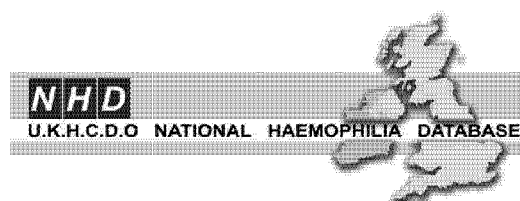


APPENDIX 1
UKHCDO DATA

National Haemophilia Database

Bleeding Disorder Statistics for the Penrose Enquiry

May 2010



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Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Guide to products listed in Table 1:

The precise date at which viral inactivation was introduced for each product should be checked with the manufacturer.

Cryoprecipitate:	Crude factor VIII replacement product. Not virally inactivated. 1 unit is one donor unit derived from a single blood donation.
FFP:	Fresh Frozen plasma. A single donor unit from a blood donation. Not virally inactivated.
FVIII (PFC):	Factor VIII concentrate from the Plasma Fractionation Centre in Edinburgh. Pooled blood product not virally inactivated until 1985/6.
FIX Defix:	Factor IX concentrate manufactured by PFC. Pooled blood product not virally inactivated until 1985/6.
Travenol/Hyland:	Factor VIII concentrate of US manufacture. Pooled blood product not virally inactivated,
Porcine VIII:	High-purity pooled blood product of porcine origin used for factor VIII inhibitor treatment. Not virally attenuated but virologically safe by virtue of its porcine origin.
“Oxford VIII”:	Bio Products Limited, Elstree. UK Plasma-derived pooled blood product factor VIII concentrate. Not virally inactivated prior to 1985.
Profilate:	Alpha factor VIII concentrate manufactured in USA from US plasma. Virally attenuated from 1984 (clinical trial). Commercially available virally inactivated product from 1986/7.
Cutter (Koate):	Commercial US factor VIII concentrate virally inactivated from 1986.
Factorate	Armour, US manufactured factor VIII concentrate. Attempts to virally inactivate this product as early as 1993 were not fully effective and it was replaced by Monoclata.

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Monoclolate:	Armour monoclonally purified and pasteurised factor VIII concentrate. Virologically safe. Introduced 1986/7.
Behring factor VIII:	? Haemate P. Pasteurised (virologically safe) factor VIII concentrate manufactured in Marburg from American and German plasma. UK Product license 1986.
Kryobulin:	Immuno factor VIII concentrate manufactured in Vienna from US and European plasma. Virally attenuated from approx 1986.
Immuno IX:	Immuno, Vienna. Plasma-derived factor IX concentrate manufactured from US and European plasma and virally inactivated from the mid eighties.
Octapharma VIII:	Octapharma factor VIII concentrate manufactured in Vienna from plasma sourced in a variety of countries. Virally attenuated.
Humanate:	Porton Factor VIII concentrate. Pooled plasma product licensed in 1976 and not virally attenuated. Plasma source probably US.
French factor VIII/IX:	CRTS French fractionated factor VIII/IX concentrates. During the eighties there was some close technical collaboration between PFC and the French state fractionator with sharing of some methods. During the mid to late eighties the French and PFC factor VIII and IX products were technically very similar and were virally inactivated.
FEIBA:	Immuno and subsequently Baxter, Vienna. Factor Eight Inhibitor Bypassing Activity . Plasma derived prothrombin complex concentrate used to treat factor VIII/IX inhibitors. Produced from at least 1977 from US and European plasma, in Vienna. Virally attenuated using steam treatment from the mid eighties, approximately.

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Table 1 – Use of factor VIII, Factor XI, cryoprecipitate and blood components by Scottish Centres from 1969 - 1991**Aberdeen**

Year	Factor type	Product Name	Units
1969		Cryoprecipitate	
1969		FFP	
1969	FVIII	FVIII (PFC)	
1970		Cryoprecipitate	
1970		FFP	
1970		Whole Blood	
1971		Cryoprecipitate	
1971		FFP	
1972		Cryoprecipitate	
1976		FFP	
1976	FVIII	FVIII (PFC)	
1977		Cryoprecipitate	
1977		FFP	
1977	FVIII	FVIII (PFC)	
1977	FVIII	Porcine FVIII	
1978		Cryoprecipitate	
1978	FVIII	FVIII (PFC)	
1978	FVIII	Travenol/Hyland/Hemofil FVIII	
1979		Cryoprecipitate	
1979		FEIBA	
1979	FIX	FIX defix (PFC)	
1979	FVIII	FVIII (PFC)	
1979	FVIII	Travenol/Hyland/Hemofil FVIII	
1980		Cryoprecipitate	139,490.00
1980		FEIBA	27,000.00
1980	FIX	FIX defix (PFC)	1,200.00
1980	FVIII	FVIII (PFC)	111,050.00
1981		Cryoprecipitate	86,480.00
1981		FEIBA	51,000.00
1981	FVIII	FVIII (PFC)	182,870.00
1982		Cryoprecipitate	20,510.00
1982		FEIBA	10,000.00
1982	FVIII	FVIII (PFC)	298,180.00
1983		Cryoprecipitate	10,710.00
1983		FEIBA	246,000.00
1983		FFP	
1983	FVIII	FVIII (PFC)	348,565.00
1983	FVIII	Porcine FVIII	1,280.00
1983		Whole Blood	

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Aberdeen (Cont'd)

Year	Factor type	Product Name	Units
1984		Cryoprecipitate	9,030.00
1984		FEIBA	23,000.00
1984		FFP	12.00
1984	FIX	FIX defix (PFC)	2,700.00
1984	FVIII	FVIII (PFC)	347,223.00
1984		Platelets	
1985		Cryoprecipitate	10,300.00
1985		FEIBA	261000
1985		FFP	3300
1985	FIX	FIX defix (PFC)	28800
1985	FVIII	FVIII (PFC)	378920
1986		Cryoprecipitate	17,080.00
1986		FEIBA	35,000.00
1986		FFP	8.00
1986	FIX	FIX defix (PFC)	49,500.00
1986	FVIII	FVIII (PFC)	286,760.00
1987		Cryoprecipitate	42,210.00
1987		FEIBA	73,000.00
1987		FFP	8.00
1987	FIX	FIX defix (PFC)	131,100.00
1987	FVIII	FVIII (PFC)	459,600.00
1987		PackedCells	6.00
1987		Platelets	
1988		Cryoprecipitate	30,590.00
1988		FEIBA	
1988		FFP	3.00
1988	FIX	FIX defix (PFC)	78,500.00
1988	FVIII	FVIII (PFC)	371,600.00
1988		PackedCells	28.00
1988		Platelets	
1988	FVIII	Profilate	25,300.00
1989		Cryoprecipitate	14,840.00
1989		FEIBA	
1989		FFP	18.00
1989	FIX	FIX defix (PFC)	146,990.00
1989	FVIII	FVIII (PFC)	400,130.00
1989		Whole Blood	
1990		Cryoprecipitate	1,680.00
1990		FEIBA	53,000.00
1990		FFP	17.00
1990	FIX	FIX defix (PFC)	114,570.00
1990	FVIII	FVIII (PFC)	353,120.00

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Aberdeen (Cont'd)

Year	Factor type	Product Name	Units
1991		Cryoprecipitate	2,170.00
1991		FEIBA	82,000.00
1991		FFP	13.00
1991	FIX	FIX defix (PFC)	97,660.00
1991	FVIII	FVIII (PFC)	398,860.00

