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
	1562	2/0078	H-235	HAUGHTON	DEREK

08/07/2019

02 Patient Registered Haemophilia Centres

Unique ID	NHD-num	Haemophilia Centre Name	Date first seen	Date Registered with NHD	Reason no longer seen	Date No Longer Seen
1562	2/0078	Oxford				
1562	2/0078	Truro			No Longer seen at Centre	01/08/1995
1562	2/0078	Coventry	17/10/2005		No Longer seen at Centre	17/10/2005
1562	2/0078	Coventry	17/10/2005	09/05/2007	No Longer seen at Centre	10/11/2010
1562	2/0078	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		80.4	
		The state of the s	The second way did
Section in the section of the sectio	No		No
		A superior of the superior of	
Control Contro	No		No
	minute mi		
	No	erge engles angun, an error tran \$2 person and er ergo an effect annothing in laboration	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	4	GRO-C 1944 GRO-C	09/07/2018 Multi-organ failure

04 Patient annual treatment record

Units issued	Product:	tyr Quarter num for Yr Haemophilia Centre Regular Home Treatment Visit		
		2018 2 Coventry Yes	2018	15622/0078
3375	ALPROLIX	2018 2 Oxford	2018	15622/0078
3375	ALPROLIX	2018 1 0xford	2018	15622/0078
600	ALPROLIX	2018 3 Coventry	2018	15622/0078
2250	ALPROLIX	2017 4 Oxford	2017	15622/0078
4050	ALPROLIX	2017 3Oxford	2017	15622/0078
3960	Replenine (BPL)	2017 2 Oxford	2017	1562 2/0078
12560	Replenine (BPL)	2017 1 0xford	2017	15622/0078
6631	Replenine (BPL)	2016 4 Oxford	2016	15622/0078
6780	Replenine (BPL)	2016 3 Oxford	2016	15622/0078
7272	Replenine (BPL)	2016 2 ^O Xford	2016	15622/0078
5796	Replenine (BPL)	2016 1 Oxford	2016	15622/0078
3374	Replenine (BPL)	2015 4 ['] Oxford	2015	15622/0078
4884	Replenine (BPL)	2015 1 Oxford	2015	15622/0078
5196	Replenine (BPL)	2015 3 Oxford	2015	15622/0078
7896	Replenine (BPL)	2015 2.0xford	2015	15622/0078
5533	Replenine (BPL)	2014 4 Oxford	2014	15622/0078
5100	Replenine (BPL)	2014 3 Oxford	2014	15622/0078
2652	Replenine (BPL)	2014 3 Oxford	2014	15622/0078
5128	Replenine (BPL)	2014 2 Oxford	2014	15622/0078
4800	Replenine (BPL)	2014 1/Oxford		15622/0078
5028	Replenine (BPL)	2013 4,Oxford	2013	1562 2/0078
7632	Replenine (BPL)	2013 3 Oxford	2013	15622/0078
5094	Replenine (BPL)	2013 2 Oxford	2013	15622/0078
509	Replenine (BPL)	2013 1 0xford	2013	15622/0078
583	Replenine (BPL)	2012 2 Oxford	2012	1562/2/0078
485	Replenine (BPL)	2012 1,0xford	2012	15622/0078
472	Replenine (BPL)	2012 4 Oxford		15622/0078
519:	Replenine (BPL)	2012 3,0xford		15622/0078
561	Replenine (BPL)	2011 4,0xford	ļ	15622/0078

04 Patient annual treatment record

que ID NHD num	Treatment yr	Quarter num for Yr Haemophilia Ce		The state of the s	Units issue
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)	
1562 2/0078	1996	Oxford	Yes	Replenine (BPL)	
15622/0078	1995	Oxford	Yes	Replenine (BPL)	
15622/0078	1994	Coventry	Yes	FIX (BPL)	
1562 2/0078	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)	
1562:2/0078	1989	Coventry		FIX (BPL)	
15622/0078	1988			FIX (BPL)	
15622/0078	1987		Yes	FIX (BPL)	<u> </u>
15622/0078	1986	<u> </u>		FIX (BPL)	Ì
15622/0078	1985		Yes	FIX (BPL)	
15622/0078	1984		Yes	FIX (BPL)	
15622/0078	1983	: 		FIX (BPL)	<u> </u>
15622/0078	1982			FIX (BPL)	<u> </u>
1562:2/0078	1982	<u> </u>	·	FIX (BPL)	
15622/0078	1981	<u> </u>		FIX (BPL)	1
15622/0078	1980			FIX (BPL)	}
15622/0078	1979	<u> </u>		FIX (BPL)	
15622/0078	1978			FIX (BPL)	

07 Patient HIV data

Unique ID: NHD nu	m Date 0	ode Haemophilia (Centre Sample date R	esult Date Form Completed
1562 2/78	06	Oxford	24/08/1990 -	03/07/1991
1562/2/78	06	Oxford	24/08/1990 -	03/07/1991
1562,2/78	06	Oxford	24/08/1990 -	(03/07/1991

08/07/2019 .

