1	Thursday, 17 June 2021	1	those minutes, and would presumably have received
2	(10.00)	2	those meetings and would have presumably have
3	SIR BRIAN LANGSTAFF: Yes.	3	received copies of the minutes that were circulated
4	PRESENTATION RE LIVERPOOL HAEMOPHILIA CENTRE (continued)	4	subsequent to the meetings.
5	MS RICHARDS: Good morning, sir. I'm going to pick up	5	There are just a handful of additional documents
6	matters with the Royal Liverpool Hospital, the	6	in relation to hepatitis to refer to.
7	Liverpool Haemophilia Centre, and look at the topic of	7	If we start with DHSC0103394_095, please,
8	knowledge of risk and any response to risk or evidence	8	Soumik.
9	of response to risk.	9	This is not directly concerned with
10	In terms of hepatitis, the UKHCDO minutes show	10	post-transfusion hepatitis, but it's "Notes of the
11	that Dr Black was a regular attender on behalf of the	11	Symposium on Hepatitis held by the Association for the
12	Liverpool Centre at meetings in 1971, '74, and '75.	12	Study of Infectious Disease on December 1970".
13	But hepatitis risks were discussed at those meetings.	13	If we go to the bottom of page 4, and we go to
14	Dr Boulton was a regular attender of UKHCDO meetings	14	the bottom of the page, we can see there there's
15	during his time at Liverpool in 1975 to 1980 and	15	a heading "Hepatitis in Dialysis Units", and there is
16	Dr McVerry a regular attender at UKHCDO meetings	16	a presentation by a Dr Finn from Liverpool:
17	during his period as Director, '80 to '85.	17	"Haemodialysis associated hepatitis in
18	- ,	18	
	Dr Mackie, who appears to have taken on the		Liverpool.
19	de facto role of director at that interregnum period	19	"A total of 57 cases were reported during the
20	between Dr McVerry leaving and Dr Hay starting,	20	period 1966-70. 16 patients, 33 staff and 8 relatives
21	attended some UKHCDO meetings '85, '86. Then	21	were involved, no deaths had occurred.
22	Professor Hay was a regular attender in his capacity	22	"The bloods of infected renal failure patients
23	as Director at Liverpool from 1987.	23	tended to remain highly infective over long periods,
24	So it may reasonably be assumed that they would	24	one patient remained antigen positive 4 years after
25	have been aware of the discussions taking place at	25	being infected. 7 antigen positive patients remained
	1		2
1	on home dialysis and were excluded from the unit being	1	perspective, but in Liverpool, in relation to
2	treated in isolation if they had to return to	2	hepatitis in dialysis.
3	hospital.	3	Returning then to direct evidence of
4	"In the speaker's view, it was unethical to	4	SIR BRIAN LANGSTAFF: That must have been hepatitis B
5	expose young nursing staff to a known risk of	5	MS RICHARDS: Yes.
6	infection and if preventative measures could not	6	SIR BRIAN LANGSTAFF: given the reference to antigen
7	reduce this risk to an acceptable level, there was	7	and testing.
8	a case for reducing the extent to which dialysis	8	MS RICHARDS: Yes, it must have been. Yes. And given the
9	should be carried out."	9	date, which is 1970.
10	"He advocated:-	10	Turning then to materials which are relevant to
11	"1. Screening of new patients.	11	bleeding disorder patients directly, if we go to
12	"2. Reduction of transfusion to a minimum and	12	HCDO001093, please, Soumik.
13	using only biologically safe blood ie from a donor	13	We've got the annual return for 1976 here, but
14	whose blood had been used on at leave five occasions	14	if we go to the third page we can see a letter from
15	without causing complications as well as being antigen	15	Dr Boulton to Ms Spooner at Oxford,
16	tested before use;	16	23rd September 1977, sending the annual returns.
17	"3. Reduction in the size of dialysis units;	17	There's a reference in the first paragraph, saying
18	"4. A strict code of practice designed to	18	well, Dr Boulton says this:
19		19	"All I can say is that the final compilation has
20	protect staff. "It was thought that the virus could be	20	not been quite so easy as some of our medical records
21	-	21	
22	non-toxic, liver damage being caused by antigen/antibody reaction. It seem logical therefore	22	have the annoying habit of going missing just when they are wanted."
23	•	23	•
	to give steroids early in the treatment of the		Then he says:
24	disease."	24 25	" this is the best I can offer you at this
25	So an early insight from a different	25	stage. As you will remember from a telephone call
	3		4 (1) Pages 1 - 4

1 some months ago I feel that I am not able to take part 2 in Dr Kirk's jaundice survey, and this is a bit 2 3 3 regrettable as two of our patients have had some form 4 of hepatitis during 1976/77." 4 5 Then he amplifies on the two cases. In relation 5 6 6 to the first, it appears that the hepatitis is 7 attributed to batches or a batch of Kryobulin. And at 7 8 8 the bottom of the page, Dr Boulton says this: period as at 1980, he says: 9 9 "... Mr [X] had the misfortune to contract 10 a very mild form of hepatitis whilst I was out of the 10 11 11 country at the end of last year, and the fact that he 12 had contracted jaundice did not come to my attention 12 until I eventually located his notes about a month 13 13 14 ago. I can only apologise for the extremely bad light 14 15 in which this has put the whole system at the Royal 15 a little. Infirmary." 16 16 MS RICHARDS: It does, yes. 17 17 Then over the page he refers to a second patient 18 18 contracting jaundice, it would seem as a result of 19 treatment with cryoprecipitate, and Dr Boulton says: 19 20 "All the units of [cryo] which were involved 20 21 have been identified, and ... the Transfusion Centre 21 He says also: 22 22 ... notified." 23 So there is an example of information about 23 24 patients infected with hepatitis being provided to 24 25 Oxford. 25 5 1 cryoprecipitate from regional transfusion centres such 1 2 2 as Liverpool." 3 Dr Boulton obviously gave evidence to the 3 4 Penrose Inquiry, and although the focus of much of 4 5 that evidence was his later period in the blood 5 6 services in Scotland, he was asked about his knowledge 6 7 7 of hepatitis in the 1970s and, if we go to 8 8 PRSE0006024, we've got to the transcript of his oral hepatitis in a patient. 9 9 evidence to the Penrose Inquiry. 10 If we go to page 8, please, Soumik. 10 "... I ordered in ..." 11 He was asked if he recalled seeing the World in 11 12 Action documentary, and at line 6 he says: 12 13 "I didn't see the programmes live but I was very 13 "... a small amount of commercial Factor VIII, shortly made aware of those programmes." 14 14 15 15 Then he refers to having a brother on the --16 16 working with Granada on the World in Action team at 17 the time and saying that he remembered being: 17 18 "... slightly cross with him because at that 18 home to me very vividly." 19 time -- and in fact on reflection, I think my brother 19 20 was right -- I felt that the World in Action programme 20 21 had exaggerated the problems. But I was then quite 21 22 22 a young and not very experienced doctor and not quite American -- Factor VIII. 23 23 so aware of how things would work out." 24 But he says then, in relation to the World in 24 25 Action programme, this is line 19: 25 7 8

And there are -- there's another letter the following -- I think two years later, 1979, from Dr Boulton, saying there hadn't been any further cases in '78 or '79 of hepatitis or jaundice. In terms of Dr Boulton's own understanding of hepatitis risks, in the statement he's provided so far to the Inquiry, he has said this -- in relation to the "I was ... aware as any of my colleagues responsible for the care of people with bleeding disorders such as haemophilia ..." SIR BRIAN LANGSTAFF: "As aware", is it? MS RICHARDS: "As aware", yes, sorry. SIR BRIAN LANGSTAFF: Because that alters the sense "... that transfusion of human-derived blood products carries a risk of transmitting viral hepatitis to any recipient although in early 1980 the degree of that risk was uncertain." "It was suspected that blood products obtained commercially carried a greater risk than products produced by the NHS laboratories, which in turn carried a greater risk of transmission by "... I certainly remember it very well and I remember conversations after it ..." He says he wasn't actually yet in Liverpool at the time the programme came out. He was in the middle Then if we go to the next page, bottom half of the page, he then sets out his recollection of This was when he was working in London, Christmas Eve 1973. He says:

This is line 23, bottom of the page:

which was just becoming available at that time, and this mild haemophilic man in his 50s did receive some commercial Factor VIII, as a result of which he got both Hepatitis B and non-A, non-B. So that struck

This is before his move to Liverpool.

"So I had a rather rude awaking into the dangers of hepatitis from commercial -- in this case it was

"So one of the naive reactions that I had in Liverpool was when we bought commercial Factor VIII it was not American, it was European. It came from

(2) Pages 5 - 8

1	Austria. So clearly there had been a concern that	1	Top of the next page:
2	American products were to be avoided. I think that	2	" and it is indeed quite possible that some
3	was a legitimate, or at least an understandable	3	of the plasma they procured and fractionated came from
4	reaction to my experience of treating and giving	4	America. I would not know that but at the time I was
5	a patient and we didn't know at that time exactly	5	clearly under the impression and had been told by
6	the consequences of non-A, non-B. It is very likely,	6	their own director, Norman Berry, that the material
7	if that man is still alive, and I remember him well,	7	was Austrian in origin but clearly from paid donors."
8	he would be in his mid-eighties now. It is quite	8	So that's Dr Boulton's evidence or part of
9	likely that he would have had quite a significant dose	9	Dr Boulton's evidence to the Penrose Inquiry. I'm not
10	of hepatitis and liver disease."	10	going to go through what was discussed at the
11	Then this sets out his understanding	11	UKHCDO meetings he attended, but the presentations
12	SIR BRIAN LANGSTAFF: The next question	12	from Dr Craske, the reports of the Hepatitis Working
13	MS RICHARDS: Yes, it is:	13	Party and so on, which we have looked at in earlier
14	"Where did Immuno get their plasma?"	14	hearings, came up on a regular basis in the second
15	From his understanding, Austria.	15	half of the 1970s, when Dr Boulton was attending these
16	SIR BRIAN LANGSTAFF: And it goes on, the exchange.	16	meetings as the consultant from Liverpool.
17	MS RICHARDS: Yes.	17	In terms of Dr McVerry's understanding of the
18	"So [he says] it was Austrian plasma?	18	risks of hepatitis, his statement says that he did
19	"Yes."	19	not, in the late seventies and early eighties, realise
20	The question is:	20	that non-A, non-B hepatitis could be serious. He was
21	"They didn't import	21	asked about whether patients were informed about the
22	And he says:	22	risks of non-A, non-B hepatitis and he says:
23	"Quite honestly, I did not at that time conduct	23	"Non-A, non-B was something that we did not
24	a detailed enquiry into where all the donors came	24	understand."
25	from"	25	And then his statement is not entirely clear as
	9	20	10
	v		10
1	to what he then means. He says:	1	to mid-1984 that there was no proven association
2	"It was something where I did not think that	2	between HIV and the use of blood products. He says it
3	here was a risk from factor concentrates in relation	3	was reasonably clear that there was a real risk that
4	to non-A, non-B hepatitis."	4	AIDS was transmitted through blood and blood products
5	He sets out a general recollection that it was	5	at the end of '83 or beginning of 1984, but difficult
6	an unknown entity and thought to be of minor	6	to say with any certainty.
7	significance and then says this:	7	He believes he would have read that January 1983
8	"Whilst I can no longer recall what was said, it	8	article by Dr Desforges in the New England article on
9	may have been that I would have avoided causing	9	AIDS because he had worked with her in the States in
10	potential anxiety and so not informed them [by which	10	Boston. He says that the Royal Liverpool did not
11	he means patients] about a condition that I thought	11	change its processes in response to the June '83
12	was benign."	12	letter from Professor Bloom and Dr Rizza with
13	So that's some of the evidence we have in	13	recommendations, but says it broadly followed the
14	relation to Dr Boulton's and Dr McVerry's knowledge of	14	position set out in that letter.
15	hepatitis in that period, 1975 to 1985. I'm not going	15	He's not sure what would have been said and when
16	to repeat anything about Professor Hay's evidence,	16	to patients about the risk of being infected with AIDS
17	which we heard orally last year, and he came on the	17	from factor concentrates due to uncertainties around
18	scene in terms of Liverpool a little later, in	18	the issue. He doesn't recall any reversion to
19	mid-1987.	19	cryoprecipitate as a response to the risk of AIDS. He
20	In terms of the risk of AIDS, HTLV-III,	20	says patients didn't like cryo. There were practical
21	Dr McVerry in his statement says that he had no	21	concerns with its use. But he doesn't set out any
22	awareness of AIDS before he attended the UKHCDO	22	positive contemplation of a return to cryoprecipitate
23	meeting at which it was first discussed, which was	23	or increased use of cryoprecipitate as a response to
24	September of 1982.	24	the risk of AIDS. And then he has a recollection of
25	He refers to Professor Bloom having said even up	25	a move to heat-treated Factor VIII in 1985.
	11		12 (3) Pages 9 - 12
			(-)

