

Witness Name: C Haughton

Statement No: WITN3125001

Exhibits: WITN3125002 - WITN3125069

Dated: April 2020

INFECTED BLOOD INQUIRY

EXHIBIT WITN3125069

01 Patient Name Record

08/07/2019

Unique ID	NHD num	Soundex	Surname	Forename
15622/0078		H-235	HAUGHTON	DEREK

02 Patient Registered Haemophilia Centres

08/07/2019

Unique ID	NHD num	Haemophilia Centre Name	Date first seen	Date Registered with NHD	Reason no longer seen	Date No Longer Seen
15622/0078		Oxford				
15622/0078		Truro			No Longer seen at Centre	01/08/1995
15622/0078		Coventry	17/10/2005		No Longer seen at Centre	17/10/2005
15622/0078		Coventry	17/10/2005	09/05/2007	No Longer seen at Centre	10/11/2010
15622/0078		Cambridge	10/09/2008	10/09/2008 2:10:08 PM	Visitor- not a regular patient	14/03/2018

Gene Mutation date tested	Registered Neo Natal	Weight (Kg)	Surgery in 2007
09/05/2016	No	80.4	No
	No		No
	No		No
	No		No
	No		No

03 General Patient Data

08/07/2019

Unique ID	NHD num	NHS Num	Oxford reg num	Yr first registered with NHD	Sex	Date of Birth	Postcode	Date of death	Cause of death	
1562	2/0078	GRO-C	2/0102	1969	M	GRO-C	1944	GRO-C	09/07/2018	Multi-organ failure

04 Patient annual treatment record

08/07/2019

Unique ID	NHD num	Treatment yr	Quarter num for Yr	Haemophilia Centre	Regular Home Treatment	Visitor	Product	Units issued
15622/0078		2018	2	Coventry		Yes	ALPROLIX	5000
15622/0078		2018	2	Oxford			ALPROLIX	33750
15622/0078		2018	1	Oxford			ALPROLIX	33750
15622/0078		2018	3	Coventry			ALPROLIX	6000
15622/0078		2017	4	Oxford			ALPROLIX	22500
15622/0078		2017	3	Oxford			ALPROLIX	40500
15622/0078		2017	2	Oxford			Replenine (BPL)	39600
15622/0078		2017	1	Oxford			Replenine (BPL)	125600
15622/0078		2016	4	Oxford			Replenine (BPL)	66310
15622/0078		2016	3	Oxford			Replenine (BPL)	67800
15622/0078		2016	2	Oxford			Replenine (BPL)	72720
15622/0078		2016	1	Oxford			Replenine (BPL)	57960
15622/0078		2015	4	Oxford			Replenine (BPL)	33740
15622/0078		2015	1	Oxford			Replenine (BPL)	48840
15622/0078		2015	3	Oxford			Replenine (BPL)	51960
15622/0078		2015	2	Oxford			Replenine (BPL)	78960
15622/0078		2014	4	Oxford			Replenine (BPL)	55335
15622/0078		2014	3	Oxford			Replenine (BPL)	51000
15622/0078		2014	3	Oxford			Replenine (BPL)	26520
15622/0078		2014	2	Oxford			Replenine (BPL)	51280
15622/0078		2014	1	Oxford			Replenine (BPL)	48000
15622/0078		2013	4	Oxford			Replenine (BPL)	50280
15622/0078		2013	3	Oxford			Replenine (BPL)	76320
15622/0078		2013	2	Oxford			Replenine (BPL)	50940
15622/0078		2013	1	Oxford			Replenine (BPL)	50955
15622/0078		2012	2	Oxford			Replenine (BPL)	58380
15622/0078		2012	1	Oxford			Replenine (BPL)	48520
15622/0078		2012	4	Oxford			Replenine (BPL)	47280
15622/0078		2012	3	Oxford			Replenine (BPL)	51920
15622/0078		2011	4	Oxford			Replenine (BPL)	56160