09 Patient vCJD data

NHD num U	inique ID Haemophilia C	entre At Risk 198	0-2001 Patient notifi	ed Assessor	Assessed Date brand_nam	e vial batch no	release date	first dose	st dose t	otal dose
2/0078	1562 Oxford	Yes	Unknown		24/09/2004 REPLENINE					
2/0078	1562 Oxford	Yes	Unknown		24/09/2004 REPLENINE					
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
				The state of the s

Hep C 2018

1562	:	1	2/78	Yes Concen	Yes Compoi	Pos	:	Pos	No	
NHD_ID		Centre No	 NHDNo	Received factor entrates before 1988	sceived blood nents before 1992	CV antibody		HCV PCR	Cirrhosis	Number of

orm 1

M.R.C. Cryoprecipitate Working Party

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

To be completed by Haempohilia 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

Jaundice: Xes/No

Date of Birth: GRO-C

1944.

London GRO-C

Sex: Male

Inhibitor: 200000/00000/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
46.69	Freel Groze Haring	1,500 ml	Twe	(1) Proon Bleen.
5.4-69	<i>O</i> 13	600 ml	700	
6.4.69	Fallow IX Colontall	boomed	~ 7	
3:4:67	Factor IX Concentraje.	(80 mc.	iwenty five	4
9469	y k		4-0	h
10 4.69	It to the		3	
11, 4,69		200 _1.	2	
29. 4-69	Frois Frozer Pissona.	400,1	TWO.	L. Proas Suid.
29/4/69	Factor TX considerate	[313 ml	Three	i- Mors ibleed.
30,4.69	Hactor IX comprate.	300 ml	Two.	1¢
1. 5. 69	Look form Masma.	Cóons	Two.	```
65.69	£	60021	- 14	11 4 11
21.5.69	fe ek. It	600 m.1.	Two	Bleed (cide,
22.5.69	14 14 14	600_i	100.	N a le
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rorm 1

M.R.C. Cryoprecipitate Working Party

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

To be completed by Haempohilia 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. THOMAT HOSPITAL LONDON S.E.I.

Survey Period 1.1.69-31.12.

Full name of patient:

PETER HETMAN, DEREK HAUGHTON

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:

Date	Type of therapeutic material given	Volume of dose material (ml.)	Number of blood donations represented in dose	Reason for Treatment
23.5.49	Fresh Flogen Plana	600~1.	Tais.	Bruid (2) Side.
24/5/64	toest foozer plans	600W	Two	Reed Onde
25/3/69	Fred frozer plane	600 ml	Two	Bleed Dudo.
24.6.69	is to be	600_1	Two.	Breed right elbow.
10969	Fresh fogen planner	-600 ml	Two	Bleed A shoulder
15-10.69	F.F.P. longo depleted	<u> 600 J.</u>	2.	Breed R. knee
######################################				
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www.				

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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 Haempohilia 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' HOTPITAL. London Full name of patient: DEREK HANGHTON	on, S.E.1.	Survey Period 1.1.69-31.12. Follow-up Period 1.3.6930,6. 70.
Address: GRO-C		Jaundice: Yes/No
Date of Birth: GRO-C 44	Sex: Male	Inhibitor: Found/Not Found/Not Tested
Coagulation defect: Christmas disease	Severity: 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
5.3.70	Yactor IX Moncentrate.	2001. ·	? 2	R. 1 Bow.
5.4.76.		6001.	2.	Litigh, foot knee.
5-4-70.	Fresh Lioner Plasma.	boal.	2	24 G 4
9-4-70.	Host Hogen Plasma.	bos.l.	2.	Et 6, 11
7.5.70.	Factor IX dancestrate.	2001.	2.2.	" Small groom bleed - left thork
1.6-70	trest troper Masma.	boal.	2.	h. ksee.
2-6-jo	From Frozen Masma.	300-1-	1	E 11
5.6.10	tacks in Consensate	200.2.	12	Partylactic -
9-6-70	From Hogin Plana	hos.	2	4
126.70	16 54 16	600 ml	Į.	le .
16.6.70	Factor IX Concentrate	200-1.		**
19, 6.70	Those From Plasma	49.4.	2	12
23.6.0	15 62 68	600 A	2	11
16-6-70	AL SE CO	1 200 L	2	**

Form 1

M.R.C. Cryoprecipitate Working Party

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

To be completed by Haempohilia 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 MONAS HOTPITAL.

Survey Period 1.1.69-31.12.

Full name of patient: JEREN HARON TEN.

