYAL FREE HOSPITALTotal number of patients with von Willebrand's disease treated during the year*: 13

Material(s) used to treat these patients:-

Type of Material Used	No. of bottles etc. used	Amount used (factor VIII units)
Plasma		
Cryoprecipitate	755	52,850
NHS Human Factor VIII Concentrate		
Abbott Factor VIII Concentrate		
Armour Factor VIII Concentrate		
Cutters Factor VIII Concentrate		
Hyland Factor VIII Concentrate		
Immuno Factor VIII Concentrate		
Other Human Factor VIII Concentrate**		
Bovine/Porcine Factor VIII Concentrate		
Other Materials (Please specify)		

* Please supply details on Form A (8)

** Please give name of manufacturer and/or trade name of product.



THE HAEMOPHILIA CENTRE

The Royal Free Hospital

Pond Street
Hampstead
London NW3 2QG

Telephone
01-794 0500
ext. GRO-C

KD/MIB

1st March, 1977

Miss R.J.D. Spooner,
Oxford Haemophilia Centre,
Churchill Hospital,
Oxford, OX3 7LJ

Dear Jean,

HEPATITIS SURVEY - Form C(4a)

Herewith our 1976 HEMOFIL records of the patients who received any of the batches named by Dr. Craske and used here - 010575, 190375, 190875, 271075 and 101175. We did not have any of the others.

Form C(4b)

We did not have any of the KRYOBULIN batches mentioned by Dr. Craske.

I don't know what happens to post from you to me! Your letter of 15th, enclosing the revised forms C(3), was franked the same day but it reached me only yesterday! Thanks for both, and for reminding me that we did belong in Dr. Craske's survey - I had forgotten about it, to my shame.

When you have time, please could you explain to me what Centres are to do, next year, about the treatment materials used by patients for home treatment but supplied either by a Blood Transfusion Centre or an Associate Centre? The record forms come to us so we know what they have had at home. I have always included our Sussex patients in our lists because they get their supplies from a non-centre, which does not send returns to you, or from us. Now many patients in North/^{East}Thames RHA, and some in North West Thames, have been registering with us but we neither supply them nor see them except in dire emergencies. Will the Associate Centres and Brentwood BTC (primarily) send you returns. If so, we should be duplicating them if we also included the patients.

New Patients

Herewith two forms B(1) for GRO-A and GRO-A

All good wishes,

Yours,

GRO-C

Encs.

(Mrs.) M.I. Britten,
Research Assistant

25th March, 1977

Dear Peggy,

Re: Annual Returns for 1976

I need two more completed forms, please, regarding your returns - Form C (Revised) for GRO-A and GRO-A. I received the yellow forms (C3) last year as soon as you had the details of their jaundice but did not ask for the Form C to be completed until the end of the year - by which time we had revised the form!

Incidentally, I see that both these patients received Elstree Factor VIII as well as other materials before developing jaundice. Has Dr. Dormandy reported these cases to Dr. Maycock? I know he likes to be informed if his material is possibly implicated.

Thanks for your letter of 22nd March, received this morning. I will let you know as soon as I know what we are to do about future returns.

Best wishes,

(Miss) R.J.D. Spooner
Mrs. M.I. Bitten,
The Haemophilia Centre,
Royal Free Hospital.



The Haemophilia Centre
The Royal Free Hospital

Pond Street
Hampstead
London NW3 2QG

Telephone
01-794 0500
ext. GRO-C

KD/MIB

30th March, 1977

Miss R.J.D. Spooner,
Oxford Haemophilia Centre,
Churchill Hospital,
Oxford, OX3 7LJ

Dear Joan,

Re: 1976 Returns - HEPATITIS

Thank you for your letter of 25th which came on 23th -
much faster than usual!

I am so sorry that I forgot to send Forms C for GRO-A
GRO-A and GRO-A. Here they are now.

Form C3 for GRO-A - the doctor's comment that he had Elstree
from 29.4.76 is incorrect. He first had it after he
had developed jaundice, on 20.5.76.

Form C3 for GRO-A - correct.

Form C (revised) was not designed for GRO-A was it?

I can find no record of Dr. Dormandy's having told
Dr. Maycock about all the batches of Elstree that GRO-A had
before becoming jaundiced. She is away at the moment -
should I tell him now?

Excuse this chewed letter! My typewriter has fits of this.

All the best,

GRO-C

Encs.

(Mrs.) M.I. Britten.