04 Patient annual treatment record

08/07/2019

Unique ID	NHD num	Treatment yr	Quarter num for Yr	Haemophilia Centre	Regular Home Treatment	Visitor	Product	Units issued
15622/0078		2000		Oxford	Yes		Replenine (BPL)	
15622/0078		1999		Oxford	Yes		Replenine (BPL)	
15622/0078		1998		Oxford	Yes		Alphanine	
15622/0078		1998		Oxford	Yes		Replenine (BPL)	
15622/0078		1997		Oxford	Yes		Alphanine	
15622/0078		1997		Oxford	Yes		Replenine (BPL)	
15622/0078		1996		Oxford	Yes		Replenine (BPL)	
15622/0078		1995		Oxford	Yes		Replenine (BPL)	
15622/0078		1994		Coventry	Yes		FIX (BPL)	
15622/0078		1994		Oxford	Yes		FIX (BPL)	
15622/0078		1993		Oxford			FIX (BPL)	
15622/0078		1993		Coventry	Yes		FIX (BPL)	
15622/0078		1992		Coventry	Yes		FIX (BPL)	
15622/0078		1992		Oxford			FIX (BPL)	
15622/0078		1991		Coventry	Yes		FIX (BPL)	
15622/0078		1991		Oxford	Yes		FIX (BPL)	
15622/0078		1990		Oxford			FIX (BPL)	
15622/0078		1989		Coventry			FIX (BPL)	
15622/0078		1988		Coventry			FIX (BPL)	
15622/0078		1987		Coventry	Yes		FIX (BPL)	
15622/0078		1986		Coventry			FIX (BPL)	
15622/0078		1985		Coventry	Yes		FIX (BPL)	
15622/0078		1984		Coventry	Yes		FIX (BPL)	
15622/0078		1983		Coventry			FIX (BPL)	
15622/0078		1982		Truro			FIX (BPL)	
15622/0078		1982		Coventry			FIX (BPL)	
15622/0078		1981		Coventry			FIX (BPL)	
15622/0078		1980		Coventry			FIX (BPL)	
15622/0078		1979		Coventry			FIX (BPL)	
15622/0078		1978		Coventry			FIX (BPL)	

07 Patient HIV data

08/07/2019

Unique ID	NHD num	Date Code	Haemophilia Centre	Sample date	Result	Date Form Completed
15622/78		06	Oxford	24/08/1990		03/07/1991
15622/78		06	Oxford	24/08/1990		03/07/1991
15622/78		06	Oxford	24/08/1990		03/07/1991

09 Patient vCJD data

08/07/2019

NHD num	Unique ID	Haemophilia Centre	At Risk 1980-2001	Patient notified	Assessor	Assessed Date	brand_name	vial	batch_no	release_date	first_dose	last_dose	total_dose
2/0078	1562	Oxford	Yes	Unknown	Dr.D.M. Keeling	24/09/2004	REPLENINE	500	FJM4596	23/04/1997	21/05/1997	30/06/1997	10200
2/0078	1562	Oxford	Yes	Unknown	Dr.D.M. Keeling	24/09/2004	REPLENINE	500	FJM4437	27/11/1995	30/08/1996	15/10/1996	10300
2/0078	1562	Oxford	Yes	Unknown	Dr.D.M. Keeling	24/09/2004	REPLENINE	500	FJM4327	10/10/1994	19/01/1995	05/05/1995	10300
2/0078	1562	Coventry	Yes	No	O Chapman	05/04/2006							

10 Hepatitis C Lookback Data

08/07/2019

Unique ID	Information submitted by	Exp.to Plasma Comp.prior to Sept 1991	Treated with clotting factor conc.prior to 1988	Comments
1562	Sheffield	No	No	patient unknown

Hep C 2018

NHD_ID	Centre No	NHDNo	Received factor Concentrates before 1988	Received blood components before 1992	HCV antibody	HCV PCR	Cirrhosis
1562	1	2/78	Yes	Yes	Pos	Pos	No

08/07/2019

Form 1

2/78

M.R.C. Cryoprecipitate Working Party

Survey of incidence of transfusion jaundice in haemophilic and Christmas disease patients.

To be completed by Haemophilia Centres and returned to Dr. Rosemary Biggs, Oxford Haemophilia Centre, Churchill Hospital, Oxford, OX3 7LJ. If jaundice occurs this form should be returned immediately, otherwise at the end of the survey period.

Centre: St. Thomas's Hospital, London, S.E.1.

Survey Period 1.1.69-31.12.

Full name of patient: Derek Haughton

Follow-up Period 1.3.69-30.6.

Address: GRO-C London GRO-C

Jaundice: Yes/No ~~Yes~~

Date of Birth: GRO-C 1944. Sex: Male

Inhibitor: ~~Factor IX~~/Not Tested

Coagulation defect: Christmas disease Severity: Factor IX 0%

Date:

General Practitioner's Name and Address: Dr. J.P. Booth, 3 Enmore Road, South Norwood, S.E.25.