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Dundee

Haemophilia Centre	Year	Factor type	Product Name	Units
Dundee	1969		Cryoprecipitate	
Dundee	1969		FFP	
Dundee	1969	FVIII	FVIII (PFC)	
Dundee	1970		Cryoprecipitate	
Dundee	1970		FFP	
Dundee	1971		Cryoprecipitate	
Dundee	1971		FFP	
Dundee	1976		Cryoprecipitate	
Dundee	1976	FIX	FIX defix (PFC)	
Dundee	1976	FVIII	FVIII (PFC)	
Dundee	1977		Cryoprecipitate	
Dundee	1977	FIX	FIX defix (PFC)	
Dundee	1977	FVIII	FVIII (PFC)	
Dundee	1978		Cryoprecipitate	
Dundee	1978		FFP	
Dundee	1978	FIX	FIX defix (PFC)	
Dundee	1978	FVIII	FVIII (PFC)	
Dundee	1979		Cryoprecipitate	
Dundee	1979	FIX	FIX defix (PFC)	
Dundee	1979	FVIII	FVIII (PFC)	
Dundee	1980		Cryoprecipitate	35,120.00
Dundee	1980		FFP	
Dundee	1980	FIX	FIX defix (PFC)	51,300.00
Dundee	1980	FVIII	FVIII (PFC)	188,940.00
Dundee	1981		Cryoprecipitate	48,800.00
Dundee	1981	FIX	FIX defix (PFC)	63,900.00
Dundee	1981	FVIII	FVIII (PFC)	512,900.00
Dundee	1982		Cryoprecipitate	13,680.00
Dundee	1982	FIX	FIX defix (PFC)	68,100.00
Dundee	1982	FVIII	FVIII (PFC)	215,000.00
Dundee	1982	FVIII	Porcine FVIII	22,750.00
Dundee	1983		Cryoprecipitate	4,240.00
Dundee	1983		FFP	800.00
Dundee	1983	FIX	FIX defix (PFC)	67,500.00
Dundee	1983	FVIII	FVIII (PFC)	359,040.00
Dundee	1984		Cryoprecipitate	2,560.00
Dundee	1984	FIX	FIX defix (PFC)	100,500.00
Dundee	1984	FVIII	FVIII (PFC)	403,920.00
Dundee	1985	FIX	FIX defix (PFC)	103,200.00
Dundee	1985	FVIII	FVIII (PFC)	346,000.00

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Dundee (Cont'd)

Haemophilia Centre	Year	Factor type	Product Name	Units
Dundee	1986		Cryoprecipitate	5,280.00
Dundee	1986	FIX	FIX defix (PFC)	168,300.00
Dundee	1986	FVIII	FVIII (PFC)	530,000.00
Dundee	1987	FIX	FIX defix (PFC)	141,000.00
Dundee	1987	FVIII	FVIII (PFC)	555,720.00
Dundee	1987	FVIII	Oxford FVIII	
Dundee	1988	FIX	FIX defix (PFC)	231,830.00
Dundee	1988	FVIII	FVIII (PFC)	502,820.00
Dundee	1988	FVIII	Profilate	20,700.00
Dundee	1989	FIX	FIX defix (PFC)	152,750.00
Dundee	1989	FVIII	FVIII (PFC)	462,700.00
Dundee	1990	FIX	FIX defix (PFC)	160,350.00
Dundee	1990	FVIII	FVIII (PFC)	210,817.00
Dundee	1991		Cryoprecipitate	960.00
Dundee	1991	FIX	FIX defix (PFC)	235,140.00
Dundee	1991	FVIII	FVIII (PFC)	488,210.00
Dundee	1991	FVIII	Oxford FVIII	

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Edinburgh

Year	Factor type	Product Name	Units
1969		FFP	
1969	FIX	FIX defix (PFC)	
1969	FVIII	FVIII (PFC)	
1970		FFP	
1970	FVIII	FVIII (PFC)	
1971		Cryoprecipitate	
1971	FVIII	FVIII (PFC)	
1972		Cryoprecipitate	
1972		FFP	
1972	FIX	FIX (BPL)	
1972	FVIII	FVIII (PFC)	
1972		PackedCells	
1972		Whole Blood	
1973		Cryoprecipitate	
1973	FIX	FIX defix (PFC)	
1973	FVIII	FVIII (PFC)	
1977		Cryoprecipitate	
1977	FIX	FIX defix (PFC)	
1977	FVIII	FVIII (PFC)	
1978		Cryoprecipitate	
1978	FIX	FIX defix (PFC)	
1978	FVIII	FVIII (PFC)	
1978	FVIII	Oxford FVIII	
1979		Cryoprecipitate	
1979	FIX	FIX defix (PFC)	
1979	FVIII	FVIII (PFC)	
1980		Cryoprecipitate	1,212,470.00
1980	FVIII	Factorate	164,000.00
1980		FFP	240.00
1980	FIX	FIX defix (PFC)	265,500.00
1980	FVIII	FVIII (PFC)	1,644,750.00
1981		Cryoprecipitate	718,270.00
1981	FVIII	Factorate	442,018.00
1981	FIX	FIX defix (PFC)	287,000.00
1981	FVIII	FVIII (PFC)	840,130.00
1982		Cryoprecipitate	597,000.00
1982	FVIII	Cutter FVIII (Koate)	5,000.00
1982		FEIBA	110,000.00
1982	FVIII	Factorate	2,300.00

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Edinburgh (Cont'd)

Year	Factor type	Product Name	Units
1982	FIX	FIX defix (PFC)	276,000.00
1982	FVIII	FVIII (PFC)	1,612,800.00
1983		Cryoprecipitate	340,000.00
1983	FVIII	Cutter FVIII (Koate)	87,000.00
1983	FVIII	Factorate	64,000.00
1983		FEIBA	37,000.00
1983	FIX	FIX defix (PFC)	506,000.00
1983	FVIII	FVIII (PFC)	1,756,000.00
1984		Cryoprecipitate	139,000.00
1984	FVIII	Factorate	35,850.00
1984		FEIBA	8,000.00
1984	FIX	FIX defix (PFC)	418,700.00
1984	FVIII	FVIII (PFC)	2,506,880.00
1984		PackedCells	1.00
1984	FVIII	Porcine FVIII	91,200.00
1985		Cryoprecipitate	127,680.00
1985		FEIBA	47,000.00
1985	FIX	FIX defix (PFC)	453,600.00
1985	FVIII	FVIII (PFC)	1,947,420.00
1985	FVIII	Porcine FVIII	45,720.00
1985		Whole Blood	
1986		Cryoprecipitate	44,930.00
1986		FEIBA	193,600.00
1986		FFP	6,000.00
1986	FIX	FIX defix (PFC)	480,500.00
1986	FVIII	FVIII (PFC)	2,073,710.00
1986	FVIII	Porcine FVIII	15,840.00
1987		Cryoprecipitate	42,560.00
1987		FEIBA	
1987	FIX	FIX defix (PFC)	483,610.00
1987	FVIII	FVIII (PFC)	2,842,810.00
1988		Cryoprecipitate	74,050.00
1988		FEIBA	169,650.00
1988	FIX	FIX defix (PFC)	579,895.00
1988	FVIII	FVIII (PFC)	2,637,280.00
1988	FVIII	Monoclote	89,735.00
1988	FVIII	Oxford FVIII	
1988	FVIII	Profilate	209,750.00
1989	FVIII	Behring FVIII	
1989		Cryoprecipitate	157,080.00
1989	FVIII	Factorate	120,170.00
1989		FEIBA	353,000.00

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Edinburgh (Cont'd)

Year	Factor type	Product Name	Units
1989	FIX	FIX defix (PFC)	624,115.00
1989	FVIII	FVIII (PFC)	1,919,650.00
1989	FVIII	Kryobulin	
1989	FVIII	Monoclate	62,070.00
1989	FVIII	Octapharma FVIII	11,000.00
1989	FVIII	Porcine FVIII	25,400.00
1989	FVIII	Profilate	392,150.00
1990		Cryoprecipitate	
1990	FVIII	Factorate	
1990		FEIBA	425,000.00
1990	FIX	FIX defix (PFC)	478,245.00
1990	FVIII	FVIII (PFC)	2,502,355.00
1990	FVIII	Monoclate	81,645.00
1990	FVIII	Octapharma FVIII	22,250.00
1990	FVIII	Porcine FVIII	16,560.00
1990	FVIII	Profilate	81,170.00
1990	FVIII	Travenol/Hyland/Hemofil FVIII	143,968.00
1991	FVIII	Factorate	
1991		FEIBA	267,000.00
1991	FIX	FIX defix (PFC)	620,535.00
1991	FIX	French FIX	
1991	FVIII	French FVIII	
1991	FVIII	FVIII (PFC)	3,193,439.00
1991	FVIII	Haemate P	3,120.00
1991	FVIII	Kryobulin	
1991	FVIII	Octapharma FVIII	59,000.00
1991	FVIII	Oxford FVIII	
1991	FVIII	Porcine FVIII	55,045.00
1991	FVIII	Profilate	

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Glasgow Royal Hospital for Sick Children