1/803

1/2811

208

5th April, 1977

Dear Peggy,

Thanks for your letter of 30th March and the forms for
[GRO-A] and [GRO-A] Yes please, I think you
should let Dr. Maycock know about the Elstree material
[GRO-A] had.

Have a Happy Easter,

Best wishes,

(Miss) R.J.D. Spooner

Mrs. M.I. Britten,
The Haemophilia Centre,
Royal Free Hospital,
Pond Street,
Hampstead,
London, NW3 2QG.

HCDO0001111_0006



THE HAEMOPHILIA CENTRE
The Royal Free Hospital

Pond Street
Hampstead
London NW3 2QG

Telephone
01-794 0500
ext. GRO-C

KD/MIB

8th July, 1976

Miss R.J.D. Spooner,
Oxford Haemophilia Centre,
Churchill Hospital,
Oxford, OX3 7LJ

Dear Jean,

Re: HEPATITIS SURVEY

Herewith Form C3 for GRO-A I am sorry that it is a bit crumby - various people filled in bits while I was in the States.

GRO-A will be our No. 1 entry on Form C for 1976. I'll complete his entry when I get the formula for cryo. units from you. Presumably you want Form C only after the end of this year...?

This seems to be 'high season' for our correspondence!

All the best,

GRO-C

Enc.

(Mrs.) M.I. Britten,
Research Assistant.

Annual Return for 1976

Centre: ROYAL FREE HOSPITAL

Haemophilic Patients treated during the year:-

Name of Patient		D.O.B.	Basic Factor VIII Level %	Inhibitor Present (Yes/No*)	Jaundiced (Yes/No**)	On Regular Home Therapy from your Centre***
GRO-A	✓	47	1	No	No	<u>Yes</u> ✓
	✓	64	<1	No	<u>Yes</u> ✓	No
	✓	60	<1	<u>Yes</u> ✓	No	No
	✓	'93	4	No	No	No
	✓	11	<1	No	No	<u>Yes</u> ✓
	✓	51	<1	No	No	No
	✓	50	?	<u>Yes</u> ✓	No	No
	✓	31	?	No	No	<u>Yes</u> ✓
	✓	47	<1	No	No	<u>Yes</u> ✓
	✓	63	<1	No	No	No
	✓	0.59	<1	<u>Yes</u> ✓	No (?)	No
	✓	52	0	No	No	<u>Yes</u> ✓
	✓	71	<1	No	No	<u>Yes</u> ✓
	✓	50	<1	No	No	<u>Yes</u> ✓
	✓	59	<1	No	No	<u>Yes</u> ✓
	✓	58	<1	No	No	<u>Yes</u> ✓
	✓	45	<1	No	No	GRO-A 76 ✓
	✓	42	<1	No	No	<u>Yes</u> ✓
	✓	56	0	<u>Yes</u> ✓	No	No
	✓	39	2	No	No	No

* If Yes, please complete and return Form B(2) unless the information requested on Form B(2) has already been sent to Oxford.

** If Yes, please complete and return Forms C and C(3) unless these have already been sent to Alton or Oxford.

*** Please enter "Yes" where appropriate.

Annual Return for 1976

Centre: ROYAL FREE HOSPITAL

Haemophilic Patients treated during the year:-

Name of Patient		D.O.B.	Basic Factor VIII Level %	Inhibitor Present (Yes/No*)	Jaundiced (Yes/No**)	On Regular Home Therapy from your Centre***
GRO-A	✓	GRO-A .38	<1	No	No	No
	✓	20	0	No	No	No
	✓	44	10	No	No	No
	✓	.44	<1	No	No	Yes ✓
	✓	57	<1	No	No	Yes ✓
	✓	.47	<1	No	No	No
	✓	GRO-A .51	1.5	No	No	No
	✓	.53	9	No	No	No
	✓	.53	0	No	No	Yes ✓
	✓	58	<1	No	No	No
	✓	.29	<1	No	No	Yes ✓
	✓	.55	1	No	No	No
	✓	GRO-A 16	7	No	No	No
	✓	GRO-A 45	<1	No	No	No
	✓	GRO-A 61	2	No	No	Yes + L.M.T.
	✓	GRO-A .55	2	No	Yes ✓	No
	✓	53	<1	No	?	Yes + Oxford
	✓	GRO-A 973	<1	No	?	No
	✓	39	<1	No	No	No
	✓	GRO-A 47	<1	No	No	No

* If Yes, please complete and return Form B(2) unless the information requested on Form B(2) has already been sent to Oxford.