1	One other document, although it doesn't involve	1	AIDS"
2	Dr McVerry himself, but again, it does involve	2	So that would suggest
3	clinicians from Liverpool is RLIT0000567.	3	SIR BRIAN LANGSTAFF: He gives reference for that.
4	This is a letter published in The Lancet,	4	MS RICHARDS: He does. The reference is, if we go to the
5	16 April 1983. If we go to the bottom of the page we	5	second page.
6	can see there's a letter headed "Kaposi's sarcoma in	6	SIR BRIAN LANGSTAFF: It is at the foot of the page.
7	patient with multiple myeloma, sideroblastic anaemia,	7	MS RICHARDS: Oh, it is, sorry, no, bottom of the
8	and T-lymphocyte abnormalities."	8	first page. His reference is the MMWR from 1982.
9	If we go over to the second page, please,	9	SIR BRIAN LANGSTAFF: That's probably the July edition, is
10	Soumik.	10	it, or not?
11	We can see, top left-hand, who this is from. So	11	MS RICHARDS: I can't say without checking whether it's
12	it includes Dr Bellingham, and it's from the	12	the July or possibly the December 1982 edition. It
13	Department of Haematology, Immunology and Dermatology,	13	doesn't give a date but we can check. It gives
14	University of Liverpool and Royal Liverpool Hospital	14	a reference and we can check which edition he's
15	and, if we go back to the first page and look at the	15	referring to. But certainly this is, as at
16	bottom right-hand corner, it's describing a particular	16	April 1983, clinicians in the department of
17	patient not concerned actually with someone with	17	haematology in the Royal Liverpool Hospital
18	bleeding disorders but a particular patient presenting	18	recognising that the receipt of multiple blood
19	with, well, possible Kaposi's sarcoma, and the last	19	transfusions was thought to be associated with the
20	eight or so lines on the right-hand side say this:	20	development of AIDS.
21	"As yet we have no evidence of generalised	21	SIR BRIAN LANGSTAFF: Yes.
22	Kaposi sarcoma in this patient", et cetera. Then it	22	MS RICHARDS: You can take that down, thank you.
23	says this:	23	One issue which is of particular significance in
24	"He has received multiple blood transfusions,	24	relation to the Liverpool Centre is the question of
25	also thought to be associated with the development of	25	the arrangements for testing patients for HTLV-III and
	13		14
1	informing them of their diagnosis. You may recall	1	of 20 severe haemophiliacs with factor VIII:C levels
2	Professor Hay giving evidence that when he arrived in	2	below [a certain level]. Sera were collected in
3	1987 in Liverpool, he had a number of concerns about	3	1980-81 in September, 1982, and again in September,
4	the way in which testing and communication of	4	1984. All these patients had received regular
5	diagnoses had been undertaken.	5	prophylactic home therapy with factor VIII
6	If we start with a publication, another	6	concentrate, with an average annual treatment rate of
7	publication in The Lancet, this one co-authored by	7	29,000 units. Between 1982 and 1984 60% (9/15) of
8	Dr McVerry. It is PRSE0001758. This is	8	these haemophiliacs seroconverted for HTLV-III
9	February 1985, 9 February 1985, The Lancet, and the	9	antibody: only 1 was seropositive in 1980-81, 5 had
10	letter is the letter on the top half of the page,	10	antibody in 1982, and 14 were seropositive in 1984.
11	left-hand side, "Seroconversion for HTLV-III since	11	These patients that received both NHS and commercial
12	1980 in British haemophiliacs". It's authored by	12	non-heat-treated factor VIII concentrates, and had
13	Dr Machin and Dr McVerry, amongst others, and says	13	44-80% of their treatment requirements as commercial
14	this:	14	product."
15	" Three UK cases of acquired immunodeficiency	15	If we look at the last paragraph:
16	syndrome in haemophilic patients and several	16	"These results confirm the increasing
17	reports of a pre-AIDS-like syndrome have been	17	seropositivity of British haemophiliacs exposed to
18	recorded."	18	regular infusions of factor VIII concentrate over the
19	Then there's a reference to a number of studies	19	past four years. We do not know what proportion of
20	including one, at least, of which that we've	20	seropositive patients will acquire AIDS or other
21	looked at.	21	HTLV-III related disease. All 16 who are seropositive
22	Then we can see in the next paragraph, it refers	22	are well including the 6 who were seropositive in
23	to:	23	1982, and only 1 has thrombocytopenia and
24	" studies to determine the source of	24	lymphopenia."
25	infection we have been able to test sera from a cohort	25	Now, this clearly involved Liverpool patients.
	15		16 (4) Pages 13 - 16

(4) Pages 13 - 16

1 One of the striking things about this is the date, MS RICHARDS: It is. 2 this is a publication in February 1985. 2 SIR BRIAN LANGSTAFF: -- and it was her study reported in 3 So some testing, some HTLV-III testing, in 3 The Lancet in, I think, September -relation to Liverpool patients had presumably been 4 4 MS RICHARDS: 1984. 5 undertaken in order for this study to be published but 5 SIR BRIAN LANGSTAFF: -- 1984, which reported on a series of tests conducted, presumably Middlesex, I think it 6 the records we have looked at and some of the witness 6 7 evidence we have received, appears to show testing at 7 was, by Tedder, and showed that at least a third were 8 8 Liverpool being undertaken rather later than this. So positive. In fact, that's Middlesex. So somewhere 9 9 we've locked at sample medical records which indicate the cohort that they were talking about had been 10 that it's after Dr McVerry leaves and when Dr Mackie 10 assembled and may have involved McVerry's patients 11 11 and, to some extent, Dr Davies, are dealing with the from somewhere. 12 care of patients with haemophilia, we see HTLV-III 12 MS RICHARDS: It would certainly seem odd for Dr McVerry tests being undertaken, roughly from mid-1985 onwards. to be involved in the co-authorship of this if it 13 13 14 The evidence we have of the communication of the 14 didn't involve Liverpool patients, having been at 15 outcome of HTLV-III tests, again, places it more in 15 Liverpool since 1980. 16 the second half of 1985 and more into 1986 territory. 16 SIR BRIAN LANGSTAFF: It would be wrong to conclude from 17 this that there were Liverpool patients necessarily So it does raise the question as to why, if, as 17 18 at early 1985, Dr McVerry was aware of this, as he 18 involved in this study, wouldn't it? 19 must have been, given his co-authorship of this letter 19 MS RICHARDS: It's a matter of inference or possibility. 20 and his involvement in this study, more urgent steps 20 **SIR BRIAN LANGSTAFF**: It may have been the case? 21 were not being apparently taken to test all the 21 MS RICHARDS: Yes. 22 patients in Liverpool and to inform them appropriately 22 **SIR BRIAN LANGSTAFF**: But the point that you're raising 23 of the results of those tests. 23 this with me for is to show that McVerry had a working 24 SIR BRIAN LANGSTAFF: Well, this letter is co-authored by 24 knowledge at any rate of the likelihood of positive 25 Cheinsong-Popov --25 testing, if it were undertaken, and the second last 17 18 1 sentence stands out to me, "We do not know what 1 "44% of 63 British patients with either 2 2 haemophilia A or B were HTLV-III antibody positive ... proportion of seropositive patients will acquire AIDS 3 or other HTLV-III related disease", which would make 3 HTLV-III was more frequent in high factor VIII concentrate users and 75% of severely affected 4 it impossible for anyone reading this or taking that 4 5 view, with that information, to say to a patient, "Oh, 5 haemophilia A patients were HTLV-III." 6 don't worry, because not very many people go on to get 6 Now, we know that this did include a cohort of 7 7 this disease, they're all well, the likelihood is Liverpool patients because we can see that set out on 8 8 they'll all stay well". the second page, under the heading "Patients and MS RICHARDS: Yes. 9 9 methods", second paragraph: 10 SIR BRIAN LANGSTAFF: Because we may hear evidence to that 10 "A cohort of 21 Liverpool haemophiliacs (19 haemophilia A, two haemophilia B; all but two 11 effect said somewhere else later on today. 11 MS RICHARDS: We may. Obviously, wherever precisely this 12 haemophilia A patients were severely affected) were 12 13 cohort of patients was drawn from, there were --13 studied retrospectively since 1980/81 for HTLV-III clearly there had been samples of sera taken over 14 antibody and in 1984 for T4/T8 subset ratios." 14 15 15 previous years and stored. It also refers to the investigation of the wives 16 16 SIR BRIAN LANGSTAFF: Yes, and for some reason starting in of 14 HTLV-III patients being investigated. If we 17 1980. 17 look at the bottom of the next page, we see again 18 MS RICHARDS: Yes. If we go to a later study, which is 18 reference to a cohort of haemophiliacs attending the 19 RLIT0000127, you'll see this a publication in the 19 Royal Liverpool Hospital Haemophilia Centre, and we 20 British Journal of Haematology in 1986, and Dr McVerry 20 have there the seroconversion or what's suggested to 21 is the first named author on this occasion. Again, we 21 be rough seroconversion dates or dates when patients 22 22 see Dr Machin, Cheinsong-Popov, Dr Tedder, who were were found to be positive, 1980, 1981, 1982 and 1984. 23 23 all named on the earlier letter, and then a range of It may increase the likelihood that the earlier 24 others. We can see it was received June 1985 accepted 24 letter did involve a Liverpool cohort but, on any

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25

for publication October 1985. The summary records:

19

(5) Pages 17 - 20

view, this, which must have been work completed by

1	June 1985, reveals HTLV-III testing and retrospective	1	So that's the evidence we have in summary form
2	testing on a cohort of Liverpool patients and their	2	from Dr McVerry. You'll recall Professor Hay telling
3	partners, yet still there doesn't appear to have been	3	the Inquiry that, when he arrived at the Liverpool
4	a programme of testing of all of the Liverpool	4	centre, he found the records to be poor and
5	patients until after this time.	5	uninformative. He was unable to obtain the results of
6	SIR BRIAN LANGSTAFF: Yes. The likelihood, given what is	6	HTLV-III tests which had apparently been carried out.
7	said here, is that this is the same cohort. The	7	He says he made enquiries with Dr McVerry about
8	numbers broadly correspond.	8	apparent testing on stored samples but didn't get
9	MS RICHARDS: Yes, or that the first was a subset of this	9	an answer to his correspondence. Dr McVerry says he
10	cohort.	10	can't recall receiving such correspondence from
11	SIR BRIAN LANGSTAFF: Yes.	11	Professor Hay.
12	MS RICHARDS: It does, and, given the date ranges that are	12	Professor Hay also told the Inquiry he was told
13	being examined, it does seem likely.	13	by Liverpool patients they'd been told they were
14	Dr McVerry in his statement couldn't recall	14	HTLV-III positive by post. Dr McVerry can't recall
15	stored sera being tested before 1984. He doesn't	15	what the arrangements were, but says he would have
16	recall the process for testing patients for HTLV-III.	16	expected it to be asking the patient to make an
17	He doesn't recall testing in Liverpool outside the	17	appointment and telling them in person.
18	Machin studies and he accepts there was testing in	18	Before we look at some of the material on that
19	relation to the Machin study. He can't recall what	19	particular topic that the Inquiry has received from
20	discussions took place with patients. He can't say	20	patients at the Liverpool Centre, if we could look
21	whether patients knew that samples of their sera were	21	back at Professor Hay's HIV litigation document
22	being stored or understood the purpose of storage. He	22	it's at NHBT0085908, thank you Mr Booker's test and
23	does say that the hospital centre would have obtained	23	the MMWR referred to in that footnote was the
24	verbal permission to obtain the original samples for	24	December 1982 MMWR.
25	tests performed at the time the test was taken.	25	SIR BRIAN LANGSTAFF: December?
	21		22
1	MS RICHARDS: December.	1	can the notes) what pre-test counselling patients had.
2	SIR BRIAN LANGSTAFF: That's the San Francisco baby?	2	The counselling, and in most cases, the first test
3	MS RICHARDS: Yes, exactly and the other cases of	3	result is not documented.
4	transfusion transmitted infection.	4	"Most patients were not adequately counselled
5	If we go to page 18, please. This was, we	5	until Dr Mackie took over the centre in 1986
6	assume, Professor Hay's understanding as at the time	6	"Most untested individuals were summoned by
7	this document was being prepared, so probably around	7	Dr Mackie in 1986 and most seen with their spouses.
8	1989 or so, about the position in Liverpool. If we	8	He counselled them and generally documented the
9	pick it up where it says paragraph 92(bh), it says:	9	counselling. This took place in his room or in OPD."
10	"Both in Liverpool and in Sheffield, samples	10	Yes, I think that's all we probably need to look
11	were sent to Dr Tedder, Middlesex Hospital for HIV	11	at from Professor Hay.
12	testing in early 1985. This was very incomplete in	12	SIR BRIAN LANGSTAFF: Well, the bottom of the page
13	Liverpool and Dr McVerry has left no record of his	13	MS RICHARDS: Yes, very bottom:
14	results even though he published them. Many Liverpool	14	"Parents and guardians were the responsibility
15	patients were not tested until late 1985 early 1986."	15	of Dr John Martin, Alder Hey."
16	Professor Hay's recollection there is consistent	16	About whom we will be hearing more.
17	with what we've seen from individual patient records.	17	In terms, then, of the witness evidence that the
18	He goes on to say:	18	Inquiry has received, and this is really just to give
19	"Some of the patients were informed of their HIV	19	a flavour of it, it's not intended to be an exhaustive
20	status by post. Parents of children were informed by	20	summary, the widow of a haemophilia B patient infected