Year	Factor type	Product Name	Units
1977		Cryoprecipitate	
1977		FFP	
1977	FIX	FIX defix (PFC)	
1977	FVIII	Factorate	
1977	FVIII	FVIII (PFC)	
1977	FVIII	Travenol/Hyland/Hemofil FVIII	
1978		Cryoprecipitate	
1978	FIX	FIX defix (PFC)	
1978	FVIII	Factorate	
1978	FVIII	FVIII (PFC)	
1978	FVIII	Travenol/Hyland/Hemofil FVIII	
1979		Cryoprecipitate	
1979	FIX	FIX defix (PFC)	
1979	FVIII	Factorate	
1979	FVIII	FVIII (PFC)	
1980	FIX	Commercial FIX - Brand not specified	77,400.00
1980		Cryoprecipitate	6,090.00
1980	FVIII	Factorate	682,732.00
1980	FIX	FIX defix (PFC)	52,200.00
1980	FVIII	FVIII (PFC)	161,242.00
1981		Cryoprecipitate	29,200.00
1981	FVIII	Factorate	629,697.00
1981	FIX	FIX defix (PFC)	83,400.00
1981	FVIII	FVIII (PFC)	453,726.00
1982		Cryoprecipitate	6,600.00
1982	FVIII	Factorate	485,880.00
1982	FIX	FIX defix (PFC)	82,200.00
1982	FVIII	FVIII (PFC)	516,300.00
1983		Cryoprecipitate	30,500.00
1983	FVIII	Factorate	36,850.00
1983	FIX	FIX defix (PFC)	69,000.00
1983	FVIII	FVIII (PFC)	1,121,075.00
1984		Cryoprecipitate	32,340.00
1984	FVIII	Factorate	5,460.00
1984	FIX	FIX defix (PFC)	95,400.00
1984	FVIII	FVIII (PFC)	1,035,396.00
1985		Cryoprecipitate	27,930.00
1985		FFP	800.00
1985	FIX	FIX defix (PFC)	63,220.00
1985	FVIII	FVIII (PFC)	739,094.00

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Glasgow Royal Hospital for Sick Children (Cont'd)

Year	Factor type	Product Name	Units
1986		Cryoprecipitate	38,780.00
1986	FIX	FIX defix (PFC)	100,140.00
1986	FVIII	FVIII (PFC)	600,360.00
1986	FVIII	Porcine FVIII	
1987		Cryoprecipitate	27,860.00
1987		FFP	900.00
1987	FIX	FIX defix (PFC)	88,300.00
1987	FVIII	FVIII (PFC)	922,700.00
1988		Cryoprecipitate	11,900.00
1988		FFP	2.00
1988	FIX	FIX defix (PFC)	122,840.00
1988	FVIII	FVIII (PFC)	5,288,770.00
1989		Cryoprecipitate	15,650.00
1989		FFP	2.00
1989	FIX	FIX defix (PFC)	263,755.00
1989	FVIII	FVIII (PFC)	1,498,830.00
1990		Cryoprecipitate	7,560.00
1990		FFP	3.00
1990	FIX	FIX defix (PFC)	246,076.00
1990	FVIII	FVIII (PFC)	1,159,450.00
1991		Cryoprecipitate	10.00
1991		FFP	564.00
1991	FIX	FIX defix (PFC)	281,105.00
1991	FVIII	FVIII (PFC)	1,188,430.00
1991	FVIII	Monoclote	
1991		PackedCells	140.00
1991	FVIII	Oxford FVIII	

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Glasgow Royal Infirmary

Year	Factor type	Product Name	Units
1969		Cryoprecipitate	
1969		FFP	
1969	FVIII	FVIII (PFC)	
1969	FVIII	Porcine FVIII	
1970		Cryoprecipitate	
1970		FFP	
1970	FVIII	FVIII (PFC)	
1970	FVIII	Porcine FVIII	
1970		Whole Blood	
1974	FVIII	FVIII (PFC)	
1976		Cryoprecipitate	
1976	FVIII	Travenol/Hyland/Hemofil FVIII	
1977		Cryoprecipitate	
1977	FVIII	Cutter FVIII (Koate)	
1977	FVIII	Factorate	
1977		FEIBA	
1977	FIX	FIX defix (PFC)	
1977	FVIII	FVIII (PFC)	
1977	FVIII	Kryobulin	
1977	FIX	Proplex	
1977	FVIII	Travenol/Hyland/Hemofil FVIII	
1978		Cryoprecipitate	
1978	FVIII	Cutter FVIII (Koate)	
1978	FVIII	Factorate	
1978		FEIBA	
1978	FIX	FIX defix (PFC)	
1978	FVIII	FVIII (PFC)	
1978	FIX	Proplex	
1978	FVIII	Travenol/Hyland/Hemofil FVIII	
1979		Cryoprecipitate	
1979	FVIII	Cutter FVIII (Koate)	
1979	FVIII	Factorate	
1979		FEIBA	
1979	FIX	FIX defix (PFC)	
1979	FVIII	FVIII (PFC)	
1979	FVIII	Travenol/Hyland/Hemofil FVIII	
1979		Whole Blood	

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Glasgow Royal Infirmary (Cont'd)

Year	Factor type	Product Name	Units
1980		Cryoprecipitate	146,950.00
1980	FVIII	Cutter FVIII (Koate)	
1980		FEIBA	144,000.00
1980		FFP	
1980	FIX	FIX defix (PFC)	444,100.00
1980	FVIII	FVIII (PFC)	1,490,449.00
1980	FVIII	Humanate	26,750.00
1980	FVIII	Porcine FVIII	
1980	FVIII	Profilate	980.00
1980	FVIII	Travenol/Hyland/Hemofil FVIII	83,979.00
1981		Cryoprecipitate	56,650.00
1981	FVIII	Cutter FVIII (Koate)	76,440.00
1981	FVIII	Factorate	37,963.00
1981		FEIBA	90,000.00
1981		FFP	
1981	FIX	FIX defix (PFC)	235,760.00
1981	FVIII	FVIII (PFC)	1,246,155.00
1981	FVIII	Humanate	20,776.00
1981	FVIII	Travenol/Hyland/Hemofil FVIII	14,990.00
1982		Cryoprecipitate	40,950.00
1982	FVIII	Cutter FVIII (Koate)	2,750.00
1982	FVIII	Factorate	15,693.00
1982		FEIBA	68,000.00
1982	FIX	FIX defix (PFC)	324,800.00
1982	FVIII	FVIII (PFC)	1,978,658.00
1982	FVIII	Travenol/Hyland/Hemofil FVIII	7,053.00
1983		Cryoprecipitate	136,550.00
1983	FVIII	Factorate	200,000.00
1983		FEIBA	187,000.00
1983	FIX	FIX defix (PFC)	434,520.00
1983	FVIII	FVIII (PFC)	1,954,490.00
1984		Cryoprecipitate	121,100.00
1984		FEIBA	69,000.00
1984		FFP	4.00
1984	FIX	FIX defix (PFC)	385,000.00
1984	FVIII	FVIII (PFC)	2,258,674.00
1984	FVIII	Travenol/Hyland/Hemofil FVIII	5,500.00
1985		Cryoprecipitate	223,990.00
1985		FEIBA	53,335.00

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Glasgow Royal Infirmary (Cont'd)

Year	Factor type	Product Name	Units
1985		FFP	8,800.00
1985	FIX	FIX defix (PFC)	133,730.00
1985	FVIII	FVIII (PFC)	1,891,567.00
1985	FIX	Immuno FIX	352,410.00
1985	FVIII	Porcine FVIII	28,665.00
1986		Cryoprecipitate	175,800.00
1986		FEIBA	261,000.00
1986		FFP	5,280.00
1986	FIX	FIX defix (PFC)	276,653.00
1986	FVIII	FVIII (PFC)	2,359,155.00
1986	FVIII	Porcine FVIII	188,830.00
1987		Cryoprecipitate	142,439.00
1987		FEIBA	742,000.00
1987		FFP	3,080.00
1987	FIX	FIX defix (PFC)	1,268,600.00
1987	FVIII	FVIII (PFC)	3,327,720.00
1987	FVIII	Porcine FVIII	111,095.00
1988		Cryoprecipitate	103,640.00
1988	FVIII	Factorate	
1988		FEIBA	
1988		FFP	1,684.00
1988	FIX	FIX defix (PFC)	1,126,340.00
1988	FVIII	FVIII (PFC)	3,256,061.00
1988	FVIII	Porcine FVIII	30,000.00
1988	FVIII	Profilate	493,180.00
1989		Cryoprecipitate	39,800.00
1989	FVIII	Factorate	
1989		FEIBA	9,000.00
1989		FFP	32,018.00
1989	FIX	FIX defix (PFC)	1,027,030.00
1989	FVIII	FVIII (PFC)	2,474,140.00
1989	FVIII	Kryobulin	
1989	FVIII	Monoclata	10,600.00
1989	FVIII	Porcine FVIII	78,210.00
1989	FVIII	Profilate	504,460.00