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:

Date	Type of therapeutic material given	Volume of dose material (ml.)	Number of blood donations represented in dose	Reason for Treatment
30.6-je	From Mora Moora,	626	ź.	Hospiads = -
4.8.70	* // //	Low.	2.	Back R. Land.
5, q. 70	factor IX Consentate	200-1.	?	Back R. Land. LoR. ankles
1.9.20	Hose Hogen Plana.	600-2	<u> </u>	b-ankle
- ' •				

-				

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Survey of Patients Treated at Haemophilia Centres

ANNUAL RETURN FOR 1971

Centre: ST THOMAS ! HOSPITAL

Director: DR. G.I.C. MGRAM.

Name of Patient	Date of Birth	Diagnosis	Inhibitor Present	Jaundiced	Total am	ount of material	received in 1971	(donor units)	Total number	
	•		[Yes/No]*	[Yes/No]**	Plasma	Cryoprecipitate	Concentrates	Others***	doses given in 1971	
									29.50.00	
	A STATE OF THE STA								grant in the same of	
	trajo e de la companya della companya della companya de la companya de la companya della company									
K HAUGHTON	GRO-C 1944	<u>e</u> 2	98 NO	Nο	Park 1970 departments on 1972, 1987 days		-8-28	-	1	

*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 4 Sheets

Survey of Patients Treated at Haemophilia Centres

ANNUAL RETURN FOR 1971

Centre: SHEFFIELD Director: professor E.K. Blackburn Name of Patient Inhibitor Present Jaundiced Date of Birth Diagnosis Total amount of material received in 1971 (donor units) Total number of [Yes/No]* [Yes/No]** doses given in Plasma Cryoprecipitate Others*** Concentrates 1971 GRO-C ∤78 If Yes, please complete and return MRC Cryoprecipitate Working Party Forms 1 and 4 ‡If Yes, "

**Please specify, e.g. Whole Blood

5 Sheets

Sheet No.

Survey of Patients Treated at Haemophilia Centres

ANNUAL RETURN FOR 1972

Director: Paf. Gic. INGRAM. Centre: ST. THOMAS 'HOSPITAL LONDON SEI. Total amount of material received in 1972 (donor units) Inhibitor Present Jaundiced Date of Birth Diagnosis Additional Name of Patient [Yes/No]** [Yes/No]* (with factor Information Concentrates Others*** Cryoprecipitate Plasma VIII/IX %) GRO-C 444 2/78 *If Yes, please complete and return MRC Cryoprecipitate Working Party Form 4 (unless already returned) **If Yes, " " " " " " Form 3 (" " ") Sheet No. 2 of 4 Sheets *** Please specify, e.g. Whole Blood

Centre: ST. THOMAS' HOSPITAL

** If Yes, "

Christmas Disease Patients Treated During the Year 1973

N	ame of Patient	Date of Birth	Basic Factor IX Level %	Inhilitor Present [Yes/No]*	Jaundiced [Yes/No]**	
wate are						
حمار	HAUGHTON	GRO-C '44.	2/78	No	No	
bond bond pages proper Asses	A grant black lands grant solut prod grant grant area from the same than the same of	- 	<u> </u>			
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Form 3

Annual Return for 1974

Centre. CONFNTRY. *. WHRWFAKALFRE.....

Christmas Disease Patients Treated During the Year

Name of Patient	Date of Birth	Basic Factor IX Level %	Inhibitor Present [Yes/No]*	Jaundiced [Yes/No]**
1/78 Hanghton, deres.	GRO-C 44	<1%	1 No	No
				1
		,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,		
we we say day she has the tag and the new ball and she had do had had had no she had be see the she had be see	and the test that had been been the test that the test test that the test test test test test test test			د. در مورد مورد مورد مورد مورد مورد مورد مو
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^{*} 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.

∴tford Hæ		2.1		ENGLS) FGA							in this arconda	nesion of twi	plants or	40.2
	RATERIAL US		100 mm	: .			1	P.F.L.	Banp or Assay	h i	Bonks		200	and the second
	Patre Name	d. o. b.	V K	Diagnosis	Bertich No.	Bostle Nosoi Bostso	Vol. given ml.	Dose u/ml.	Consumptibilities of the Consumption of the Consump	%, AN	Reason fo	r treatment "		Commen
7/10/34	-USATON DOM	GRO- C	6	CHRESTONS I	90454	<u>C.</u> \$.	}	35	o*/a	11%	Manyor T	corr Bus		
7/10/24	tolichou oca	∡ GRO-	<u>u</u> 6.	CHRONIO PARE DE	Po 1454	64		35	of	10%	Maz-Marg 1	COOT Bis		
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Annual Return for 1975.

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* If Yes, please complete and return Form B (2) unless the information requested on Form B(2) has

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

already been sent to Oxford.

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 Haemophilla, 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 Lymohoma 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 haemophiliac 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@ukhcdo.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.

IJKHCDO Executive/NHD Director

email to and from UKHCDO AUG 2019.doc