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Alder Hey in a similar way [and we'll be looking at

Alder Hey later this morning]. Not all patients were

Then bottom of the page he says:

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"I was not in post and can not tell you (neither

informed with results until later in 1986."

24 (6) Pages 21 - 24

with HIV following treatment with Factor IX has

asking for a test. He had the test and she says:

of 1985 stating that he was positive. I remember the

described her husband attending the Centre and himself

"We received a letter in the post in the summer

letter." anything about that'. The consultant basically said 1 2 Her husband read it to her and passed it to her. 2 words to the effect of 'Yes, you have this'." 3 3 She recalls it was a short letter of no more than two Another patient gives an account of being told 4 or three sentences. She says, unsurprisingly, her 4 in person that they were positive. The evidence about 5 husband should have been told in person: 5 that patient suggests that that was later, that was 6 6 "... and we weren't given any information to 1987, might possibly have been told by Dr Hay. 7 help us to understand or manage the infection." 7 Then I think it may be worth actually looking at 8 8 The widow of a haemophilia A patient describes a further account, which is at -- and I should say we 9 9 her husband being told during a routine appointment don't yet have -- in relation to a number of these that a stored sample of blood had tested positive for 10 accounts, we don't have responses yet from Dr McVerry. 10 HIV, despite the patient not knowing that his blood 11 11 Some of these do not necessarily involve Dr McVerry, 12 would be stored or tested, and says: 12 they are talking about the later stage of HIV testing, 13 "We were told by the doctor not to worry about 13 which took place after he'd left, because not all 14 anything, the hospital would look after us." 14 patients had been tested while he was still there. 15 The widow of another haemophilia A patient 15 Some of the accounts do involve Dr McVerry. The one 16 describes, again, her husband receiving the 16 I'm going to refer to next does. We haven't yet had 17 information that he had HIV during a routine 17 a response from him, not I think through any fault of appointment, her account is this, perhaps worth just 18 18 his own, so it may be he would have a different 19 reading out: 19 account to give. 20 "This consultant was flicking through my 20 But if we go to WITN1403001, please. This is 21 husband's medical records and came to a page which was 21 a statement from a widow who it describes her 22 marked with the words 'HIV'. The consultant just said 22 husband's care at the Royal Liverpool Hospital. If we 23 the words HIV in a very matter of fact way and then 23 go to the second page, we can pick it up, paragraph 9, 24 continued to flick through the notes. My husband 24 she says: 25 stopped and said 'HIV, what is that? I did not know 25 "[He] was not to my knowledge given any 25 26 1 information relating to the risks associated with the 1 form of targeted treatment. 2 use of Factor VIII or any associated risks of 2 "The junior doctor confirmed that he believed 3 infections, and neither was I. 3 [her husband] was suffering with AIDS ... this was 4 "Whilst I have no specific dates or treatment 4 never confirmed by [Dr] McVerry who was the consultant 5 batch information relating to [his] infection with 5 overseeing [his] care at the time. Dr McVerry simply 6 HIV, it is clear [he] first, displayed clear 6 dismissed my concerns. 7 7 indications of a suppressed immune system and a rapid "I had blood taken twice to be tested. I was 8 8 decline in his health from 1984 onwards." never informed this was due to any risk of HIV but was 9 9 It refers to him undergoing surgery at the Royal told this was to test for Salmonella. I recall asking 10 Liverpool in 1984, after which his health started to 10 why our daughters were not being tested as we all ate 11 deteriorate rapidly. They were told he had contracted 11 the same food at home, but I was reassured this wasn't 12 a virus they suspected to be Salmonella and she was 12 necessary as it was me who was in closest contact with 13 made to wear protective clothing when visiting him. 13 Next page, and I should say it's not clear 14 14 If we go down the page: whether the dates can be right, or entirely right, 15 "The only information I was getting was from the 15 because they refer to Dr McVerry and Dr McVerry had 16 16 media coverage. I read about symptoms of HIV/AIDS in 17 left by this time. So either it's a different doctor 17 the news and I thought they were very similar to the 18 or the dates may not be entirely right. But whatever 18 symptoms [he] was suffering from. 19 it is, the thrust of the account is a remarkable one: 19 "When I raised my concerns with Dr McVerry that 20 "The first discussion that we had with a doctor 20 [he] was suffering from the symptoms of AIDS, he 21 regarding the possibility of HIV infection was with 21 advised me that [my husband's] symptoms could be 22 22 a junior doctor at the Liverpool Royal Hospital in explained by numerous viruses or infections. He 23 23 October 1985. This was long after I had suspected denied it was AIDS and told me not to be neurotic. In 24 [he] had been infected and I had repeatedly asked 24 one such meeting with Dr McVerry, when I was

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frantically explaining how concerned I was for my

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medical professionals to test ... and offer him some

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(7) Pages 25 - 28

husband's health, he was swinging around in a swivel chair whilst eating a KitKat. This shows the kind of treatment I received from Dr McVerry.

"Without confirmation of infection from the staff treating [my husband], I sought desperate measures for a firm diagnosis and treatment options."

She then describes in October 1985 travelling to Saint Mary's Hospital in an attempt to speak to Professor Pinching.

He was unavailable, she says, but staff at the hospital facilitated a telephone conversation during which Professor Pinching agreed that her husband's symptoms and history were likely to be associated with HIV and he agreed he would discuss her husband's case with Dr McVerry.

Then if we look at paragraph 21:

"After my consultation with Professor Pinching, Dr McVerry told me not to question his standing or undermine his opinions, as he was my husband's treating consultant; the clear implication was that he knew best."

Then she refers in paragraph 23 to her husband's records showing his sample bags sent for testing were labelled as "high risk", and we do have some documents, not I think relating to this individual

in the first half of the 1980s.

I should just say there's a document at HSOC0011245. This is a letter sent from the same widow. It looks as though it was sent to The Haemophilia Society. It's a Haemophilia Society originated document, in any event. We don't have a date for it but you will see she gives, essentially, the same or very similar account to the account that is set out in the witness statement that she has kindly provided to the Inquiry, and refers to the fact that she was tested. If we go towards the bottom of the page, we see it refers to her speaking to Dr Pinching. As I say, we don't have, I think, a date for that, but it is clearly an account given -- an earlier account given of the same sequence of events.

Just again, to give an indication about dates of testing more generally in Liverpool, if we go to -- actually, I'm going to come to that later. There's a handful of documents and medical records, sample medical records that we've looked at which confirm a testing process being undertaken for other patients, as I say, in the second half of 1985 or later.

Then in terms of the communication of results in the period after Dr McVerry had left, if we look at

patient but we've got some documents we've looked at from Liverpool which have that "high risk" label:

"They also show he was first tested for HTLV III in January 1985. There were also tests sent in June 1985 to the hospital for tropical diseases in London where he was tested for pneumocystis ... Neither of us was warned that [he] may be suffering from HIV or any potentially infectious disease."

Her husband died, as you will see, not long after that.

Leaving aside the issue about dates, and the fact that we know Dr McVerry had left some time in the course of 1985, I don't think we know the precise date, however. The account that's given there is not inconsistent with her husband having been one of that cohort of patients.

17 SIR BRIAN LANGSTAFF: One thing which I just want to be
18 clear about this witness statement, does it identify
19 her husband as having suffered haemophilia, or was
20 there some other reason that he had the surgery?

21 MS RICHARDS: Severe haemophilia A.22 SIR BRIAN LANGSTAFF: Thank you.

**MS RICHARDS**: Sorry, I didn't go to that passage, but yes, and received most of his care from the Royal Liverpool

25 Hospital, received intensive Factor VIII concentrates

WITN3381002. Sorry, actually, can we not put that up. I'm going to read out the letter. I'm not sure whether the name should have been redacted and hasn't been. I have an identical letter with a redacted

Yes. If we put up this version, Soumik. Yes, it's the same letter but with the full redactions. LBHT0000001 009.

We can see it's a later dated 1 July 1986, it's from Dr Davies, consultant haematologist. Again, it's in this interregnum period after Dr McVerry leaves and before Dr Hay takes over:

"We now have your final HTLV 3 results from Manchester and unfortunately they are positive. They do add the rider that we should repeat this test when next we see you but I think you should now assume that you are HLTV positive and take the precautions which we discussed the last time we met. I am sorry this is not good news, if you do want to discuss this further then of course I will see you in the department any time."

Now, it's a letter that suggests there had been some prior discussion that testing was going to be undertaken but you'll see the communication of the result is undertaken by post in this short fashion,

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1 and not in person. 30, had received treatment with Factor 8 blood 2 There are others, as we've seen, who have been 2 [concentrate] through the Royal Liverpool Hospital." 3 3 So we don't know who that relates to but you'll described being informed of their results by letter 4 and that was clearly Dr Hay's understanding, 4 see it being documented there. 5 Professor Hay's understanding when he took over. 5 There's then another account from a patient 6 6 at -- I'm just going to read a handful of the relevant There's another witness, who recalls being 7 phoned at work, although in their case the result was 7 passages. 8 negative. But that witness also describes a period of 8 Sir, this is a patient who is deaf, with severe 9 9 testing, that it goes on through 1986. So, again, it haemophilia A, treated both at Alder Hey as a child suggests that the process of testing all patients or 10 and would then, in the first half of the 1980s, see 10 Dr McVerry at the Royal Liverpool Hospital. 11 all patients who were -- might have been infected at 11 12 the Liverpool hospital was taking place really over 12 Soumik, could we go to page 12 of WITN0375001, a rather prolonged period of time and much later than 13 we pick it up at the bottom of the page: 13 14 you might think it should have been. 14 "In 1981, when I was 20, I used to see Dr McVerry at the Royal Liverpool Hospital. Every six 15 If we go to HSOC0015592, please, and if we go to 15 16 the second page and we just zoom in on the heading 16 months, Dr McVerry, my foster father and I would be in "Wife infected in test delay": 17 a consultation. Dr McVerry would talk to my foster 17 "A haemophiliac who was found in hospital tests 18 father, who would ask me to leave the room. A nurse 18 19 to be infected with the Aids virus was not told of the 19 would take me by the hand and place me in another 20 result for several months. He has now passed on the 20 room. I was always sent out. I wanted to stay. It 21 infection to his wife ... 21 seemed to me that Dr McVerry told my foster rather 22 "The couple, who come from Merseyside and have 22 that I had to leave. He kept the nature of my illness 23 a young daughter, are furious that the wife's life was 23 between him and my foster father. 24 put needlessly at risk ... 24 "After these appointments, I spoke to my father 25 "Their solicitor said that the husband, who is 25 in the hospital café. I asked him what he was talking 33 34 1 to Dr McVerry about when I was not in the room. He 1 if one accepts the account. The first is that an 2 2 would not say. He always said it was about my leg and adult was not told and, secondly, that he plainly, 3 about my foot. He would not tell me any detail, 3 according to his account, questioned his foster father 4 although I would always ask him." 4 several times but never spoke, never asked McVerry. 5 Then in paragraph 54: 5 So presumably he felt that he couldn't or shouldn't 6 "In 1985, my Dad went into hospital so he could 6 ask the person who would give him the information. 7 7 no longer attend my appointments." MS RICHARDS: Yes. It's part of a much longer statement, 8 Then he refers to going to appointments with his 8 sir, which merits reading in full, but it does appear 9 9 foster sister: to show a very concerning delay in this young man, as 10 "Dr McVerry would talk to whichever foster 10 he then was, being informed of -sister attended with me, but not for long. I would 11 11 SIR BRIAN LANGSTAFF: It's not simply the delay; it's the 12 have blood tests and go home. [They] would never tell 12 quality of the communication which he expected --13 me what Dr McVerry said." 13 MS RICHARDS: Yes. He describes at the bottom of that page how he SIR BRIAN LANGSTAFF: -- from the medical profession as he 14 14 only learnt he had HIV in October 1991 -- so a number 15 15 had experienced it. 16 of years after, when he was told by Dr Hay. He 16 MS RICHARDS: Yes. We can take that down, thank you, 17 recounts Dr Hay having looked through the medical 17 Soumik. 18 records and found out the witness's foster family knew 18 In terms of the numbers of patients infected, 19 he had HIV and the records indicating that Dr McVerry 19 Dr Hay's information, as provided to the Inquiry, was 20 had told the foster father but the patient himself, 20 43 patients at the Royal Liverpool Hospital infected 21 although an adult, had not been told. 21 with HIV, of whom four were under the age of 18. The SIR BRIAN LANGSTAFF: At the time he describes the 22 22 evidence we have suggests that the transfer from Alder 23 23 conversations taking place, he says he was 20. Hey to the Royal Liverpool took place at around 16. 24 MS RICHARDS: Yes. He was an adult. 24 The table that we've more recently received SIR BRIAN LANGSTAFF: So there are two concerning aspects, 25 from -- sorry, the table that the Inquiry team has put