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Glasgow Royal Infirmary (Cont'd)

Year	Factor type	Product Name	Units
1990		FEIBA	107,000.00
1990	FIX	FIX defix (PFC)	1,039,290.00
1990	FVIII	FVIII (BPL)	31,900.00
1990	FVIII	FVIII (PFC)	2,877,330.00
1990	FVIII	FVIII 8Y (BPL)	12,481.00
1990	FVIII	Monoclote	121,630.00
1990	FVIII	Porcine FVIII	41,460.00
1990	FVIII	Profilate	208,410.00
1991	FIX	Commercial FIX - Brand not specified	144,000.00
1991		FEIBA	
1991		FFP	974.00
1991	FIX	FIX defix (PFC)	1,058,300.00
1991	FIX	French FIX	14,400.00
1991	FVIII	French FVIII	598,860.00
1991	FVIII	FVIII (PFC)	2,174,245.00
1991	FVIII	Haemate P	14,066.00
1991	FVIII	Monoclote	165,270.00
1991	FVIII	Oxford FVIII	
1991	FVIII	Porcine FVIII	165,230.00

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Inverness

Year	Factor type	Product Name	Units
1969		Cryoprecipitate	
1969	FVIII	FVIII (PFC)	
1970		Cryoprecipitate	
1971		Cryoprecipitate	
1971		Whole Blood	
1971	FVIII	FVIII (PFC)	
1977	FVIII	FVIII (PFC)	
1978	FVIII	FVIII (PFC)	
1979	FIX	FIX defix (PFC)	
1979	FVIII	FVIII (PFC)	
1980	FIX	FIX defix (PFC)	6,000.00
1980	FVIII	FVIII (PFC)	270,420.00
1981	FIX	FIX defix (PFC)	7,500.00
1981	FVIII	FVIII (PFC)	246,540.00
1982	FVIII	FVIII (PFC)	133,720.00
1983		Cryoprecipitate	184,900.00
1983	FIX	FIX defix (PFC)	600.00
1983	FVIII	FVIII (PFC)	195,620.00
1984	FVIII	FVIII (PFC)	337,070.00
1985	FIX	FIX defix (PFC)	2,400.00
1985	FVIII	FVIII (PFC)	359,240.00
1986		Cryoprecipitate	70.00
1986	FIX	FIX defix (PFC)	2,700.00
1986	FVIII	FVIII (PFC)	303,450.00
1987	FIX	FIX defix (PFC)	1,800.00
1987	FVIII	FVIII (PFC)	369,730.00
1988	FIX	FIX defix (PFC)	
1988	FVIII	FVIII (PFC)	385,715.00
1989	FVIII	FVIII (PFC)	298,725.00
1990	FIX	FIX defix (PFC)	1,360.00
1990	FVIII	FVIII (PFC)	282,020.00
1991	FVIII	FVIII (PFC)	262,870.00

Appendix 1: UKHCDO Data

**Table 2 – Number of patients registered at Scottish Haemophilia centres
- 5 year intervals 1970 - 2010**

Early registrations may be incomplete; hence the apparently rapid increase in numbers of registered patients in the first decade after the database was established. Some patients are registered and managed in more than one centre in a hub and spoke care model and may therefore appear for more than one of these centres. For that reason, the totals for the whole of Scotland at the bottom of each table have been corrected for this double counting and will be less than the sum of the individual centre figures.

1970	Haemophilia Centre	Haemophilia A	Haemophilia B	Females with VIII deficiency	Females with IX deficiency	von Willebrand disease	Total
	Aberdeen	29	1	0	0	0	30
	Dundee	8	1	0	0	0	9
	Edinburgh	76	9	0	0	1	86
	Glasgow (R.H.S.C.)	3	0	0	0	0	3
	Glasgow (R.I.)	71	7	0	0	1	79
	Inverness	26	0	0	0	0	26
	Grand Total	213	18	0	0	2	233
	Total excluding duplicate registrations	159	17	0	0	2	178

1975	Haemophilia Centre	Haemophilia A	Haemophilia B	Females with VIII deficiency	Females with IX deficiency	von Willebrand disease	Total
	Aberdeen	47	3	0	0	0	50
	Dundee	21	9	0	0	0	30
	Edinburgh	135	27	0	0	1	163
	Glasgow (R.H.S.C.)	8	0	0	0	0	8
	Glasgow (R.I.)	102	15	0	0	1	118
	Inverness	38	1	0	0	0	39
	Grand Total	351	55	0	0	2	408
	Total excluding duplicate registrations	274	47	0	0	2	323

Appendix 1: UKHCDO Data

**Table 2 (Cont'd)– Number of patients registered at Scottish Haemophilia centres
- 5 year intervals 1985 - 2010**

1980	Haemophilia Centre	Haemophilia A	Haemophilia B	Females with VIII deficiency	Females with IX deficiency	von Willebrand disease	Total
	Aberdeen	57	4	2	0	13	76
	Dundee	27	12	0	0	3	42
	Edinburgh	156	30	2	0	14	202
	Glasgow (R.H.S.C.)	55	14	0	0	1	70
	Glasgow (R.I.)	196	52	2	3	15	268
	Inverness	51	2	0	0	0	53
	Grand Total	542	114	6	3	46	711
	Total excluding duplicate registrations	409	88	5	3	44	549
1985	Haemophilia Centre	Haemophilia A	Haemophilia B	Females with VIII deficiency	Females with IX deficiency	von Willebrand disease	Total
	Aberdeen	61	6	5	0	41	113
	Dundee	32	11	0	0	11	54
	Edinburgh	170	36	3	0	53	262
	Glasgow (R.H.S.C.)	73	20	1	1	13	108
	Glasgow (R.I.)	210	56	4	6	36	312
	Inverness	53	3	0	0	3	59
	Grand Total	599	132	13	7	157	908
	Total excluding duplicate registrations	443	95	11	6	134	689

Appendix 1: UKHCDO Data

**Table 2 (Cont'd)- Number of patients registered at Scottish Haemophilia centres
- 5 year intervals 1985 - 2010**

1990	Haemophilia Centre	Haemophilia A	Haemophilia B	Females with VIII deficiency	Females with IX deficiency	von Willebrand disease	Total
	Aberdeen	60	7	7	1	48	123
	Dundee	28	12	0	0	14	54
	Edinburgh	177	38	5	1	60	281
	Glasgow (R.H.S.C.)	85	26	2	1	22	136
	Glasgow (R.I.)	212	59	9	8	56	344
	Inverness	62	3	0	0	13	78
	Grand Total	624	145	23	11	213	1016
	Total excluding duplicate registrations	462	102	20	9	184	777

1995	Haemophilia Centre	Haemophilia A	Haemophilia B	Females with VIII deficiency	Females with IX deficiency	von Willebrand disease	Total
	Aberdeen	62	9	10	1	63	145
	Dundee	32	15	0	0	25	72
	Edinburgh	175	42	8	1	90	316
	Glasgow (R.I.)	206	63	18	11	189	487
	Glasgow (R.H.S.C.)	96	30	3	2	62	193
	Inverness	60	3	0	0	24	87
	Grand Total	631	162	39	15	453	1300
	Total excluding duplicate registrations	475	116	34	12	394	1031

Appendix 1: UKHCDO Data

**Table 2 (Cont'd)– Number of patients registered at Scottish Haemophilia centres
- 5 year intervals 1985 - 2010**

2000	Haemophilia Centre	Haemophilia A	Haemophilia B	Females with VIII deficiency	Females with IX deficiency	von Willebrand disease	Total
	Aberdeen	41	9	9	1	81	141
	Dundee	27	11	5	3	95	141
	Edinburgh	122	28	4	1	86	241
	Glasgow (R.H.S.C.)	59	20	2	4	67	152
	Glasgow (R.I.)	186	59	25	12	298	580
	Inverness	30	1	0	1	24	56
	Grand Total	465	128	45	22	651	1311
	Total excluding duplicate registrations	398	107	45	20	616	1186
2005	Haemophilia Centre	Haemophilia A	Haemophilia B	Females with VIII deficiency	Females with IX deficiency	von Willebrand disease	Total
	Aberdeen	41	7	10	1	120	179
	Dundee	31	13	8	12	136	200
	Edinburgh	115	31	6	1	113	266
	Glasgow (R.H.S.C.)	48	9	3	2	82	144
	Glasgow (R.I.)	155	51	29	12	349	596
	Inverness	31	1	2	1	24	59
	Grand Total	421	112	58	29	824	1444
	Total excluding duplicate registrations	397	107	58	28	805	1395