Date	Type of therapeutic material given	Volume of dose material (ml.)	Number of blood donations represented in dose	Reason for Treatment
4.4.69	Fresh Frozen Plasma	1,500 ml	five	(L) Proas bleed.
5.4.69	" " "	600 ml	Two	" " "
6.4.69	Factor IX concentrate	600 ml	4	" " "
8.4.69	Factor IX concentrate	80 ml	Twenty five	" " "
9.4.69	" " "	"	4	" " "
10.4.69	" " "	"	3	" " "
11.4.69	" " "	200 ml	2	" " "
29.4.69	Fresh Frozen Plasma	1,000 ml	Two	L. Proas bleed.
29/4/69	Factor IX concentrate	312 ml	Three	L. Proas bleed.
30.4.69	Factor IX concentrate	200 ml	Two	" " "
1.5.69	Fresh Frozen Plasma	600 ml	Two	" " "
6.5.69	" " "	600 ml	"	" " "
21.5.69	" " "	600 ml	Two	Bleed (L) side
22.5.69	" " "	600 ml	Two	" " "

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Form 1

2/78

M.R.C. Cryoprecipitate Working Party

Survey of incidence of transfusion jaundice in haemophilic and Christmas disease patients.

To be completed by Haemophilia Centres and returned to Dr. Rosemary Biggs, Oxford Haemophilia Centre, Churchill Hospital, Oxford, OX3 7LJ. If jaundice occurs this form should be returned immediately, otherwise at the end of the survey period.

Centre: St. Thomas' Hospital. London, S.E.1.

Survey Period 1.1.69-31.12.

Full name of patient: DEREK HAUGHTON.

Follow-up Period 1.3.69-30.6.70.

Address: GRO-C

Jaundice: Yes/No

Date of Birth: GRO-C 44

Sex: Male

Inhibitor: Found/Not Found/Not Tested

Coagulation defect: Christmas diseaseSeverity: 0% factor IX

Date:

General Practitioner's Name and Address: Dr. Cogavin, Arnham Drive, New Addington, Croydon, Surrey.

Date	Type of therapeutic material given	Volume of dose material (ml.)	Number of blood donations represented in dose	Reason for Treatment
25.3.70	Factor IX concentrate.	200 l.	? 2	R. elbow.
25.4.70.	Fresh Frozen Plasma.	600 l.	2.	L. thigh, foot, knee.
25.4.70.	Fresh Frozen Plasma.	600 l.	2	" " "
29.4.70.	Fresh Frozen Plasma.	600 l.	2.	" " "
27.5.70.	Factor IX concentrate.	200 l.	? 2.	? Small groin bleed - left thigh.
1.6.70	Fresh Frozen Plasma.	600 l.	2.	L. knee.
2.6.70	Fresh Frozen Plasma.	300 l.	1	" "
5.6.70	Factor IX Concentrate	200 l.	20	Rephylactic.
9.6.70	Fresh Frozen Plasma	600 l.	2	"
12.6.70	" " "	600 ml	2	"
16.6.70	Factor IX Concentrate	200 l.		"
19.6.70	Fresh Frozen Plasma	600 l.	2	"
23.6.70	" " "	600 l	2	"
26.6.70	" " "	600 l	2	"

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M.R.C. Cryoprecipitate Working Party

Survey of incidence of transfusion jaundice in haemophilic and Christmas disease patients.

To be completed by Haemophilia Centres and returned to Dr. Rosemary Biggs, Oxford Haemophilia Centre, Churchill Hospital, Oxford, OX3 7LJ. If jaundice occurs this form should be returned immediately, otherwise at the end of the survey period.

Centre: St. Marys, 11.58 PM.

Survey Period 1.1.69-31.12.

Full name of patient: John Harrison

Follow-up Period 1.3.69.-30.6.

Address:

Jaundice: Yes/No

Date of Birth:

Sex:

Inhibitor: Found/Not Found/Not Tested

Coagulation defect:

Severity:

Date:

General Practitioner's Name and Address:

[illegible]

ANNUAL RETURN FOR 1971

Director: DR. G. I. C. INGRAM.