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(9) Pages 33 - 36

1	together based upon data received from UKHCDO gives	1	It says:
2	a figure for the Royal Infirmary of 42. Whether it's	2	"He is now completely recovered and his liver
3	42 or 43, it's clearly a significant number of	3	function tests are essentially normal."
4	patients infected with HIV.	4	If we then look at the same reference, Soumik,
5	Just in terms then of process of testing for	5	but 006.
6	hepatitis C, if we consider, first, the undertaking of	6	It's just interesting to note that the letter
7	liver function tests prior to the availability of	7	from Dr McVerry to the patient on the same date uses
8	a hepatitis C test, Dr McVerry couldn't recall how	8	the term "inflammation on your liver", doesn't use the
9	regularly liver function tests were performed but he	9	term "hepatitis".
10	knew they did. He says:	10	If we then in relation to the process for
11	"If a patient came in for a review then a liver	11	testing for hepatitis C, once a hepatitis C test
12	function test would be done as one of a range of tests	12	became available, Professor Hay addressed that in his
13	that were carried out at the patient review."	13	oral evidence and written evidence so I wouldn't go
14	He can't recall what was said to patients about	14	back over that, other than to remind you, sir,
15	the results. He says:	15	although I know you're well aware of this, that there
16	"We were unsure what caused these abnormal	16	are a number of patient accounts at Liverpool as at
17	results."	17	elsewhere of there being delays between patients being
18	There are a couple of letters that I think it's	18	tested for hepatitis C and being informed of the
19	instructive to look at, in that regard.	19	outcome of those test results.
20	Soumik, can we look at LBHT0000001_005, please.	20	We've referred in our written note to a number
21	This is a letter from Dr McVerry, 17 January 1983, to	21	of accounts in that regard.
22	a GP about a particular patient.	22	If I then come to the question of the treatment
23	"As you know, [the patient] had an episode of	23	arrangements, first of all, for HIV. Dr McVerry
24	acute hepatitis, which most likely was related to his	24	recalls little about treatment for HIV positive
25	factor infusions."	25	patients, but there are some accounts from individual
20	37	20	38
	31		30
1	witnesses which paint a distressing picture of HIV	1	infection with HIV and hepatitis C. And if we just
1 2	witnesses which paint a distressing picture of HIV care at the Royal Liverpool Hospital	1 2	infection with HIV and hepatitis C. And if we just
2	care at the Royal Liverpool Hospital.	2	pick this up at page 7, paragraph 31, the witness says
2 3	care at the Royal Liverpool Hospital.  If we look at I'll just check the reference	2	pick this up at page 7, paragraph 31, the witness says that:
2 3 4	care at the Royal Liverpool Hospital.  If we look at I'll just check the reference there. WITN2783001.	2 3 4	pick this up at page 7, paragraph 31, the witness says that:  "[His son] had numerous hospital admissions in
2 3 4 5	care at the Royal Liverpool Hospital.  If we look at I'll just check the reference there. WITN2783001.  This is a statement from the widow of a patient	2 3 4 5	pick this up at page 7, paragraph 31, the witness says that:  "[His son] had numerous hospital admissions in The Royal Liverpool Hospital where he was treated very
2 3 4 5 6	care at the Royal Liverpool Hospital.  If we look at I'll just check the reference there. WITN2783001.  This is a statement from the widow of a patient with haemophilia A. If we go to page 4 again, it	2 3 4 5 6	pick this up at page 7, paragraph 31, the witness says that:  "[His son] had numerous hospital admissions in The Royal Liverpool Hospital where he was treated very badly and received extremely poor standards of care.
2 3 4 5 6 7	care at the Royal Liverpool Hospital.  If we look at I'll just check the reference there. WITN2783001.  This is a statement from the widow of a patient with haemophilia A. If we go to page 4 again, it may, of course, be the case that Dr McVerry would say	2 3 4 5 6 7	pick this up at page 7, paragraph 31, the witness says that:  "[His son] had numerous hospital admissions in The Royal Liverpool Hospital where he was treated very badly and received extremely poor standards of care. It was horrendous. It was as if the nurses had
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1 he became ill and died. PRESENTATION RE ALDER HEY CHILDREN'S HOSPITAL 2 So if we just go back to WITN1403001, and we go 2 3 to page 5. Paragraph 27. She recalls: 3 MS RICHARDS: Alder Hey. Oh, I'll deal with Walton very 4 4 briefly after I've dealt with Alder Hey, because "[Her husband] was treated terribly whilst he 5 was in the Royal Liverpool Hospital receiving 5 there's comparatively little information. I'm just 6 treatment. It was largely left to me to change his 6 going to move files round. 7 clothing and bedding as the nurses appeared to not 7 So the Alder Hey Children's Hospital was the 8 8 want to go in his room. On occasions when I was not principal treatment site for treatment of children 9 9 present, food and drink was left on a trolley outside with bleeding disorders, at least from the late 1970s 10 of his room and [he] was left unchanged lying in 10 onwards probably earlier. From the mid-1970s until a dirty bed in his own faeces and body fluids with 11 11 1989 the Centre Director was Dr John Martin, and we 12 blood all over the floor." 12 have a letter, I won't display it, but August 1975 13 13 Dr Martin writes that he has now taken over care of Again, Dr Hay, Professor Hay told the Inquiry in 14 his oral evidence and written evidence a little about 14 haemophiliacs at this hospital. the arrangements for treating HIV and HCV positive 15 15 Dr Martin, however, appears to have been 16 patients in his time as director at the Royal 16 essentially a paediatrician or paediatric oncologist 17 Liverpool Hospital, so in that period from 1987 17 rather than a haematologist, and he is generally through to the early 1990s, and we've summarised it. 18 18 described or referred to as such in communications. 19 But as the Inquiry has heard that evidence orally, I'm 19 We do have a recent statement in response to 20 not proposing to go through it again. 20 various criticisms which I'll describe over the next 21 So that, sir, is the Royal Liverpool Hospital 21 period of time of Alder Hey. We have a statement from 22 and the Liverpool Royal Haemophilia Centre for adults. 22 the current Director of Corporate Affairs at Alder Hey 23 I'm going to turn now to Alder Hey, the 23 who has said that Dr Martin established one of the 24 Children's Hospital. 24 early childhood cancer centres at Alder Hey but was SIR BRIAN LANGSTAFF: You're going to go to Walton, are 25 not a specifically trained paediatric haematologist. 25 41 42 1 Dr Martin ceased holding that position in 1989, 1 would then organise the provision of the concentrates 2 2 Dr Lynne Ball took over as the Centre's director for or other products to Alder Hey. 3 about fourteen years, 1980 to 1993, and I'm going to 3 There's then an article -- again, I'm not 4 refer to her statement at various stages. 4 proposing to put it on screen, but there's an article 5 And then Dr Paula Bolton-Maggs, who had 5 from 1990 in The Haemophilia Society Bulletin from 6 previously, I think, spent a period of time, 6 Professor Hay, in which he says that haemophilia care 7 7 a relatively short period of time in a more junior in Liverpool was traditionally divided between Alder 8 8 capacity there, took over as director from 1993 to Hey and the Royal Liverpool, with patients graduating 9 9 2003, and she has also provided a statement to the from one to the other in their mid-teens. 10 Inquiry. 10 I referred yesterday, when we started looking at 11 The evidence suggests that children, certainly 11 the Liverpool Centre, to the relationship with North 12 younger children, those under the age of being 12 Wales, and that was also the position in relation to 13 a mid-teen, were the responsibility of Alder Hey 13 children and Alder Hey. So Dr David Edwards, again rather than the Centre at the Royal Liverpool who I referred to yesterday, consultant haematologist 14 14 Hospital. That reflects both the evidence of 15 at Glan Clwyd Hospital from 1982 to 2006, has 15 16 16 Dr Boulton and the evidence of Dr McVerry. And it's explained in his statement to the Inquiry that 17 consistent with the evidence that we've seen, which 17 paediatric cases were essentially managed by 18 suggests that treatment decisions were the 18 paediatricians with outreach consultants from Alder 19 responsibility of Dr Martin. 19 Hey Hospital in Liverpool. 20 In terms of the mechanics for supplying 20 There is some evidence of cryoprecipitate being 21 products, Dr Ball's understanding is that products 21 provided directly from the Regional Transfusion 22 22 were ordered and supplied via the adult Haemophilia Centre, the Mersey Regional Transfusion Centre, to 23 23 Centre. So it received concentrates -- her Alder Hey. 24 understanding is by the -- telephoning the on-call 24 Then there is some evidence to suggest that, 25 haematologist at the Royal Liverpool Hospital, who 25 just as with the Liverpool Centre at the Royal

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Liverpool Hospital, the children's centre, the Alder Hey Centre, formed part of two regional groups: the Manchester supra-region and then a regional group of Mersey and North Wales haematologists. But it doesn't appear that Dr Martin played a significant part, or participated significantly in either of those groups, so we don't see, for example, in some of the meetings at the Manchester supra-region, we don't see Dr Martin attending, although it's right to say we don't have a full set of minutes in that regard. We do see Dr Martin attending at one meeting of the regional group, Mersey and North Wales haematologists, in November 1983.

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Dr Bolton-Maggs's recollection as a senior registrar between '87 and '88 at Alder Hey was that there was no consultant haematologist, hence the care was undertaken by Dr Martin, and no specific facilities for patients with bleeding disorders. She says:

"Patients would have been seen for acute bleeding problems on the oncology ward and followed in general haematology outpatients."

And she says her understanding was that: "Haemophilia child patients would have been under the care of Dr John Martin, consultant

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cell counter was out of date and on loan from Coulter and there was no onsite facility for monitoring anything other than basic coagulation screening. Pre-operative and therapeutic monitoring of Factor 8/9 levels had to be transported to the Royal Liverpool Hospital (a thirty-minute transport time) for analysis and any suspected inhibitors similarly analysed off site. Laboratory staff had no protective area to prepare contaminated samples prior to analysis and there were no facilities to monitor immunological parameters for affected children."

Then if we go over the page, I'm going to come back to what she says about the position of the HIV infected children at a later stage.