Appendix 1: UKHCDO Data

**Table 2 (Cont'd)- Number of patients registered at Scottish Haemophilia centres
- 5 year intervals 1985 - 2010**

2010	Haemophilia Centre	Haemophilia A	Haemophilia B	Females with VIII deficiency	Females with IX deficiency	von Willebrand disease	Total
	Aberdeen	45	8	11	4	139	207
	Dundee	32	14	10	13	148	217
	Edinburgh	106	27	9	1	124	267
	Glasgow (R.H.S.C.)	51	12	9	4	93	169
	Glasgow (R.I.)	146	51	30	12	374	613
	Inverness	28	1	2	1	26	58
	Grand Total	408	113	71	35	904	1531
	Total excluding duplicate registrations	405	112	71	34	900	1522

Table 3 – HIV – Scottish Haemophilia Centres

This table represents the number of patients *with all bleeding disorders* testing positive or negative for HIV in Scottish Centres. We have reported the year of the first sample to test positive or the year of the test first reported to us and the last to test negative for +ve and –ve patients, respectively. Please note that some samples date from years before the introduction of HIV testing in 1984/5. These were presumably stored samples tested retrospectively when a test became available. Most patients with bleeding disorders at risk will have been first tested in 1985/6, when a test became widely available. Although patients may have been managed in more than one centre over this period, there is no double counting amongst the HIV- positive results tabulated.

There was initially no obligation to report these results to UKHCDO and so +ve results reported for 1986/7 do not necessarily imply that this was the first test or that seroconversion occurred at that time. These tables therefore provide no data on the time of seroconversion of the group. Since most centres did not store samples for retrospective sampling, the date of seroconversion is unknown for most patients. We do have data on a minority of patients whose stored samples were tested retrospectively which indicates their approximate time of seroconversion (last –ve and 1st +ve test dates). Where stored samples were available in UK patients with bleeding disorders, they show the earliest seroconversions to be in 1980 and most seroconversions to be in 1982/3. The last seroconversions of which I am aware occurred in 1985.

Scotland accounts for about 10% of the UK haemophilia population but only about 5% of the patients with bleeding disorders infected with HIV. 1382 patients with bleeding disorders are known to have been infected with HIV in the UK and were reported to NHD, of whom 72 were registered to Scottish Centres. A small proportion of these may also have been infected from treatment given outside Scotland, but we do not have the data to dissect this out.

The relatively low proportion of Scottish patients infected with HIV reflects the fact that Scotland was largely self-sufficient in blood and blood products from PFC during the period of risk. BPL fractionated most of England's requirement for factor IX but only approximately 40% of England's requirement for factor VIII. England was therefore far more dependent on imported factor VIII concentrates than Scotland. These imported products were largely manufactured from US-sourced plasma. HIV spread earlier through the US donor population than the UK donor population and so patients using commercial products had a much higher risk of contracting HIV. Where English patients were maintained on a single brand of concentrate during the period of risk the risk of contracting HIV was much higher (approaching 100% in some centres) in those patients using US-sourced concentrates.

The origin of the factor VIII concentrate made no difference whatsoever to the risk of contracting hepatitis C or B. (See Craske Pavier, Trowell et al BMJ 1983).

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Table 3 (Cont'd) – HIV – Scottish Haemophilia Centres

Haemophilia Centre	Result Year	HIV Result		Grand Total
		-	+	
Aberdeen	1982		1	1
	1984	1		1
	1985	10	1	11
	1986	6	1	7
	1987	20	4	24
	1988	5		5
	1989	1		1
	1992	1		1
	1994	2		2
	1995	2		2
Aberdeen Total		48	7	55
Haemophilia Centre	Result Year	HIV Result		Grand Total
		-	+	
Dundee	1985	7		7
	1986	5		5
	1987	12		12
Dundee Total		24	0	24
Edinburgh	1983	3	1	4
	1984	2	2	4
	1985	22		22
	1986	42	11	53
	1987	15	11	26
	1988	4		4
	1990	1		1
	1991	2		2
	1993		1	1
	1994	1	1	2
	1995	1		1
	Unknown	1	2	3
Edinburgh Total		94	29	123

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Table 3 (Cont'd) – HIV – Scottish Haemophilia Centres

Haemophilia Centre	Result Year	HIV Result		Grand Total
		-	+	
Glasgow (R.H.S.C.)	1983		1	1
	1984	1		1
	1985	2		2
	1986	18		18
	1987	32	7	39
	1988	6		6
	1989	1		1
	1990	8		8
	Unknown		3	3
Glasgow (R.H.S.C.) Total		68	11	79
Glasgow (R.I.)	1982		1	1
	1985	20	1	21
	1986	32	1	33
	1987	92	19	111
	1988	2	1	3
	1991	1		1
	Unknown	16		16
Glasgow (R.I.) Total		163	23	186
Inverness	1985	15	2	17
	1986	2		2
Inverness Total		17	2	19
Grand Total		414	72	486

14 patients, who have negative results, were also tested at another Scottish Centre

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Table 4 – HIV – Non-Scottish Haemophilia Centres

Result Year	HIV Result		Grand Total
	-	+	
1969		1	1
1975	1		1
1979		1	1
1980		1	1
1981		9	9
1982	1	16	17
1983	21	42	63
1984	51	111	162
1985	765	459	1224
1986	750	281	1031
1987	980	298	1278
1988	194	18	212
1989	220	9	229
1990	454	15	469
1991	83	5	88
1992	45	5	50
1993	15	1	16
1994	3	3	6
1995	7	2	9
1996	13	4	17
1997		1	1
1998	1	1	2
1999		1	1
2000		1	1
Unknown	252	25	277
Total	3856	1310	5166

Table 5 – Hepatitis C – Patients treated at Scottish Haemophilia Centres – Alive in 2010

Estimate of the number of patients exposed to hepatitis C, based on historical clotting factor concentrate exposure from a Scottish Haemophilia Centre – alive. We are about to start collecting data from Haemophilia Centres on hepatitis C test results. Until this collection is complete, we have been obliged to estimate the number of patients exposed to hepatitis C based on their reported exposure to clotting factor concentrates during the period of risk. 85% or so of these patients will have developed chronic hepatitis C since all recipients of concentrate at that time will have been exposed to HCV and 15% will clear the virus. This total is probably an under-estimate, since it does not include an estimate for the number of patients likely to have been exposed to hepatitis C through treatment with blood or blood components. Since we do not have full data on the number of units of blood products used in each individual, and since the risk per unit decreased during the period of risk due to exclusion of high-risk donors after in the early eighties, it has not been possible for us to estimate the number infected in that way. This is the subject of an ongoing hepatitis C look-back exercise.

If we assume that the latest time at which a patient will have contracted hepatitis C is their first exposure to clotting factor concentrate, then we are also in a position to estimate the time of hepatitis C transmission. Many patients, especially those with severe haemophilia A, B and von Willebrand's disease, will have been infected with hepatitis C from plasma or cryoprecipitate at an earlier date, however. Most will have been infected in the mid nineteen-seventies and the last infected in the mid eighties.

Table 5 shows the estimated number of patients infected with hepatitis C from clotting factor concentrates, corrected for double counting and based on their reported treatment history.