DICK HAUGHTON	GRO-C	1944	c	2	38 NO	NO			8 28		1
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*If Yes, " " " " " " " " " " 1 and 3

Sheet No. (2) of 4 Sheets

Survey of Patients Treated at Haemophilia Centres

ANNUAL RETURN FOR 1971

Centre: **SHEFFIELD**

Director: Professor E.K. Blackburn

Name of Patient	Date of Birth	Diagnosis	Inhibitor Present [Yes/No]*	Jaundiced [Yes/No]**	Total amount of material received in 1971 (donor units)				Total number of doses given in 1971
					Plasma	Cryoprecipitate	Concentrates	Others***	
✓ HAUGHTON Derek	GRO-C/78	XMAS	No -/-	No	-	-	8 25	-	8

If Yes, please complete and return MRC Cryoprecipitate Working Party Forms 1 and 4

*If Yes, " " " " " " " " " " 1 and 3

**Please specify, e.g. Whole Blood

Sheet No. 2 of 5 Sheets

ANNUAL RETURN FOR '1972

Director: Prof. G. C. INGRAM.

Name of Patient	Date of Birth	Diagnosis (with factor VIII/IX %)	Inhibitor Present [Yes/No]*	Jaundiced [Yes/No]**	Total amount of material received in 1972 (donor units)				Additional Information
					Plasma	Cryoprecipitate	Concentrates	Others***	
Derek HUGHTON	GRO-C 44	CHRISTMAS FAST = ZERO	NO 2/78	NO	6				

Form 3 (" " ")

Sheet No. 2 of 4 Sheets

[illegible]

* If Yes, " " " " " " " " Form 3

Annual Return for 1974

Centre. COVENTRY & WARWICKSHIRE.....

Christmas Disease Patients Treated During the Year

[illegible]

- * 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(2) and C(3) unless these have already been sent to Alton or Oxford.

Factor IX Concentrate

To: Dr. E. Bidwell,
Plasma Fractionation Laboratory,
Oxford Haemophilia Centre,
Churchill Hospital, Oxford.

REQUEST FOR FURTHER SUPPLY

From: _____

Please supply Factor IX type B(1). Indicate No. of bottles

Urgency: Is this a confirmation of telephone request?

How long do you expect your present stock to last?

DATA ON MATERIAL USED

Complete even if no assays.

P.F.L. Sent: Batch Bottles Date Initials

	Patient			Diagnosis	Dose			Your Assays**		Reason for treatment	Comment
	Name	d. o. b.	V. K.		Batch No.	Bottle No.	Vol. given ml.	Dose u/ml.	Patient % AN		
7/10/74	HAUGHTON, DEBORAH	GRO-C	6	CHRONIC DISEASE	90454	68	40	35	0% 11%	MINOR TREAT BLEED	
						62		35			
7/10/74	HAUGHTON, DEBORAH	GRO-C	6	CHRONIC DISEASE	90454	64	40	35	0% 10%	MINOR TREAT BLEED	
					90521	34		50			
28/12/74	HAUGHTON, DEBORAH	GRO-C	68	CHRONIC DISEASE	90521	—	40	50?		MINOR TREAT BLEED	
					90521	—		50?			
2/78	a. 2/375										

** Assay Description

Type 1

Factor IX Concentrate

To: Dr. E. Bidwell,
Plasma Fractionation Laboratory,
Oxford Haemophilia Centre,
Churchill Hospital, Oxford.

REQUEST FOR FURTHER SUPPLY

From: _____

Please supply Factor IX type DE(1)*, indicate No. of bottles

Urgency: Is this a confirmation of telephone request? ☐

How long do you expect your present stock to last? days

DATA ON MATERIAL USED

Please complete even if no assays.

P.F.L. use only

Sent: Batch Bottles Date Initials

Date used	Patient		Diagnosis	Dose			Your Assays**			Reason for treatment	Comments
	Name	Wt. Kg.		Batch No.	Nos of Bottles	Vol. given ml.	Dose u/ml.	Patient "., AN			
								Pre	Post		
										MINOR TOXIC SUBD.	
										" " "	
										" " "	
25/3/75	HAUGHTON DEREK	68	" "	42538	54.55	40	/			" " "	
										" " "	
										" " "	
										" " "	
										" " "	
										" " "	
31/7/75	HAUGHTON DEREK	68	" "	42539	12.68	40	/			" " "	

** Assay Description.....

Type 1-stage ☐ 2-stage ☐

* Please state if other type required.