Third paragraph:

"There was no established treatment centre, no specialist nurse or social worker provision, no outpatient clinics, no immunological monitoring or screening and the majority of children had not received routine vaccination against Hepatitis B and there was a paucity of successful home treatment and self-administration programmes. This meant that for acute minor bleeds boys accessed the haematology-oncology ward (C3) and were treated with concentrate ordered and supplied ad hoc from the Royal oncologist, and additionally managed by rotating senior registrars in haematology, with advice as required from haematology consultants at the Royal Liverpool Hospital."

When Dr Ball took up her post as director in January 1989, she set out in her statement the critical observations of the position. If we just look at part of her statement, WITN4739001, and we go to page 13, she says:

"I started mid-January [1989] as Dr Martin took vacation commencing the first day of my tenure. I was not provided with any overview or patient summaries but was nonetheless required to take on all acute clinical inpatient and outpatient care for the whole unit as well as all diagnostic responsibility for the haematology laboratory including the on-call commitment single handed until his return to duties.

"In stark contrast to my experience at [Great Ormond Street] [where Dr Ball had previously worked] the provision of clinical and laboratory services offered to children with haemophilia especially those with HIV at the time of my appointment was severely compromised.

"There had been no investment in laboratory facilities or equipment for a decade. The automated

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Liverpool Hospital. As there was no batch reservation to reduce donor exposure it was difficult to determine what the individual usage per child had been prior to my appointment. A large proportion of the clinical notes of children affected by HIV were on close inspection missing essential treatment and decision-making details. As far as I could ascertain there were no protocols for the use of alternatives such as cryoprecipitate or DDAVP."

Then the next page -- sorry, I should say she wrote an extensive case for the need for a second consultant, which she submitted to the newly-appointed medical director of the hospital, who was, in fact, Dr John Martin. Then she describes, on the advice of Dr Hay, who had taken over at the adult Centre more recently, she was able to access a regional fund to provide some additional funding for the provision of care at the Children's Hospital and to make out a case for a nurse social worker, and to develop the services and build up clinics.

SIR BRIAN LANGSTAFF: The description she gives amounts to there being no expert doctor, no expert nurse, so nobody in the clinical staff who actually has any developed expertise in what they're doing.

MS RICHARDS: Yes. Alder Hey were invited to respond to

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1 Dr Ball's statement, and it's right to now note that partly precipitated by the need to care for a cohort 2 they have done so. I have referred, I think, earlier 2 of boys infected with HIV." 3 3 to Erica Saunders, Director of Corporate Affairs at I'll come back to that issue, that's about how 4 Alder Hey Children's Hospital, having responded, and 4 the children infected with HIV were actually treated 5 perhaps if we look at WITN4194006, if we go to the 5 at Alder Hey, about which Dr Ball has a lot to say, 6 6 third page, she says this at paragraph 9: and to which Ms Saunders has responded. 7 "Dr John Martin had established one of the early 7 Sir, I'll come back to that and I'll come back 8 8 childhood cancer centres at Alder Hey. Due to the to Ms Saunders' response, and indeed the apology she 9 9 lack of specifically trained paediatric offers, when we get to that stage in relation to haematologists, much of the care of children with 10 Alder Hey. 10 11 non-malignant haematological conditions defaulted to 11 I'm going to pick matters up with the annual 12 clinicians running the malignant service and was 12 returns from Alder Hey from 1977 onwards, so it might provided on the Oncology Ward. Very sadly, the 13 13 be a good moment to take a break. 14 information I have received is that this led to 14 SIR BRIAN LANGSTAFF: Yes. Yes. Thank you. 15 children with bleeding disorders being exposed to 15 MS RICHARDS: What time do you wish to return, sir? 16 inappropriate treatment and delays in adopting 16 SIR BRIAN LANGSTAFF: Sorry, yes, of course. I was just 17 improvements to their management." 17 thinking about this -- this last piece of evidence. 18 18 She then says: It's 25 to. 19 "The appointment of [and she's referring there 19 MS RICHARDS: Certainly. 20 to Dr Ball] was in recognition of the developing 20 SIR BRIAN LANGSTAFF: Twenty-five to 12. 21 speciality of Paediatric Haematology but there was a 21 (11.16 am) 22 22 lack of additional support for the non-malignant (A short break) 23 clinical elements and the laboratory service. The 23 (11.35 am) 24 separation of clinical care of patients with inherited 24 MS RICHARDS: Sir, I'm going to look at the annual returns bleeding disorders with the Oncology service was 25 25 for Alder Hey starting in 1977. HCDO0001177. 49 50 concentrate and then there's reference to a smaller 1 We can see there reference to cryoprecipitate, 1 2 643 packs. And then in relation to NHS concentrate 2 amount of the Armour product, Factorate, being used, 3 and commercial concentrates, it's said. 3 although I think there's -- no patients with "All supplied by Dr FE Boulton Liverpool Royal 4 4 von Willebrand's appear to have been treated during 5 Infirmary." 5 that year and I don't think we have details in 6 Then if we look to the comment, it's not 6 relation to haemophilia B patients either. 7 7 entirely clear what it says, but it's "[Something] 1979 is HCDO0001343. We can see 13 haemophilic 8 8 cryoprecipitate provided directly by" -patients treated during that year, no haemophilia B 9 SIR BRIAN LANGSTAFF: "Only cryoprecipitate"? 9 patients treated. And then we can see, again, the 10 MS RICHARDS: Yes. 10 volumes of cryoprecipitate: so 27,790 cryoprecipitate, "... by ..." what appears to be 37,500 units of NHS factor 11 11 12 And then I'm not entirely sure what the last two 12 concentrate, and then 14,000 units of the Armour 13 letters are supposed to say. But may be a reference 13 Factorate, used that year. to the Transfusion Centre. 14 1980 is HCDO0001439. I think we see 16 patients 14 "All other preparations supplied via Liverpool 15 with haemophilia A treated, no von Willebrand's and 15 Royal Infirmary." 16 16 then we only have the packs or bottles rather than the 17 So we don't have information directly from Alder 17 units. So it's down as 114 packs of cryoprecipitate, 18 Hey about the volume and type of products used. 18 136 bottles of NHS concentrate, and 268 bottles of 19 If we go, however, to the next year, we can see 19 Armour Factorate. So we can see, in any event, the 20 the returns in a more standard form so HCDO0001274. 20 proportion of Armour being used increasing. 21 We can see ten patients treated during the year. In 21 Then if we move to 1981, HCDO0001541. We're 22 22 terms of cryoprecipitate, 48,930 -- I'm not sure told 12 haemophilia A patients, no von Willebrand's. 23 23 whether that's 20 or 30 units. But anyway, somewhere Again, we've got the information in terms of packs and 24 under 49,000 units of cryoprecipitate. And then it 24 bottles. So a greatly reduced volume of 25 looks like just over 46,000 units of NHS factor 25 cryoprecipitate, four packs, an increased volume of

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1	NHS concentrate, 386 bottles. And a smaller volume of	1	like it's identified as being 54,500 units. And then
2	the Armour Factorate, 29 bottles.	2	the largest volume of treatment being with
3	Then handwritten across appears to be "NB All	3	Armour Factorate: 749 bottles, given as 187,250 units.
4	HT", which presumably	4	It's not then easy to see what's written across,
5	SIR BRIAN LANGSTAFF: Home treatment.	5	except it looks like something to similar effect as
6	MS RICHARDS: is home treatment, "supplied by [Royal	6	previously about the supplies for home treatment
7	Liverpool Hospital] mil, from Alder Hey". So the	7	coming from the Royal Liverpool.
8	annual returns may not be giving a clear or	8	Then 1984, is HCDO0001831. 14 haemophilia A
9	comprehensive reflection of what products were	9	patients treated. No cryoprecipitate usage recorded
10	actually used to treat the Alder Hey patients.	10	at all. NHS concentrate, 339 bottles used in
11	If we go to 1982, HCDO0001639, we see 19	11	hospital. You'll see home treatment again is said to
12	patients with haemophilia A treated, no	12	be supplied from the Royal Liverpool Hospital and then
13	von Willebrand's. Then we've got the figures in packs	13	hospital treatment with Armour Factorate, 352 bottles.
14	and bottles but with what appears to be units written	14	So the proportions are more evenly balanced in terms
15	in. So 16 packs of cryo, 1,120 units. 155 bottles of	15	of home treatment there as between NHS and commercia
16	NHS concentrate, 38,750 units. And then this year by	16	concentrate.
17	far and away the largest in terms of treatment is the	17	Then we don't have a return for 1985.
18	Armour Factorate, 647 bottles, 161,750 units. So	18	If we look briefly at 1986, HCDO0002021. We can
19	a marked change in the pattern of treatment in 1982.	19	see 19 haemophilia A patients, two von Willebrand's
20	And we see over the page, one haemophilia B patient	20	patients treated. Again, we see no cryo. The figures
21	treated that year with NHS factor concentrate.	21	in hospital show use of NHS concentrate and Armour.
22	1983's return is at HCDO0001739. Again, it's	22	Presumably, in 1986, a heat-treated product.
23	a similar pattern. It's not, again, entirely easy to	23	We can see there's a reference "Other Human
24	read. Eleven packs of cryo, so cryo in very modest	24	Factor VIII [Concentrate], 9,000 units", and someone
25	use indeed. NHS concentrate, 218 bottles, which looks	25	has written "? which" and "Type not specified" and
	53		54
	•		•
1	then a small amount of concentrate for home treatment.	1 1	WS RICHARDS: We haven't, I'm afraid.
2	And we see DDAVP being used for von Willebrand's	2	There are then two documents I want to refer to
3	patients.	3	which are expert reports in relation to an individual
4	There are also some stock cards, which may	4	patient but which throw some light, potentially, upon
5	reflect usage of Alder Hey. So we looked at a sample	5	the approach to treatment at Alder Hey. The first is
6	yesterday of those in relation to the Liverpool	6	at DHSC0043164_068.
7	Centre.	7	This is a medical report, it's date March 1992,
8	If we go, for example, to LUHT0000024, we can	8	and it's from Dr Savidge, St Thomas' Hospital, and it
9	see that this is the Royal Liverpool Hospital's stock	9	is looking at an individual patient treated at
10	cards, but there's reference, if we go down the page,	10	Alder Hey. If we go a little further down the page,
11	to Alder Hey. So we can see there a supply, for	11	we'll see it was a patient with severe haemophilia A,
12	example, of the Elstree, the NHS product, to Alder Hey	12	diagnosed as such as a baby. Just so that you note,
13	as well as to Dr Korn, Bangor.	13	it is someone born in 1980. The significance from
14	Again, there are a handful of other stock cards,	14	that appears from the second paragraph on screen:
15	so if we go just by way of example, LUHT0000031, we	15	"The young boy was first treated on
	can see there the first entry for Armour. It records	16	01.03.82"
16 17	products being sent to Alder Hey, as well, again, as	17	So aged two.
	to Dr Korn at Bangor and the like.	18	-
18	That's the information	19	" with US commercial factor VIII concentrates. There is no documentation at that time
19			
20	SIR BRIAN LANGSTAFF: When it provides for both home	20	to indicate that the treatment alternatives with
21	therapy and Alder Hey, it doesn't say how many of the	21	single donor pool cryoprecipitate or NHS Factor VIII
22	home therapy treatments might have been Alder Hey	22	concentrates were ever entertained. During 1982, [he]
23	patients.	23	was treated on 32 occasions with US concentrate
24	MS RICHARDS: It doesn't, no.	24	(Armour) and on 5 occasions with NHS material
25	SIR BRIAN LANGSTAFF: So we've just no way of knowing?	25	(factor VIII concentrate). This year proved to be the