Diagnosis	Num Pts
Haemophilia A	170
Haemophilia B	61
Females with VIII deficiency	7
Females with IX deficiency	4
von Willebrand disease	22
Acquired Haemophilia A	2
Haemophilia A with Liver Transplant	1
Temporary coagulation defect, now normal	1
	268

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Table 6 – Hepatitis C – Patients treated at Scottish Haemophilia Centres – Alive in 2010, per Haemophilia Centre

Haemophilia Centre	Diagnosis	Num Pts
Aberdeen	Haemophilia A	22
Aberdeen	Haemophilia B	1
Aberdeen	Females with VIII deficiency	5
Aberdeen	von Willebrand disease	13
Aberdeen Total		41
Dundee	Haemophilia A	10
Dundee	Haemophilia B	9
Dundee	von Willebrand disease	2
Dundee	Haemophilia A with Liver Transplant	1
Dundee Total		22
Edinburgh	Haemophilia A	51
Edinburgh	Haemophilia B	21
Edinburgh	von Willebrand disease	5
Edinburgh Total		77
Glasgow (R.H.S.C.)	Haemophilia A	35
Glasgow (R.H.S.C.)	Haemophilia B	16
Glasgow (R.H.S.C.)	Females with VIII deficiency	1
Glasgow (R.H.S.C.)	Females with IX deficiency	1
Glasgow (R.H.S.C.) Total		53
Glasgow (R.I.)	Haemophilia A	59
Glasgow (R.I.)	Haemophilia B	24
Glasgow (R.I.)	Females with VIII deficiency	1
Glasgow (R.I.)	Females with IX deficiency	3
Glasgow (R.I.)	von Willebrand disease	1
Glasgow (R.I.)	Acquired Haemophilia A	2
Glasgow (R.I.)	Temporary coagulation defect, now normal	1
Glasgow (R.I.) Total		91
Inverness	Haemophilia A	23
Inverness	Haemophilia B	2
Inverness	von Willebrand disease	1
Inverness Total		121

Some patients will have been treated at more than one Scottish Haemophilia Centre

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

**Table 7 – Hepatitis C – Patients treated at Scottish Haemophilia Centres
- Deceased and cause of death 1969-2010**

Estimate of the number of patients exposed to hepatitis C, based on historical clotting factor concentrate exposure from a Scottish Haemophilia Centre, and their causes of death

Diagnosis	Num Pts	Cause of Death
Haemophilia A	11	Liver failure
Haemophilia A	4	Liver failure associated with cirrhosis and alcoholic liver disease
Haemophilia A	2	Hepatitis
Haemophilia A	1	Hepatoma
Haemophilia A	1	Ruptured hepatoma
Haemophilia A	3	Accident
Haemophilia A	1	Acute asthmatic attack
Haemophilia A	47	AIDS
Haemophilia A	1	Bronchitis
Haemophilia A	11	Cancer
Haemophilia A	1	Cardiac failure and cardiac arrest
Haemophilia A	28	Cerebral haemorrhage
Haemophilia A	1	Cerebrovascular Accident
Haemophilia A	1	Chest infection
Haemophilia A	1	Chronic obstructive airway disease
Haemophilia A	4	Details not known
Haemophilia A	1	G.I. bleed
Haemophilia A	2	Haemophilia only on death certificate
Haemophilia A	2	Heart disease
Haemophilia A	1	Motor Neurone Disease
Haemophilia A	4	Myocardial infarct
Haemophilia A	1	Natural causes
Haemophilia A	3	Overdose
Haemophilia A	1	Pneumocystitis Pneumonia (reported as "not AIDS")
Haemophilia A	3	Pneumonia
Haemophilia A	1	Post-operative haemorrhage
Haemophilia A	2	Pulmonary oedema
Haemophilia A	2	Renal failure
Haemophilia A	1	Retroperitoneal bleed
Haemophilia A	2	Ruptured atheromatous aneurysm aorta
Haemophilia A	1	Sepsis
Haemophilia A	1	Septicaemia
Haemophilia A	2	Suicide
Haemophilia A with Liver Transplant	1	Hepatoma
Haemophilia A with Liver Transplant	1	Cancer
Acquired Haemophilia A	1	Cancer
Acquired Haemophilia A	1	Cerebral haemorrhage

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

**Table 7 (Cont'd) – Hepatitis C – Patients treated at Scottish Haemophilia Centres
- Deceased and cause of death 1969-2010**

Diagnosis	Num Pts	Cause of Death
Haemophilia B	3	Cancer
Haemophilia B	1	Cerebral haemorrhage
Haemophilia B	2	G.I. bleed
Haemophilia B	1	Heart disease
Haemophilia B	1	Motor Neurone Disease
Haemophilia B	1	Myocardial infarct
Haemophilia B	3	Pneumonia
Haemophilia B	1	Renal failure
Haemophilia B	2	Suicide
von Willebrand disease	1	Liver failure
von Willebrand disease	2	Cancer
von Willebrand disease	1	Cardiac failure and cardiac arrest
von Willebrand disease	1	Cerebral haemorrhage
von Willebrand disease	1	Pneumonia
Total	154	

Appendix 1: UKHCDO Data

**Table 8 – Hepatitis C – Patients treated at Scottish Haemophilia Centres
– Deceased, per Haemophilia Centre and causes of death 1969-2010**

Haemophilia Centre	Diagnosis	Num Pts	Cause of Death
Aberdeen	Haemophilia A	8	AIDS
Aberdeen	Haemophilia A	6	Cerebral haemorrhage
Aberdeen	Haemophilia A	1	Cancer
Aberdeen	Haemophilia A	1	Details not known
Aberdeen	Haemophilia A	1	Liver failure
Aberdeen	von Willebrand disease	1	Cerebral haemorrhage
Aberdeen Total		18	
Dundee	Haemophilia A	3	Cerebral haemorrhage
Dundee	Haemophilia A	2	AIDS
Dundee	Haemophilia A	1	Chest infection
Dundee	Haemophilia A	1	Haemophilia only on death certificate
Dundee	Haemophilia B	1	Cerebral haemorrhage
Dundee Total		8	
Edinburgh	Haemophilia A	22	AIDS
Edinburgh	Haemophilia A	8	Cerebral haemorrhage
Edinburgh	Haemophilia A	5	Cancer
Edinburgh	Haemophilia A	4	Liver failure
Edinburgh	Haemophilia A	2	Suicide
Edinburgh	Haemophilia A	1	Details not known
Edinburgh	Haemophilia A	1	Natural causes
Edinburgh	Haemophilia A	1	Pneumonia
Edinburgh	Haemophilia A	1	Post-operative haemorrhage
Edinburgh	Haemophilia A	1	Renal failure
Edinburgh	Haemophilia A	1	Retroperitoneal bleed
Edinburgh	Haemophilia A	1	Ruptured atheromatous aneurysm aorta
Edinburgh	Haemophilia A	1	Sepsis

Appendix 1: UKHCDO Data

**Table 8 (Cont'd) – Hepatitis C – Patients treated at Scottish Haemophilia Centres
– Deceased, per Haemophilia Centre and causes of death 1969-2010**

Haemophilia Centre	Diagnosis	Num Pts	Cause of Death
Edinburgh	Acquired Haemophilia A	1	Cancer
Edinburgh	Acquired Haemophilia A	1	Cerebral haemorrhage
Edinburgh	Haemophilia B	1	Cancer
Edinburgh	Haemophilia B	1	G.I. bleed
Edinburgh	Haemophilia B	1	Heart disease
Edinburgh	Haemophilia B	1	Motor Neurone Disease
Edinburgh	Haemophilia B	1	Pneumonia
Edinburgh	von Willebrand disease	1	Cancer
Edinburgh	von Willebrand disease	1	Pneumonia
	Edinburgh Total	58	
Glasgow (R.H.S.C.)	Haemophilia A	7	AIDS
Glasgow (R.H.S.C.)	Haemophilia A	1	Accident
Glasgow (R.H.S.C.)	Haemophilia A	1	Bronchitis
Glasgow (R.H.S.C.)	Haemophilia A	1	Heart disease
Glasgow (R.H.S.C.)	Haemophilia A	1	Pneumocystitis Pneumonia (reported as "not AIDS")
	Glasgow (R.H.S.C.) Total	11	
Glasgow (R.I.)	Haemophilia A	14	AIDS
Glasgow (R.I.)	Haemophilia A	13	Cerebral haemorrhage
Glasgow (R.I.)	Haemophilia A	5	Cancer
Glasgow (R.I.)	Haemophilia A	2	Accident
Glasgow (R.I.)	Haemophilia A	2	Details not known
Glasgow (R.I.)	Haemophilia A	1	Acute asthmatic attack
Glasgow (R.I.)	Haemophilia A	1	Cardiac failure and cardiac arrest
Glasgow (R.I.)	Haemophilia A	1	Cerebrovascular Accident
Glasgow (R.I.)	Haemophilia A	1	Chronic obstructive airway disease
Glasgow (R.I.)	Haemophilia A	1	G.I. bleed

Appendix 1: UKHCDO Data

**Table 8 (Cont'd) - Hepatitis C - Patients treated at Scottish Haemophilia Centres
- Deceased, per Haemophilia Centre and causes of death 1969-2010**