Signed

Date

Factor IX Concentrate

To: Dr. E. Bidwell,
Plasma Fractionation Laboratory,
Oxford Haemophilia Centre,
Churchill Hospital, Oxford.

REQUEST FOR FURTHER SUPPLY

From: _____

Please supply Factor IX type DE(1)*, indicate No. of bottles

10	
20-25	
40-50	

Urgency: Is this a confirmation of telephone request? ☐

How long do you expect your present stock to last? days

DATA ON MATERIAL USED

Please complete even if no assays.

P.F.L. use only

Sent: Batch

Bottles

Date

Initials

Date used	Patient		Diagnosis	Dose			Your Assays**			Reason for treatment	Comments
	Name	Wt. Kg.		Batch No.	Nos. of Bottles	Vol. given ml.	Dose u/ml.	Patient "... AN			
								Pre	Post		
											</

** Assay Description.....

* Please state if other type required.

Type 1-stage ☐

2-stage ☐

Signed

Date

Christmas Disease Patients Treated During the Year

* 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.

From: Cressida Haughton <cressida@GRO-C>
Sent: 11 August 2019 13:14
To: Support@ukhcdo.org
Subject: Medical notes and batch codes

To whoever it may concern

I received a package of my late fathers records from you, cover letter dated 9th July 2019. Thank you.

Your reference number: NHD ID 1562.
Name: Derek William Haughton

I have been advised to contact you again to ask you make a search for the following regarding my father's medical records.

I request that a further search is performed to find any further paper or digital records, including any kept for longevity surveys / studies or otherwise, including dates prior to the inception of the Haemophilia Database. I also request any information held post mortem / pathology held on my father.

I am asking you to send all other digital or paper records relating to my late father's condition, treatment, references to blood or tissue retained, including any post mortem information shared, relating to his Haemophilia, infections or haematological malignancies with any university, consultant, researcher or other agency.

I ask for any references to inclusion in any trials /surveys / studies and all batch codes of treatment received at hospitals or self input via haem track.

There appears to be a large gap in the digital record, from 1972 to 1976 inclusive. I request that this be looked at again. Why are these dates not listed please?

I have it on good authority that you do have an archive of paper records which predate the inception of the database in 1969. I request that these are looked at in the hope of finding more of my father's records.

I have reason to believe my father may have been one of those studied by John Poole at Oxford, at the time Christmas disease was 'discovered' (1952-1953) and wonder if you have any records relating to this? If not, do you know where I may find out about this?

I am aware that you have many registers at UKHCDO, (e.g the Lymphoma Register), and in the interest of transparency, I would like to know which registers my father was listed on and any data relating to my father contained within.

I know that you are a repository of data for Haemophilia Centre doctors and clinical researchers. I have to say, there appears to be a wealth of information available for clinicians and researchers and I would hope that retention of documents/data on individual haemophilic patients is comparable and is fully available to patients, their next of kin and legal representatives.

Finally, I hope that there are no documents relating to my father that are being withheld, stored elsewhere or that you know have been destroyed. I request if

there are, that you confirm whether this is the case in your reply and if so, that you explain why please.

Thank you for your time, I genuinely appreciate any assistance you can give.

Regards

Cressida Haughton

From support@ukhcd.org

Wed, 28 Aug 2019 2:42:58 PM +0000

To "Cressida Haughton" <cressida@GRO-C>

Dear Ms Haughton,

Thank you for your e-mail dated 11/8/19 and we apologise for the delay in responding. We are very aware of the difficulties faced by individuals who have been infected by blood products and the impact this has had on their lives and their families. We would like to reassure you that the UK Haemophilia Centre Doctors' Organisation and the National Haemophilia Database have been and will continue to engage fully with Sir Brian Langstaff and the whole of the Public Inquiry team to ensure that we help the process to reach a positive conclusion.

We apologise that the data provided to you in July 2019 was not as complete as you expected. We have been through our entire paper archive and we have uploaded it in its entirety and we are completely confident that we have disclosed to you the complete dataset (both on paper and electronic) that has previously been submitted to us by the clinicians treating your father Derek William Haughton. We have never held any data or paperwork that precedes the inception of the database in 1968/9 and suggest that you approach your father's hospital/s to request his hospital notes and any other information they may have retained on your father.

The answers to the specific questions posed in your email are below in italics.