(14) Pages 53 - 56

The Infected Blood Inquiry 1 12 months prior to 1985 that required the most and was not used subsequently. To my knowledge, at 2 frequent hospital visits necessitating infusions with 2 other Centres, much of this unheated batch had been 3 3 factor VIII concentrates. During 1982 some 19,000 returned to the manufacturer, who consequently heated 4 units of factor VIII were used ... 1983, 7 treatments 4 the product in one of their facilities in [West] 5 were administered with US commercial concentrates and 5 Germany." 6 6 2 with NHS concentrates, totalling in all Then bottom of that page, so where we are. 7 approximately 5,500 units. In 1984, 4 treatments were 7 "Although the child was seen on several 8 8 given with US commercial concentrates and 4 with occasions in 1985, the first documentation of blood 9 9 NHS concentrates giving a total of approximately sampling for anti-body to HTLV-III was on 05.08.85, 10 4,000 units for the year. The last treatment given 10 and the result indicating HTLV-III seropositivity was 11 during 1984 was on 02.12.84 with Armour factor VIII 11 reported on 08.08.85. No previous negative results 12 concentrate [and the batch number is given]. This 12 were obtained in this case rendering a possible date 13 occasion was the only time this batch of unheated 13 for the initial viral transmission difficult or 14 material was used." 14 impossible." 15 Then: 15 And then if we go to Dr Savidge's or 16 "In 1985, [he] was treated on 9 occasions with 16 Professor Savidge's opinion, bottom half of the page, 17 he says this: 17 heat treated US concentrates, on 2 occasions [this is 1985, and he's five] with the US unheated 18 18 "This case concerns a young child with severe 19 concentrates, on 2 occasions with NHS unheated 19 haemophilia who was treated from 1982 to 1985 with 20 concentrate and on 6 occasions with the earliest NHS 20 unheated US commercial and NHS factor VIII 21 heated factor VIII material ..." 21 concentrates for haemorrhagic symptoms. On 08.08.85, 22 22 Then details are given about the use of the the patient was shown to have been infected with 23 unheated Armour product, reference to the batch. 23 HTLV-III with out a previous negative test result, 24 "This unheated material was batch number Y 88908 24 presumably by transmission of the virus through 25 which had not been administered to the patient before, 25 contaminated blood products. The major issue in this 57 58 1 case relating to possible negligence and causation 1 subsequently heated products were available. "In the late 1970s and early 1980s, the majority 2 rest upon the choice of therapeutic products to use 2 3 treat haemorrhagic symptoms. The therapeutic policy 3 of UK paediatricians treating infants and children 4 adopted to manage this child is evaluated in terms of 4 with severe haemophilia considered cryoprecipitate 5 orthodox practice and knowledge of HTLV-III 5 obtained from single blood donations to be the 6 transmission from blood products at the time, and to 6 therapeutic product of choice, but if not available 7 7 the specific recommendations available in the medical NHS factor VIII concentrate should be used." 8 8 literature and proposed by [UKHCDO]." Then he refers to an '85 publication by 9 9 So you'll see that Dr Savidge's approach is not Dr Jones, and sets out the recommendation about 10 to look at things with the benefit of hindsight, but 10 treating children under the age of four with cryo, to try to compare what was done at Alder Hey with what 11 11 et cetera. 12 would have been his view of the orthodox approach at 12 Then if we go to the bottom of the page, 13 the time. 13 Professor Savidge then continues: Over the page he says this, under the heading 14 "At that time, this practice was deemed to 14 15 "Use of Concentrates as opposed to Cryoprecipitate": 15 confer a greater margin of safety from transfusion 16 16

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"There are two notable features of this case with respect to the adopted therapeutic approach. Firstly, there is no documentary evidence to suggest that single donor pool cryoprecipitate was ever contemplated in the management of this case, not even when the patient was initially treated. Secondly, there is evidence to indicate a defined preference to use US commercial products (45 treatments) over NHS factor VIII concentrate (9 treatments) during the period 1982-1985 when initially only unheated, but

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related viral diseases such as hepatitis B and non-A, non-B hepatitis, on the grounds that treatment with a small (less than 50 individual single donations) of cryoprecipitate preparations resulted in a reduced incidence of clinical and laboratory indices of hepatitis. In contrast, the donor pools of factor VIII concentrates were derived from several hundreds or thousands of plasma donations ..."

Then he gives an indication about pool sizes by reference to a UKHCDO minute in 1980.

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(15) Pages 57 - 60

"The increased morbidity in small children following infection with hepatitis B and non-A non-B hepatitis was an additional reason for choosing cryoprecipitate over concentrate.

"Furthermore, sufficient amounts of factor VIII necessary to control haemorrhagic symptoms in such small children, were available in only a few single donor bags of cryoprecipitate, providing a safe and highly cost-effective approach to such cases. The somewhat larger infusion volumes with such treatments

somewhat larger infusion volumes with such treatments
compared to the smaller reconstitution volumes of
concentrates were not considered to disadvantage the
increased safety aspects of this therapeutic approach.
As small amounts of cryoprecipitate were usually

material from the local BTS was in general no
 particular problem, and orders could be placed in
 advance to ensure adequate supplies for individu

advance to ensure adequate supplies for individual patients. The side effects occasionally encountered with cryoprecipitate (rashes, asthma-like symptoms)

required to manage such children, availability of the

were usually easily controllable with antihistamines, and did not impose a relative or absolute

and did not impose a relative or absolute
 contraindication for its use. As the child required
 treatment in hospital for each bleed, often leading to

subsequent inpatient management, any perceived

set aside. A reflection of the orthodox management of children at that time is apparent from the minutes of the UK Haemophilia Centre Directors Meeting of May 1983 ..."

That's that 13 May meeting we're familiar with.

"... when particular emphasis was placed upon use of domestic plasma derivatives."

Then there's a quote from that, and then Professor Savidge continues:

"Although a slightly modified version of these minutes were circulated as recommendations to all UK Haemophilia Centre Directors dated 24.06.83, they were clearly not followed in this case."

Top of the next page:

"During 1983 and 1984, both the mass media and the medical press were inundated with reports of AIDS cases in haemophilia and the potential dangers of large donor pool concentrates and by June 1984 ... it was clear that the factor VIII concentrates in their then present form, transmitted HTLV-III."

Then reference is made by Professor Savidge to reports in relation to the heat sensitivity of HTLV-III. He records that:

"US heat treated factor VIII products had just become available on a named patient basis in the UK."

additional convenience for using factor VIII concentrates cannot be considered a pertinent argument for their exclusive use over cryoprecipitate when the issues of safety and cost-effectiveness are also addressed.

"The lack of consideration and disregard of the then current therapeutic recommendations for the treatment of children under the age of 4 years regarding the use of cryoprecipitate in this case was negligent. Any argument that cryoprecipitate was in poor supply at the time is untenable since the material was being used in significant amounts for home therapy ... The overwhelming use of commercial US concentrates in preference to cryoprecipitate or NHS Factor VIII is remarkable, particularly in a large city such as Liverpool known to have an active [Blood Transfusion Service] with facilities for cryoprecipitate production and regularly supplying plasma to Elstree for fractionation. The lack of a well-defined therapeutic policy regarding preferential use of domestic plasma derivatives in children at this time was negligent, particularly since the factor VIII requirement in this case during 1983 and 1984 was so minimal ... that special reserves of cryoprecipitate or NHS factor VIII could have been

Refers then to recommendations published in 1984 in the -- October 1984 in the US, and then says:

"These were closely followed in December 1984 by the UKHCDO AIDS advisory document to all UK Haemophilia Centre Directors ..."

And then there's a reference to the first meeting of the AIDS group of Haemophilia Centre Directors on the 11 January 1985.

Then Professor Savidge says this:

"Despite this information with which a competent practising paediatric haematologist could be expected to be conversant, and a further report by Bloom in January 1985 ... which stated that at least 2 batches of NHS concentrate had transmitted HIV and urged the use of heat treated concentrates, [the patient] was given two in fusions of unheated US concentrate in January 1985 and two infusions of unheated NHS concentrates in March 1985."

Just to remind you, the age of the patient at that point in time was around 5 years old.

The infusion of these untreated therapeutic agents at this times when heat treated concentrates were commercially available was negligent, and from the available data these treatments could have been the likely causation whereby HTLV-III was transmitted

(16) Pages 61 - 64

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	to the patient which subsequently led to the	1	into what it was, apparently, that Dr Martin or and
2	development of AIDS in this child."	2	Dr McVerry had been saying about the availability of
3	Professor Savidge, it's fair to say, pulling no	3	products. So under the heading "Opinion":
4	punches in his analysis of the approach to treatment	4	"[The patient] was first found to be
5	taken in relation to this child at Alder Hey Hospital.	5	anti-HTLV-III positive on a blood sample collected on
6	There is a draft report on the same patient	6	8th August 1985. Prior to this he had received
7	and again, we're not identifying the patient from	7	infusions of factor VIII concentrate predominantly of
8	Dr Ludlam, April 1992. It's at DHSC0043164_067.	8	commercial origin. It is likely therefore that he
9	We'll see the date, 6 April 1992, at the bottom	9	obtained the HIV infection from the factor VIII
10	of the page. You'll also see reference sorry, if	10	concentrate infusions.
11	we just go back up again, the patient as identified as	11	"His haemophilic bleeds clearly required
12	JKP 37, and we'll look at some of the internal	12	treatment but it would be useful to know the policy
13	documents relating to the HIV litigation in that	13	for treating children with severe haemophilia. In
14	regard.	14	Dr Martin's evidence"
15	Dr Ludlam's report details the patient's	15	And we don't know what that refers to, sir. It
6	treatment and symptoms over a period of years. I'm	16	may be something we'll try and track down. But it
17	not going to go into the detail of that, but I just	17	would appear, for the purposes of defending the
18	ask you to look at page 7, when you will see, from	18	litigation, information had been sought by
9	just over halfway down the page, this child patient at	19	Dr Martin from Dr Martin.
20	Alder Hey died in 1989. He died at the age of around	20	"In Dr Martin's evidence it is stated that he
21	9 years old, having been infected with HIV.	21	was aware of the risks of hepatitis transmission by
22	If we go over to page 9, it's right to say that	22	concentrates, that cryoprecipitate was effectively
23	Dr Ludlam is perhaps more circumspect in his	23	phased out in 1980, and that treatment was advised by
4	observations, but nonetheless raises a number of	24	the Royal Liverpool Hospital. It is therefore
5	questions, and we get some insight from this report	25	necessary to know what policy was operated by the
.0	65	20	
	03		66
	Deval Liverneel beenite! Dr MeVernile evidence land		MAZI PLATI II II PLATI II II
1	Royal Liverpool hospital. Drivid verry's evidence jand	1	"When did Alder Hey Hospital change over to the
	Royal Liverpool hospital. Dr McVerry's evidence [and again we don't know what material was gathered from		"When did Alder Hey Hospital change over to the use of heat treated concentrate?"
2	again we don't know what material was gathered from	2	use of heat treated concentrate?"
2 3	again we don't know what material was gathered from Dr McVerry in this regard] does not accord with this.	2	use of heat treated concentrate?"  And then Dr Ludlam says:
2 3 4	again we don't know what material was gathered from Dr McVerry in this regard] does not accord with this. Why was it decided to phase out cryoprecipitate in	2 3 4	use of heat treated concentrate?"  And then Dr Ludlam says: "It is impossible from the clinical history to
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1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25	again we don't know what material was gathered from Dr McVerry in this regard] does not accord with this. Why was it decided to phase out cryoprecipitate in 1980? Was there a policy about which patients should receive NHS and which commercial concentrate? Why was concentrate purchased from Armour rather than another supplier? The patient could have been treated effectively with cryoprecipitate in the first few years of life whilst receiving treatment as an out-patient. If cryoprecipitate was not available then NHS concentrate would be the most appropriate therapy. In the absence of both these products then commercial should have been used."  Then we're told in the next paragraph: "Dr Martin has no recollection of receiving the letter of 24th June 1983 from Professor Bloom and Dr Rizza. This same letter was presumably received by the [Royal Liverpool Hospital] Haemophilia Centre and it would be useful to learn of any changes in treatment policy which resulted."  Then Dr Ludlam suggests that Dr Martin should	2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22	use of heat treated concentrate?"  And then Dr Ludlam says:  "It is impossible from the clinical history to identify when the patient seroconvert to HIV. He had recurrent sore throats from early life which were most likely to have been caused by ordinary respiratory viruses and not HIV."  He refers to seroconversion rising rapidly in 1981 to 1983, but says:  "Many haemophiliacs became infected after 1983 from concentrate which was likely to contain an increasing amount of HIV.  "No mention is made in the case notes, or in Dr Martin's submission, about what was said either specifically, or in general, about the possibility of virus transmission by blood products. It would be useful to know what information was made available to patients or parents."  I should say we've seen no evidence of any information about the risks of AIDS being made available to patients or parents.