** If Yes, please complete and return Forms C and C(3) unless these have already been sent to Alton or Oxford.

*** Please enter "Yes" where appropriate.

Annual Return for 1976Centre: ROYAL FREE HOSPITALHaemophilic Patients treated during the year:-

Name of Patient		D.O.B.	Basic Factor VIII Level %	Inhibitor Present (Yes/No*)	Jaundiced (Yes/No**)	On Regular Home Therapy from your Centre***
GRO-A	✓	.52	0	<u>Yes</u> ✓	No	No
	✓	GRO-A 29	1	No	No	<u>Yes</u> ✓
	✓	.48	<1	No	No	<u>Yes</u> ✓
	✓	.55	<1	No	No	<u>Yes</u> ✓
	✓	19	0	No	No	<u>Yes</u> ✓
	✓	46	<1	<u>Yes</u> ✓	No	No
	✓	61	<1	<u>Yes</u> ✓	No	No
	✓	.19	<1	No	No	No
	✓	.23	0	No	No	<u>Yes</u> ✓
	✓	GRO-A 57	0	No	No	No
	✓	.53	0	<u>Yes</u> ✓	No	No
	✓	69	<1	No	No	<u>Yes</u> ✓
	✓	34	0	<u>Yes</u> ✓	No	No
	✓	55	<1	No	No	<u>Yes</u> ✓
	✓	42	<1	No	No	<u>Yes</u> ✓
	✓	57	<1	No	No	<u>Yes</u> ✓
	✓	GRO-A 60	<1	No	No	<u>Yes</u> ✓
	✓	.54	0	No	No	<u>Yes</u> + Oxford ✓
	✓	GRO-A 51	<1	No	No	No
	✓	GRO-A 61	2	No	No	No

* If Yes, please complete and return Form B(2) unless the information requested on Form B(2) has already been sent to Oxford.

** If Yes, please complete and return Forms C and C(3) unless these have already been sent to Alton or Oxford.

*** Please enter "Yes" where appropriate.

Annual Return for 1976

Centre: ROYAL FREE HOSPITALHaemophilic Patients treated during the year:-

Name of Patient		D.O.B.	Basic Factor VIII Level %	Inhibitor Present (Yes/No*)	Jaundiced (Yes/No**)	On Regular Home Therapy from your Centre***
GRO-A	✓	.42	0	<u>Yes</u> ✓	No	No. He is now at the Middlesex.
	✓	62	6	No	No	No
	✓	.36	0	No	No	No
	✓	.20	3	No	No	No
	✓	40	<1	No	No	<u>Yes</u> ✓
	✓	.43	<1	No	No	<u>Yes</u> ✓
	✓	.52	3	No	No	No
	✓	57	<1	No	No	<u>Yes</u> ✓
	✓	.61	<1	No	No	<u>Yes</u> + L.M.T. ✓
	✓	53	0	No	No	No
	✓	.05	<1	No	No	No
	✗	.51	19	No	No	No
	✓	.62	<1	No	<u>Yes</u> ✓	<u>Yes</u> ✓
	✓	62	<1	No	No	<u>Yes</u> + L.M.T.
	✓	.61	<1	No	No	<u>Yes</u> + L.M.T.
	✓	58	<1	No	No	<u>Yes</u> ✓
	✓	66	<1	No	No	<u>Yes</u> ✓
	✓	.66	6	No	No	No
	✓	50	.8	No	No	No
	✓	.55	1	No	No	<u>Yes</u> ✓

* If Yes, please complete and return Form B(2) unless the information requested on Form B(2) has already been sent to Oxford.

** If Yes, please complete and return Forms C and C(3) unless these have already been sent to Alton or Oxford.

*** Please enter "Yes" where appropriate.

Annual Return for 1976

Centre: ROYAL FREE HOSPITAL

Haemophilic Patients treated during the year:-

Name of Patient		D.O.B.	Basic Factor VIII Level %	Inhibitor Present (Yes/No*)	Jaundiced (Yes/No**)	On Regular Hom Therapy from your Centre***
GRO-A	✓	63	0	No	No	No
	✓	59	0	No	No	No
	✓	53	0	No	No	Yes ✓
	✓	GRO-A 71	<1	No	No	No
	✓	61	<1	No	No	No
	✓	65	11	No	No	No
	✓	51	0	No	No	No
	✓	GRO-A 60	0	Yes ✓	No	No
	✓	55	0	Yes ✓	No	No
	✓	GRO-A 30	8	No	No	No
	✓	GRO-A 74	12	No	No	No
	✓	61	5	No	No	No
<u>PATIENTS FROM OTHER U.K. CENTRES</u>						
GRO-A	✓	GRO-A 58	1	Yes	?	Oxford patient
	✓	?	?	No	?	From Taunton

* If Yes, please complete and return Form B(2) unless the information requested on Form B(2) has already been sent to Oxford.