Haemophilia Centre	Diagnosis	Num Pts	Cause of Death
Glasgow (R.I.)	Haemophilia A	7	Liver failure
Glasgow (R.I.)	Haemophilia A	3	Liver failure associated with cirrhosis and alcoholic liver disease
Glasgow (R.I.)	Haemophilia A	3	Myocardial infarct
Glasgow (R.I.)	Haemophilia A	3	Overdose
Glasgow (R.I.)	Haemophilia A	2	Pulmonary oedema
Glasgow (R.I.)	Haemophilia A	1	Heart disease
Glasgow (R.I.)	Haemophilia A	1	Hepatitis
Glasgow (R.I.)	Haemophilia A	1	Motor Neurone Disease
Glasgow (R.I.)	Haemophilia A	1	Pneumonia
Glasgow (R.I.)	Haemophilia A	1	Renal failure
Glasgow (R.I.)	Haemophilia A	1	Ruptured atheromatous aneurysm aorta
Glasgow (R.I.)	Haemophilia A	1	Ruptured hepatoma
Glasgow (R.I.)	Haemophilia A	1	Septicaemia
Glasgow (R.I.)	Haemophilia A with Liver Transplant	1	Cancer
Glasgow (R.I.)	Haemophilia A with Liver Transplant	1	Hepatoma
Glasgow (R.I.)	Haemophilia B	2	Pneumonia
Glasgow (R.I.)	Haemophilia B	2	Suicide
Glasgow (R.I.)	Haemophilia B	1	Cancer
Glasgow (R.I.)	Haemophilia B	1	G.I. bleed
Glasgow (R.I.)	Haemophilia B	1	Myocardial infarct
Glasgow (R.I.)	Haemophilia B	1	Renal failure
Glasgow (R.I.)	von Willebrand disease	1	Cancer
Glasgow (R.I.)	von Willebrand disease	1	Cardiac failure and cardiac arrest
Glasgow (R.I.)	von Willebrand disease	1	Liver failure
Glasgow R.I. Total		80	

Appendix 1: UKHCDO Data

**Table 8 (Cont'd) – Hepatitis C – Patients treated at Scottish Haemophilia Centres
– Deceased, per Haemophilia Centre and causes of death**

Haemophilia Centre	Diagnosis	Num Pts	Cause of Death
Inverness	Haemophilia A	6	AIDS
Inverness	Haemophilia A	4	Cerebral haemorrhage
Inverness	Haemophilia A	1	Haemophilia only on death certificate
Inverness	Haemophilia A	1	Hepatitis
Inverness	Haemophilia A	1	Hepatoma
Inverness	Haemophilia A	1	Liver failure
Inverness	Haemophilia A	1	Liver failure associated with cirrhosis and alcoholic liver disease
Inverness	Haemophilia A	1	Myocardial infarct
Inverness	Haemophilia A	1	Pneumonia
Inverness	Haemophilia A	1	Pulmonary oedema
Inverness	Haemophilia A	1	Renal failure
Inverness	Haemophilia A	1	Ruptured atheromatous aneurysm aorta
Inverness	Haemophilia B	1	Cancer
Inverness Total		21	

The number and causes of death data are derived from reports from centres and reports from the Office of National Statistics. We provide them with details of all (25000+) patients registered with the database and they flag them up when they die and send us death certification data. Some patients will have been treated at more than one Scottish Haemophilia Centre and their death may appear in the statistics from both of those centres. This double counting is reconciled when deriving the total number of deaths for the whole of Scotland.

Appendix 1: UKHCDO Data

National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Table 9 – Hepatitis C – Patients treated at Non-Scottish Haemophilia Centres - Alive

Estimate of the number of patients exposed to hepatitis C, based on historical clotting factor concentrate exposure from a non-Scottish Haemophilia Centres - Alive

Diagnosis	Num Pts
Haemophilia A	1760
Haemophilia B	471
Females with VIII deficiency	73
Females with IX deficiency	36
von Willebrand disease	186
F.VII deficiency	5
F.X deficiency	7
F.XI Deficiency	4
F.XII (Hageman) defect	1
Prothrombin Deficiency	1
Combined von Willebrands + IX deficiency	1
Combined Haemophilia A + von Willebrands	1
Combined XI + VIII deficiency	1
Combined V+VIII Deficiency	2
Acquired Haemophilia B	1
Acquired von Willebrands	1
Platelet defects (misc)	1
Haemophilia A with Liver Transplant	8
Haemophilia B with Liver Transplant	2
Unclassified	9
Temporary coagulation defect, now normal	13
	2584

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National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Table 10 – Hepatitis C – Patients treated at Non-Scottish Haemophilia Centres – Deceased and cause of death 1969-2010

Diagnosis	Num Pts	Cause of Death
Haemophilia A	91	Liver failure
	16	Liver failure associated with cirrhosis and alcoholic liver disease
	12	Hepatoma
	11	Hepatitis
	4	Hepatitis C
	1	Hepatic Encephalopathy
	27	Accident
	2	Acute asthmatic attack
	2	Acute infection
	3	Acute left ventricular failure
	2	Acute myeloid leukaemia
	567	AIDS
	1	AIDS related complex
	2	Aortic stenosis
	1	Bowel perforation
	123	Cancer
	22	Cardiac failure and cardiac arrest
	1	Cardiogenic shock
	2	Cardiomyopathy
	3	Cardiovascular accident
	166	Cerebral haemorrhage
	1	Cerebral Infarct
	2	Cerebrovascular Accident
	1	Chest infection
	6	Chronic obstructive airway disease
	1	Chronic obstructive pulmonary disease
	1	Coronary atherosclerosis
	1	Coronary occlusion
	3	Coronary thrombosis
	1	Cryptococcal meningitis
	14	Details not known
	1	Diabetic coma
	1	Emphysema
	1	Encephalopathy
	1	Epileptic fit
	23	G.I. bleed
	1	Gastroenteritis
	1	General debility

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National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Table 10 (Cont'd) – Hepatitis C – Patients treated at Non-Scottish Haemophilia Centres – Deceased and cause of death 1969 - 2010

Diagnosis	Num Pts	Cause of Death
Haemophilia A	91	Liver failure
	16	Liver failure associated with cirrhosis and alcoholic liver disease
	12	Hepatoma
	11	Hepatitis
	4	Hepatitis C
	1	Hepatic Encephalopathy
	27	Accident
	2	Acute asthmatic attack
	2	Acute infection
	3	Acute left ventricular failure
	2	Acute myeloid leukaemia
	567	AIDS
	1	AIDS related complex
	2	Aortic stenosis
	1	Bowel perforation
	123	Cancer
	22	Cardiac failure and cardiac arrest
	1	Cardiogenic shock
	2	Cardiomyopathy
	3	Cardiovascular accident
	166	Cerebral haemorrhage
	1	Cerebral Infarct
	2	Cerebrovascular Accident
	1	Chest infection
	6	Chronic obstructive airway disease
	1	Chronic obstructive pulmonary disease
	1	Coronary atherosclerosis
	1	Coronary occlusion
	3	Coronary thrombosis
	1	Cryptococcal meningitis
	14	Details not known
	1	Diabetic coma
	1	Emphysema
	1	Encephalopathy
	1	Epileptic fit
	23	G.I. bleed
	1	Gastroenteritis
	1	General debility

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National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Table 10 (Cont'd) - Hepatitis C - Patients treated at Non-Scottish Haemophilia Centres - Deceased and cause of death 1969 - 2010

Diagnosis	Num Pts	Cause of Death
Haemophilia A	1	Haemopericardium
	2	Haemophilia only on death certificate
	3	Haemophilic pseudotumor
	2	Haemoptysis
	32	Haemorrhage (misc.)
	2	Hanging
	24	Heart disease
	5	HIV-related (No AIDS-defining illness)
	1	Hodgkins disease
	3	Hodgkins lymphoma
	1	Hypothermia
	1	Iliopsoas bleed
	1	Infection small bowel
	2	Intestinal obstruction
	5	Intra-abdominal bleed
	1	Intrathoracic bleed
	1	Legionnaires disease
	6	Lymphoma
	2	Meningitis
	1	Mixed drug toxicity
	1	Motor Neurone Disease
	3	Multi-organ failure
	36	Myocardial infarct
	1	Non-haemorrhagic but details not known
	1	Non-hodgkins lymphoma
	3	Old age
	6	Overdose
	1	Perforated peptic ulcer
	1	Peritonitis
	1	Pneumocystitis Pneumonia (reported as "not AIDS")
	87	Pneumonia
	19	Post-operative complications
	5	Post-operative haemorrhage
	2	Progressive encephalopathy
	4	Pulmonary embolism
	1	Pulmonary hypertension
	4	Pulmonary oedema
	1	Pyelonephritis
	1	Rectal haemorrhage