"I request that a further search is performed to find any further paper or digital records, including any kept for longevity surveys / studies or otherwise, including dates prior to the inception of the Haemophilia Database. I also request any information held post mortem / pathology held on my father." *As stated above we have already searched our whole paper archive which contains all the information that has ever been supplied by the hospitals treating the haemophilia patients to the National Haemophilia Database. The most detailed information on all patients and their treatment is held by the hospital from where the treatment is prescribed and issued and the database only receives that information as a secondary event – this used to be a manual written process prior to 2000 and is now electronic. Historically treatment centres were not obliged to send in data and what was received was very*

variable from patient to patient and centre to centre as data-handling prior to computerisation was very labour-intensive. It is not normal practice for hospitals to send post-mortem reports to the National Haemophilia Database.

"I am asking you to send all other digital or paper records relating to my late father's condition, treatment, references to blood or tissue retained, including any post mortem information shared, relating to his Haemophilia, infections or haematological malignancies with any university, consultant, researcher or other agency". Please see responses above.

"I ask for any references to inclusion in any trials /surveys / studies and all batch codes of treatment received at hospitals or self input via haem track." *The most complete record of batch numbers given to each patient has always been held at the treating hospital and has not routinely been collected by the National Haemophilia Database which has collected products and volumes given but not batch numbers. Some Database patient records do have incomplete records of batch numbers which were sent in by the hospitals but this has never been mandatory. Haemtrack is a Phone app and web based program developed over the last decade which allows patients to electronically record their treatments and batch numbers. Your father was recording these himself between 2009 and 2018. As this data is submitted by patients themselves and they have access to this information we haven't been routinely been sending Haemtrack records back to the patients when they have requested their information but I have attached copies of his submissions for you so that you have access to these.*

"There appears to be a large gap in the digital record, from 1972 to 1976 inclusive. I request that this be looked at again. Why are these dates not listed please?" *As explained above we only have the data that was sent in to us by the treating hospitals and the quality of this was inconsistent. As you will have seen from the extract there are some paper records from those years.*

"I have it on good authority that you do have an archive of paper records which predate the inception of the database in 1969. I request that these are looked at in the hope of finding more of my father's records." *We have no records on any patients prior to the inception of the database in 1969. The archive of paper records has already been fully catalogued and uploaded as explained above.*

"I have reason to believe my father may have been one of those studied by John Poole at Oxford, at the time Christmas disease was 'discovered' (1952-1953) and wonder if you have any records relating to this? If not, do you know where I may find out about this?" *Unfortunately Dr Poole's work pre-dated the Database and we have no information on his work in the 1950's. The Churchill Hospital or haemophilia centre at Oxford may have some records from that time and you may*

wish to check with them if you have not already done so. Their details can be found on our website www.ukhcdo.org

"I am aware that you have many registers at UKHCDO, (e.g. the Lymphoma Register), and in the interest of transparency, I would like to know which registers my father was listed on and any data relating to my father contained within." *The UKHCDO has only one Database or Register namely the National Haemophilia Database. We do not host any other Registries although it is possible that a Lymphoma Registry may employ the same software support company (MDSAS). If that is the case then we can reassure you that there is no data sharing between Registries and we are not aware of any other Registries your father was listed on.*

"I know that you are a repository of data for Haemophilia Centre doctors and clinical researchers. I have to say, there appears to be a wealth of information available for clinicians and researchers and I would hope that retention of documents/data on individual haemophiliac patients is comparable and is fully available to patients, their next of kin and legal representatives." *All data held by the Database on individual patients is fully available to them, their next of kin and their legal representatives if consent has been given by the patient/next of kin. All data submitted to the National Haemophilia Database has been retained.*

"Finally, I hope that there are no documents relating to my father that are being withheld, stored elsewhere or that you know have been destroyed. I request if there are, that you confirm whether this is the case in your reply and if so, that you explain why please." *We know of no records on your father that have been withheld from you. We have no other archived records stored anywhere in addition to those already disclosed to you and we know of no database records that have been destroyed.*

We hope that we have answered your queries fully but apologise for not providing as much information as you hoped for. We attach a further copy of our 'guide' to the data held in the National Haemophilia Database which describes in more detail what was collected at different times in the development of the database. If you have any further queries please do not hesitate to contact us again.

UKHCDO Executive/NHD Director

email to and from UKHCDO AUG 2019.doc