** If Yes, please complete and return Forms C and C(3) unless these have already been sent to Alton or Oxford.

*** Please enter "Yes" where appropriate.

Annual Return for 1976

Centre: ROYAL FREE HOSPITAL

Haemophilic Patients treated during the year:-

[illegible]

*** Please enter "Yes" where appropriate.

Annual Return for 1976

Centre: ROYAL FREE HOSPITALChristmas disease patients treated during the year:-

Name of Patient	D.O.B.	Basic Factor IX Level %	Inhibitor Present (Yes/No*)	Jaundiced (Yes/No**)	On Regular Home Therapy from your Centre***
GRO-A	✓ GRO-A 59	<1	No	No	Yes x ✓
	✓ A .66	<1	No	No	No
	.53	<1	No	No	No
	GRO-A 33	0	No	No	Yes x ✓
	60	4	No	No	No
	.50	3-4	No	No	No
	GRO-A 46	0	No	No	Yes x ✓
	28	2	No	No	Yes x ✓
	51	7	No	No	No
	48	7	No	No	No
	GRO-A .60	<1	No	No	Yes x ✓
	.44	6	No	No	No
	GRO-A 29	<1	No	No	No
	54	<1	No	No	Yes x ✓
	GRO-A .45	<1	No	No	Yes x ✓
	.34	1	No	No	No
	✓ GRO-A 13	<1	No	No	Yes x ✓
	✓ 1951	2	No	No	No

* If yes, please complete and return Form B (2) unless the information requested on Form B (2) has already been sent to Oxford.

** If Yes, please complete and return Forms C and C(3) unless these have already been sent to Alton or Oxford.

*** Please enter "Yes" where appropriate.

Annual Return for 1976Centre: ROYAL FREE HOSPITALvon Willebrand's Disease Patients treated during the year:-

Full Name of Patient	Date of Birth	Basic F.VIII Level %	Jaundiced (Yes/No*)	Comment
GRO-A	✓ GRO-A .60	50	No	Abdominal pain
	✓ 48	3	No	Menorrhagia
	✓ GRO-A .53	35	No	Epistaxis
	✓ 48	12	No	L. elbow bleed
	✓ 61	2	No	++ haemarthroses
	✓ GRO-A .56	25	No	Epistaxis; injury
	✓ 55	32	No	Appendicectomy
	✓ 29	25	No	Epistaxis; removal nasal polyp.
	✓ 47	33	No	Misc. minor bleeds
	✓ GRO-A .41	1	No	Dental extractions
	✓ .44	13	No	Dental extractions
	✓ .53	<1	No	++ haemarthroses
FROM ABROAD - Malta				
GRO-A	✓ GRO-A .41	21	No	Repair of inguinal hernia.

*If Yes, please complete and return Forms C and C(3) unless these have already been sent to Oxford or Alton.

Survey of Patients Treated at Haemophilia Centres in the U.K.

Annual Return for 1976 - Carriers of Haemophilia or Christmas Disease

Centre: ROYAL FREE HOSPITAL

Total number of Carriers of Haemophilia treated during the year*: 3

Total number of Carriers of Christmas Disease treated during the year**: 0

Material(s) used to treat these patients:-

Type of Material Used	No. of bottles etc. used	Amount used (units of activity)	
		F. VIII Units	F.IX Units
Plasma			
Cryoprecipitate	102	7140	
NHS Human Factor VIII Concentrate			
Abbott Factor VIII Concentrate			
Armour Factor VIII Concentrate			
Cutters Factor VIII Concentrate			
Hyland Factor VIII Concentrate			
Immuno Factor VIII Concentrate			
Other Human Factor VIII Concentrate***			
Bovine/Porcine Factor VIII Concentrate			
NHS Factor IX Concentrate			
Commercial Factor IX Concentrate***			
Other Materials (please specify)			

* Please supply details on Form A(5)

** Please supply details on Form A(6)

*** Please give name of manufacturer and/or trade name of product.

Carriers of Haemophilia treated during the year:-

*If Yes, please complete and return Forms C and C(3) unless these have already been sent to Oxford or Alton.