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1 expressed conclusions but an indication that may give from this material. 2 rise to a number of concerns about the approach to 2 3 treatment of children in Alder Hey Children's Hospital 3 4 in the 1980s. 4 5 SIR BRIAN LANGSTAFF: Well, contrary to the general 5 6 6 practice, if Professor Savidge is right and, by 7 implication, Professor Ludlam, cryoprecipitate was 7 8 8 reduced --MS RICHARDS: Yes. 9 9 **SIR BRIAN LANGSTAFF:** -- in the general supply. Children 10 10 were exposed, according to both doctors, to obviously 11 11 an Alder Hey case. So: 12 an increased risk of contracting hepatitis and HIV 12 infections. There was no recorded reason for 13 13 14 differing from the usual practice which he gives. 14 15 Both doctors, I think, identify exactly the same 15 16 point, there was no available treatment protocol, and 16 17 the letters which were later on, from the UKHCDO, do 17 baby in 1984: not appear to have alerted Dr Martin to anything. 18 18 19 MS RICHARDS: No. We cannot, of course, ask Dr Martin 19 20 because he is dead. 20 21 SIR BRIAN LANGSTAFF: Yes. 21 MS RICHARDS: So we can't, I'm afraid, do anything other 22 22 23 than explore through documents these alarming matters. 23 SIR BRIAN LANGSTAFF: Well, it may be -- well, I shall 24 24 25 simply have to draw whatever inferences are proper 25 69

beginning of 1985, but I cannot tell from the batch numbers whether the material administered to the Plaintiff in 1985 was exclusively heat treated; in any event, the type of heat-treatment used by Armour subsequently proved to be incompletely effective in destroying HIV."

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"The Statement of Claim gives the date of the first HIV positive test as [21 February 1987] but the notes contain no record of HIV test results before 1988. The note for [30 August 1985] states 'blood for HTLV taken again' and a letter from Dr John Martin in the notes of the Plaintiff's brother, dated [31 December 1985], states that both brothers were then HTLV3 ... positive, although the first mention of HIV positivity in the Plaintiff's own notes is in a letter dated [July 1987], it therefore appears that seroconversion took place in 1985 or earlier.

"The risk of AIDS to haemophiliacs, and the possibility of removing these risks by the heat-treatment of concentrate, were already beginning to be appreciated at the end of 1984 [that's obviously the perspective of this particular author, rather than necessarily a more widely accepted view], when the plaintiff was first treated ..."

MS RICHARDS: There's then some further information we can glean about the approach at Alder Hey from DHSC0045373 118.

> Sir, this is the internal status report on medical negligence cases, and there are, I think, four Alder Hey cases. We looked at some of the Liverpool adult hospital cases yesterday. So if we go to page 10, the case of JKP 027, and there's a reference to Dr Martin, which is how we understand this to be

> "Severe haemophilia born [1984] (younger brother of [another plaintiff]), diagnosed at the age of 2 months and treated from that time onwards exclusively with Factor VIII concentrate."

So concentrates being given to a two-month old

"There is no record of the type of concentrate given in August 1984, but he received commercial (Armour) concentrate from February 1985 to September 1986 (apart from a single dose of heat-treated NHS concentrate (8Y) on [January 1986]). He was switched to 8Y concentrate in November 1986 and continued to receive this through 1987. Heat-treated commercial concentrate became available at the

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Then the author says this:

"... I think it must be accepted that it was negligent to treat him with concentrate at this time rather than with cryoprecipitate. There appears to have been no good clinical reason (eg major haemorrhage, home treatment) for preferring concentrate to cryoprecipitate, and it would certainly be indefensible if any of the commercial concentrate given in 1985 was unheat-treated. If cryoprecipitate was unavailable at this time, then either heat-treated commercial concentrate or unheated NHS concentrate should have been used until such time as NHS heat-treated concentrate became available. Conclusion -- Negligence."

If we go over the page, we can see the case of what's said to be the brother, diagnosed November 1982, aged six months, treated exclusively with Factor VIII concentrate from that time onwards, so again another case of a baby being treated with concentrate, two doses in 1982, 16 in 1983, 19 in 1984 and about 30 in 1985:

"Commercial material was given in March 1983, but apart from this there is no record of source or batch numbers until December 1984 when he received a dose of NHS concentrate. From the 2nd to

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72 (18) Pages 69 - 72 19th January 1985, he was treated with a total of 26 ampoules of commercial concentrate batch Y88908: this was probably unheat-treated [so a baby or toddler being given unheat-treated commercial concentrates in January 1985], since heat-treated commercial concentrate only became available sometime during that month. A single dose of NHS concentrate was given on 29.3.85, and subsequently more commercial concentrate (presumably heat-treated) during 1985 and 1986."

Then, again, we can see it's an Alder Hey case from the reference to Dr Martin in the next paragraph:

"The first mention in the notes that the Plaintiff was HIV positive occurs in a letter from Dr Martin dated 31.12.85, but a note dated 8.8.85 states 'blood taken for HTLV3 screening'. There are no actual laboratory results of HIV testing earlier than 1988."

Then, again, the view given here may not accord with the views of others but, in any event, this is what the person analysing this for the purposes of defending the litigation says:

"I do not believe that it can be held to have been negligent to treat a baby boy with commercial Factor VIII concentrate at the end of 1982, when the risks of AIDS were not well appreciated. During the

MS RICHARDS: Yes.

Then if we turn to page 19, there's less information available about this case, referred to as JKP 60:

"This child haemophiliac severe, born in ...
1976 died in ... 1986. It is alleged that from 1979
onwards treated with concentrate but his mother says
he was on cryo up to the age of 3 with no adverse
reaction.

"Professor Hardisty comments that the Plaintiff was treated at Alder Hey Hospital Liverpool until May 1984 ..."

Then we can see transferred, it would appear to home treatment from North Wales:

"Treatment was evidently with concentrate from an early age but the Liverpool notes are currently not available. Treatment in Wales was almost exclusively with NHS concentrate with the occasional doses of commercial concentrate presumably because of insufficient NHS material being available. HIV positive in July 1985 with no previous negative results although a sample was taken on the 30th January 1985 but evidently not reported on.

"Currently Professor Hardisty can only make the general point here that the treatment of a severely

following year however, and particularly after June 1983, when the Haemophilia Reference Centre Directors issued their first recommendations on treatment, the risk should have been recognised: a switch to cryoprecipitate at that time might still have protected the Plaintiff against HIV infection. In the light of the further recommendations of December 1984, it must have been held to have been negligent to treat the Plaintiff with unheat-treated commercial concentrate in January 1985 (if this was indeed the case). I do not think this case is defensible.

13 "Conclusion -- Negligence."

SIR BRIAN LANGSTAFF: Is this the same case as ProfessorsSavidge and Ludlam were reporting on?

16 MS RICHARDS: No, because the date -- the year of birth17 doesn't match up.

18 SIR BRIAN LANGSTAFF: Right, the author of this takes
 19 a generous view of when risk was first appreciated - 20 generous that is, to the hospital --

21 MS RICHARDS: Yes.

22 SIR BRIAN LANGSTAFF: -- but, even on that basis, comes

23 the conclusion that there is set out at the end.

24 MS RICHARDS: Yes.

25 SIR BRIAN LANGSTAFF: So these are two brothers?

affected infant or young child with concentrate is not of itself negligent, cryoprecipitate is unsuitable for home treatment in many instances and has many disadvantages. NHS concentrate should have been preferred to commercial from about mid-1983 but supplies were inadequate to adhere entirely to this counsel of perfection, only heat-treated concentrates should have been used from early 1985 as was indeed the case here.

"Needs reconsideration once Liverpool notes are available, in the meantime no evidence of negligence."

Again, the purpose of referring to this is really, as with all this, about what it indicates more widely about the approach taken to treatment at Alder Hey. It would appear here, the case of a child switched at the age of three from cryoprecipitate, to which the child had had no adverse reactions, to concentrate, and treated at Alder Hey with concentrates from 1979 to May 1984.

You can see here again reference to not having the Liverpool notes, at least at that point in time.

**SIR BRIAN LANGSTAFF**: The note retention and taking system

23 seems to have been a mess.

24 MS RICHARDS: Yes.

5 SIR BRIAN LANGSTAFF: It confirms what we heard from

(19) Pages 73 - 76

1 Professor Hay, I think. December 1987 ..." 2 MS RICHARDS: Well, Professor Hay is dealing with the 2 So again a very muddled picture in relation to 3 adult centre but Dr Ball says the same thing about the 3 the process for HIV testing of these children: 4 Alder Hey notes and I'll come back to her statement, 4 "... and there is no mention in the notes of his 5 5 being HIV positive before this date. shortly. Then the last Alder Hey case in this document is 6 6 "The Plaintiff was treated with Factor VIII 7 at page 24. So JKP 105: 7 concentrate from [I think that's 1979] onwards ie 8 8 "... severe haemophiliac child born in ... 1976 about four years before AIDS was described ... This 9 9 ... given no treatment other than concentrate save for was probably mainly commercial material since NHS one isolated treatment in 1982 with cryoprecipitate. 10 10 concentrate was in very short supply in the early 11 "Professor Hardisty [who has presumably been 11 1980s. An attempt was made in 1983 to switch to NHS 12 asked to give an opinion on these cases] states that 12 concentrate, although the extent to which this was in accordance with the policy at Liverpool Children's 13 achieved cannot be judged in the absence of complete 13 14 Hospital [Alder Hey] he was treated with concentrate 14 records." 15 from 1978 onwards." 15 Then the assertion is made by the author, again, 16 So from the age of two, that would roughly place 16 of this document, presumably from the perspective of 17 it: 17 defending litigation: 18 18 "There are no records of the type or batch "HIV infection was probably derived from 19 number until January 1983 when he received commercial 19 concentrate before the risks were appreciated. 20 concentrate, March 1983 NHS, and December 1983 20 A switch to cryoprecipitate in 1983 would have 21 commercial. In June and August 1984 he received NHS 21 deprived the Plaintiff of the great advantage of home 22 22 concentrate, and thereafter heat-treated concentrate treatment and would probably have been too late in any 23 first commercial and then NHS. There is a record that 23 event." 24 blood was taken for HIV testing in August 1985 but the 24 Quite what the basis for saying that is, given 25 earliest positive laboratory result is dated 25 the paucity of information, is wholly unclear. 77 78 SIR BRIAN LANGSTAFF: Well, it relies on the absence of 1 the top of the next page: 1 2 2 records, essentially. "Although Dr Martin says he did his best to 3 MS RICHARDS: Yes. 3 discourage the operation, he did not do so in the 4 Then there's a further status report. So that 4 specific context of the risk of viral infection or the 5 status report on cases is July 1991. There's one from 5 risk of infection of AIDS and the parents were not 6 September 1991, which provides some further insight 6 warned in relation to these aspects." 7 7 into the approach at Alder Hey, it's DHSC0045721\_051. Then it is suggested there needs to be a further 8 8 If we go to the second page, you'll see there's review, and it's likely the case will need to be 9 an update on the cases of JKP 27 and 28, the brothers 9 reclassified. 10 whose cases were looked at in the previous note. Then 10 Towards the bottom of the page, you'll see if we look at the bottom of the page, we see a third 11 11 JKP 37. That is, I think, the case that 12 case. This JKP 33, an Alder Hey case. 12 Professor Savidge and Dr Ludlam were discussing in 13 "Haemophiliac classified as mild/moderate. The 13 notes are insufficiently detailed to identify whether Then if we go over the page to page 4, please, 14 14 Soumik. The case JKP 47: all treatment given was NHS product but Dr Martin's 15 15 16 16 statement confirms that no distinction was made at "Mild haemophiliac child. Alder Hey Hospital 17 Alder Hey Hospital in terms of which product to prefer 17 case." 18 and the product he would have received would have been 18 Second paragraph: 19 that which was available." 19 "After further investigations into the case with 20 That would appear to give the clearest possible 20 Dr Martin it would appear that the Plaintiff did 21 indication from Dr Martin that, whether it was NHS or 21 receive commercial Factor VIII in December 1983 for 22 22 commercial concentrate for the treatment of these a tooth extraction and this treatment would not seem 23 23 young children, didn't seem to make any difference. to be justified. This appears to be a case for 24 We then see a reference to the plaintiff having 24 settlement." 25 elective surgery for "bat ears" in 1983. If we go to 25 So commercial concentrates, December 1983, child