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National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Table 10 (Cont'd) – Hepatitis C – Patients treated at Non-Scottish Haemophilia Centres – Deceased and cause of death 1969 - 2010

Diagnosis	Num Pts	Cause of Death
Haemophilia A	12	Renal failure
	7	Respiratory failure
	1	Respiratory tract infection
	5	Retroperitoneal bleed
	3	Ruptured atheromatous aneurysm aorta
	4	Ruptured spleen
	1	Sepsis
	20	Septicaemia
	1	Staphylococcal peritonitis
	6	Stroke
	1	Sudden unexpected death
	17	Suicide
	1	Throat haemorrhage
	3	Unknown/unascertainable on death certificate
Haemophilia A Total	1475	
Haemophilia A with Liver Transplant	3	Liver failure
	1	Hepatoma
	1	Haemorrhage (misc.)
	1	Heart disease
	2	Renal failure
	1	Septicaemia
Combined Haemophilia A, Haemophilia B	1	Liver failure associated with cirrhosis and alcoholic liver disease
Combined Haemophilia A + XII deficiency	1	Cancer
Acquired Haemophilia A	1	Hepatitis
	1	Liver failure
	1	Accident
	1	Acute myeloid leukaemia
	3	Cancer
	1	Cardiac failure and cardiac arrest
	2	Cerebral haemorrhage
	1	Diabetic coma
	4	Intra-abdominal bleed
	1	Pneumonia
	1	Post-operative complications
	1	Post-operative haemorrhage
	1	Respiratory failure
	1	Senile myocardial degeneration
	1	Senility/Alzheimer's disease
1	Systemic lupus erythematosus (SLE)	

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National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Table 10 (Cont'd) – Hepatitis C – Patients treated at Non-Scottish Haemophilia Centres – Deceased and cause of death 1969 - 2010

Diagnosis	Num Pts	Cause of Death
Haemophilia B	1	Hepatic Artery Aneurysm
	2	Hepatitis
	1	Hepatitis C
	1	Hepatoma
	1	Hepatorenal Syndrome
	6	Liver failure
	3	Liver failure associated with cirrhosis and alcoholic liver disease
	8	Accident
	10	AIDS
	1	Bronchitis
	31	Cancer
	7	Cardiac failure and cardiac arrest
	1	Cardiovascular accident
	33	Cerebral haemorrhage
	1	Cerebrovascular Accident
	1	Chronic obstructive airway disease
	2	Chronic obstructive pulmonary disease
	1	Coronary atherosclerosis
	9	Details not known
	1	Encephalitis
	3	G.I. bleed
	1	Gastroenteritis
	6	Haemorrhage (misc.)
	5	Heart disease
	1	Intestinal obstruction
	1	Intra-abdominal bleed
	2	Multi-organ failure
	8	Myocardial infarct
	1	Old age
	1	Overdose
	10	Pneumonia
	3	Post-operative complications
	1	Pulmonary oedema
	5	Renal failure
	1	Respiratory failure
	2	Septicaemia
	2	Stroke
	5	Suicide
	1	Unknown/unascertainable on death certificate
	Haemophilia B Total	180

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National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Table 10 (Cont'd) – Hepatitis C – Patients treated at Non-Scottish Haemophilia Centres – Deceased and cause of death 1969 - 2010

Diagnosis	Num Pts	Cause of Death
Haemophilia B with Liver Transplant	1	Cerebral haemorrhage
	1	Details not known
Acquired Haemophilia B	1	Heart disease
Females with VIII deficiency	3	Cancer
	1	Chest infection
	12	Details not known
	1	Myocardial infarct
	1	Septicaemia
Females with IX deficiency	3	Cancer
	1	Cardiovascular accident
	1	Sepsis
von Willebrand disease	2	Liver failure
	1	Hepatitis C
	1	Liver failure associated with cirrhosis and alcoholic liver disease
	1	Accident
	5	AIDS
	18	Cancer
	4	Cardiac failure and cardiac arrest
	9	Cerebral haemorrhage
	1	Details not known
	2	G.I. bleed
	3	Heart disease
	1	Myocardial infarct
	1	Overdose
	6	Pneumonia
	2	Renal failure
	2	Respiratory failure
	1	Ruptured atheromatous aneurysm aorta
1	Ruptured splenic artery aneurysm	
Acquired von Willebrands	1	Cancer
F.X deficiency	1	Respiratory failure
Factor X deficiency with Liver Transplant	1	Liver failure associated with cirrhosis and alcoholic liver disease
F.XI Deficiency	1	Liver failure associated with cirrhosis and alcoholic liver disease
	1	G.I. bleed
	1	Heart disease
Misc.	1	G.I. bleed
Grand Total	1782	

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National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Table 11 – Liver Transplants – Number of patients who have undergone liver transplant currently registered at a Scottish Haemophilia Centre

Diagnosis	Cause of Death	Total
Haemophilia A with Liver Transplant	Cancer	1
	Hepatoma	1
	Renal failure *	1
	Alive	2
Haemophilia B with Liver Transplant	Alive	2
Grand Total		7

* This patient is currently registered at a Scottish Centre but was not treated in Scotland during the period of risk, although he was treated at another centre during the period of risk. We suspect under-reporting of liver transplantation. This will be the focus of part of the hepatitis C look-back exercise.

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National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Table 12 – Liver Transplants – Number of patients who have undergone liver transplant currently registered at a Non-Scottish Haemophilia Centre

Diagnosis	Cause of Death	Total
Haemophilia A with Liver Transplant	Cancer	1
	Details not known	1
	Haemorrhage (misc.)	1
	Heart disease	1
	Hepatoma *	1
	Liver failure	4
	Lymphoma	1
	Perforated peptic ulcer	1
	Renal failure *	2
	Septicaemia	1
	Alive *	12
Haemophilia B with Liver Transplant	Cerebral haemorrhage	1
	Details not known	1
	Multi-organ failure	1
	Alive	5
von Willebrand with Liver Transplant	Cancer	1
	Alive	1
Factor X deficiency with Liver Transplant	Liver failure associated with cirrhosis and alcoholic liver disease	1
Grand Total		37

* One from each of these groups of patients has also been registered at a Scottish Centre

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National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Table 13 - Annualised UK Deaths from Liver Disease 1969-2010

Annualised UK Deaths from Liver Disease 1969-2010				
Year	Hepatoma	Hepatorenal Syndrome	Liver failure	Liver failure associated with cirrhosis and alcoholic liver disease
1969			2	
1970			2	
1972			2	
1973			1	
1974			1	
1975			1	
1979			1	1
1980			1	
1983				2
1984			1	2
1985			4	
1986			7	
1987			2	3
1988			1	1
1989			2	3
1990			3	1
1991			9	
1992			9	
1993			14	1
1994			10	3
1995			3	3
1996			8	2
1997			10	
1998			9	
1999			4	
2000			15	
2001			6	
2002	3		4	4
2003	2		1	1
2004	2		3	1
2005	1		1	1
2006	4	1	1	2
2007	2		3	
2008	3		4	1
2009	2		6	2
2010			1	

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National Haemophilia Database Bleeding Disorder Statistics for the Penrose Enquiry

Table 13: shows deaths reported to the National Haemophilia Database attributable to liver disease (all causes, not just viral liver disease) since the inception of the database in 1968. This is broken down by year of reporting. Haemophilia centres are expected to report all deaths and causes of death to the National Haemophilia Database. This has, over the past ten years or more been supplemented by death certification data on all patients registered with the database from the Office for National Statistics (recently renamed the Medical Research Information Service). This shows a peak in liver failure deaths in the nineteen nineties which is attributable to co-infection with HIV and HIV-related immunosuppression. The subsequent reduction in deaths from this cause is probably attributable to a combination of the introduction of HAART, eradication of hepatitis C with interferon, peginterferon and ribavarin and liver transplantation. We also see the long lag period (assuming all hepatitis C infections from concentrate occurred prior to 1987) before some patients developed hepatocellular carcinoma as a complication of hepatitis C.