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(20) Pages 77 - 80

1	with mild haemophilia. Again, there doesn't appear to	1	"Severe haemophiliac child. Alder Hey. He was
2	have been any particular distinction drawn at	2	regularly treated with concentrate at least some of it
3	Alder Hey between the treatment of those with mild	3	commercial after mid-1983. This case is therefore
4	haemophilia and the treatment of those with severe	4	difficult to defend."
5	haemophilia.	5	So that's the insights we get into the approach
	·		
6	SIR BRIAN LANGSTAFF: Can we just go back to the very last	6	to treatment at Alder Hey.
7	line of the previous page?	7	We can take that down, thank you, Soumik.
8	MS RICHARDS: Certainly.	8	Dr Bolton-Maggs was the senior registrar
9	THE CHAIRMAN: This is an adult, I see.	9	slightly later than this, 1987 to 1988, but her
10	MS RICHARDS: It is. I should say it's a Liverpool case.	10	recollection is that DDAVP was not used until a later
11	It's an adult Liverpool case. It might have been one	11	stage, the late 1980s.
12	of the ones we looked at yesterday, I'm afraid I can't	12	Then, in relation to Dr Ball's evidence, we've
13	remember the JKP number we looked at yesterday. That	13	already looked at her observation that when she came
14	was the case of a mild haemophilia adult treated at	14	on the scene at Alder Hey in 1989 and looked at
15	Liverpool. If we go to the top of the next page, the	15	records, she could find no batch reservation system
16	first long paragraph, four lines from the end:	16	and she then also says in her statement:
17	"Dr McVerry comments that no specific priority	17	"A large proportion of the clinical notes of
18	was given to mild haemophiliacs for treatment with NHS	18	children affected by HIV were on close inspection
19	product at the time."	19	missing essential treatment and decision making
20	SIR BRIAN LANGSTAFF: Yes.	20	details."
21	MS RICHARDS: So it would appear, both in terms of adults	21	She observes, and it's consistent with what
22	and children, in the Liverpool area, a similar	22	we've looked at here, that factor concentrates were
23	approach being adopted.	23	used in mild cases before her tenure.
24	Then the last Alder Hey case in this document is	24	Then we have a witness statement, I'm not going
25	top of page 5, JKP 92:	25	to put it up on screen but I just want to read
	81		82
	01		02
1	a couple of passages from it aloud.	1	disorders, although there's no reason to think he
1 2	a couple of passages from it aloud. So it's a statement from a mother whose three	1 2	disorders, although there's no reason to think he wouldn't have been sent the minutes of those meetings.
2	So it's a statement from a mother whose three	2	wouldn't have been sent the minutes of those meetings.
2	So it's a statement from a mother whose three children were treated at Alder Hey: two of them	2	wouldn't have been sent the minutes of those meetings.  There are a handful of documents about
2 3 4	So it's a statement from a mother whose three children were treated at Alder Hey: two of them infected with HIV, and both died; the third child	2 3 4	wouldn't have been sent the minutes of those meetings. There are a handful of documents about hepatitis. I'm not going to go to the individual
2 3 4 5	So it's a statement from a mother whose three children were treated at Alder Hey: two of them infected with HIV, and both died; the third child infected with hepatitis C. She describes incomplete	2 3 4 5	wouldn't have been sent the minutes of those meetings.  There are a handful of documents about hepatitis. I'm not going to go to the individual documents but there are the hepatitis survey forms
2 3 4 5 6	So it's a statement from a mother whose three children were treated at Alder Hey: two of them infected with HIV, and both died; the third child infected with hepatitis C. She describes incomplete records. She was not given information about risks.	2 3 4 5 6	wouldn't have been sent the minutes of those meetings.  There are a handful of documents about hepatitis. I'm not going to go to the individual documents but there are the hepatitis survey forms from time to time completed by Alder Hey. There's
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2 3 4 5 6 7 8	So it's a statement from a mother whose three children were treated at Alder Hey: two of them infected with HIV, and both died; the third child infected with hepatitis C. She describes incomplete records. She was not given information about risks. So she says this:  "We were not told anything about Factor VIII.	2 3 4 5 6 7 8	wouldn't have been sent the minutes of those meetings.  There are a handful of documents about hepatitis. I'm not going to go to the individual documents but there are the hepatitis survey forms from time to time completed by Alder Hey. There's a form completed by a registrar to Dr Martin in March 1979 recording a patient treated with
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1 March 1983 letter which contained Dr Craske's report, She refers to how difficult that was for parents 2 and the forms for reporting AIDS symptoms in patients. 2 and the atmosphere of stigmatisation at the time. 3 3 In terms of the arrangements then for testing There is other evidence which is consistent with 4 patients for HTLV-III and informing them of their 4 Dr Ball's understanding that HTLV-III test results 5 diagnosis, as with the Liverpool Centre at the Royal 5 were communicated by letter and that appears, when we looked at Professor Hay's HIV litigation statement, to 6 Liverpool Hospital, this is a significant issue at 6 7 Alder Hey as well. If we go to Dr Ball's evidence, 7 have been his understanding of the position at 8 8 she says -- I don't think I need to put it up on Alder Hey as well. 9 9 screen it's just a few lines -- she says: We've got an example of one such letter, at 10 "I am not directly aware of the circumstance 10 DHSC0039356 -- 536, sorry. Yes. So it's 11 whereby the process of testing was undertaken. But 11 28 August 1985: 12 parents informed me that they were not counselled 12 "We have now received the results of the special before testing and received a 'positive' outcome by 13 antibody test that we performed on your son as part of 13 14 means of a letter addressed to the parents." 14 the screening programme for all children with haemophilia and related disorders. I have to tell you 15 She recalls also in her statement one mother 15 16 thinking that a positive test was a good outcome, 16 that [he] does show the presence of HTLVIII unsurprisingly; and one mother hearing that letters 17 antibodies, ie he has evidence of antibodies against 17 had been sent was so distressed that she was unable to 18 18 the virus that it has thought to cause AIDS. This 19 open the letter for months. 19 does not mean that your son has AIDS but just that he has been exposed to the virus. Most people who are 20 Dr Ball, again, also describes in her statement 20 21 in relation to the question of telling the children 21 positive for HTLVIII antibody do indeed remain well 22 themselves of their HIV infection, that was something 22 and never develop features of AIDS. A small minority 23 that she would, once she came on board in 1989, 23 run a risk of developing this condition in the 24 discuss with parents and as to how and when the 24 future." 25 children themselves would be informed. SIR BRIAN LANGSTAFF: So this is not at all -- remember 85 86 1 I drew your attention to part of what was in the 1 present, that's scheduled for 4 September 1985. 2 2 report, wasn't it, in the journal in which Dr McVerry Again, there's a question as to why testing and 3 was writing. So at the same time as the Liverpool 3 provision of information about test results is taking Hospital was saying "We just don't know", he is 4 4 place only in the late summer or early autumn of 1985. 5 saying, or the author of this is saying --5 There is an account from a witness of her 6 MS RICHARDS: If we go to the bottom of the page we'll see 6 attendance at that meeting, which I will just read 7 7 out. Just check I've got the right one. Yes. So it's Dr Martin. 8 8 SIR BRIAN LANGSTAFF: Dr Martin, who had no particular this is an account from a mother whose son was 9 knowledge of haemophilia care or the risks, is saying 9 infected with HIV and hepatitis C. It says: 10 something he you could not possibly say --10 "The seminar took place in the C3 ward at 11 MS RICHARDS: Yes. 11 Alder Hey on 4 September 1985. I attended the seminar SIR BRIAN LANGSTAFF: -- on the state of knowledge at the 12 with my husband and the room was full with between 60 12 13 13 and 100 people. The seminar was for families of those MS RICHARDS: Yes. who had been tested for HIV and we knew many of the 14 14 SIR BRIAN LANGSTAFF: Yes. 15 families from meeting them at Alder Hey. Dr Martin 15 MS RICHARDS: There are statements from other witnesses 16 16 led the seminar and then handed over to Dr Hart who 17 who received the letter in similar or identical form. 17 was a consultant microbiologist. People were shouting 18 Again, I won't put it up on screen but we've 18 and asking questions and the meeting ended up being 19 copies of effectively an identical letter. I'm sorry, 19 very emotional and hostile. No explanation was 20 if we just put that one back. 20 provided during the meeting about why this had 21 You'll see from the last paragraph: 21 happened and no one apologised or took blame. I felt 22 22 "... we have arranged a short seminar on as though it was pushed under the carpet that people 23 23 had been infected with HIV. People left feeling upset haemophilia and AIDS to endeavour to answer any 24 questions you may have." 24 and angry about what was raised during the meeting. 25 There's going to be a microbiologist, Dr Hart, 25 Dr Martin was very abrupt and I clearly remember him

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1 saying 'If you think you can take this to court, you colds'. He basically told us that if they had 2 haven't got a case'." 2 symptoms he didn't want them to bring them to hospital 3 3 as not all symptoms was a result of HIV." Then just -- again, I'm not going to put it on the screen, but I'll just read very briefly from the 4 4 She says: 5 statement of the mother of three boys, two of whom 5 "I was not provided with any information about 6 6 were infected with HIV and died. the virus itself. I was given no information as to 7 She confirms that they -- well, in terms of the 7 the possible routes of transmission or risk of 8 8 testing and the communication of the diagnosis she infection to others." 9 9 says: In terms of the numbers infected -- and sir, 10 10 "We were told that the boys needed to go for you'll have seen from the annual returns the kinds of 11 blood tests. I never even thought to ask what the 11 numbers treated at Alder Hey Hospital over the years. 12 tests were for as it was just the norm as they were 12 So it ranges from ten patients in 1978 with haemophiliacs, they were always having blood taken. 13 haemophilia A to 19 patients in 1982, 16 patients with 13 14 We later received a letter which said that they had 14 haemophilia A in 1983, 14 in 1984. been infected with HIV. My dad saw my extreme 15 15 The provisional data supplied by the UKHCDO from reaction to the letter and came over to ask what was 16 16 the National Haemophilia Database to the Inquiry 17 wrong." 17 suggests that 13 patients at Alder Hey were infected 18 18 She observes, you may think unsurprisingly: with HIV, having tested positive in the course of 19 "I find it disgusting that I was informed of my 19 20 sons' HIV status by a letter." 20 That's pretty consistent with Dr Ball's 21 She then talks about being asked to go to 21 recollection that there were approximately 12 boys 22 Alder Hey the following week, maybe a reference to the 22 with haemophilia who were HIV positive. Her 23 same meeting. 23 recollection was that as a proportion of children 24 "Dr Martin was standing there and he said 24 registered per Centre in the UK, this was one of the 25 'I don't want you all coming up here with coughs and 25 highest, if not the highest, proportion of HIV 89 90 positive haemophiliacs." 1 Again, there is evidence of delays, as we've 1 SIR BRIAN LANGSTAFF: Well, it's over 90 per cent. 2 2 heard, in relation to many of the centres. 3 MS RICHARDS: Yes. The statement I referred to a few 3 And then the last topic, I think, in relation to 4 minutes ago, the mother of two boys who died, also 4 Alder Hey, is how children infected with HIV were 5 commented in her statement, she said: 5 treated for their HIV at Alder Hev. And again, 6 "At Alder Hey it was like a conveyor belt of 6 I think I can probably best take this from the 7 7 statement of Dr Ball. children dying. We would constantly get phone calls 8 8 from other parents and families telling us that If we put it back up on the screen, please, 9 9 Soumik, it's WITN4739001. If we start at the bottom another child had died." 10 In relation to hepatitis C testing, sir, at 10 of page 13, very bottom of the page, she says: Alder Hey, Dr Ball's recollection or understanding was 11 11 "Unlike the boys in [Great Ormond Street], 12 that that began during Dr Bolton-Maggs' tenure, so 12 a number of children at the beginning of 1989 were 13 after Dr Ball had left. She couldn't recall having 13 already beginning to show evidence/signs of severe direct involvement other than monitoring liver immune dysfunction as a result of the virus 14 14 function. It may be because -- or she tells us in her 15 manifesting in the development of opportunistic 15 16 16 statement she was absent but -- on maternity leave and infections." 17 then a period of illness from late 1991 for a period 17 Then if we go to page 16, she describes, in the 18 of time. So -- and during that period of time she 18 bottom of the page, that: 19 says Dr Bolton-Maggs acted as locum. So the position, 19 "... it became evident that a significant 20 therefore, is not entirely clear as to when 20 proportion of the HIV affected boys were severely 21 hepatitis C testing was undertaken at Alder Hey. 21 immune compromised, which at the time was not the 22 22 Dr Bolton-Maggs's recollection is that once the experience of many paediatric haematology colleagues I 23 23 testing became available, and she thinks it was in consulted." 24 1992, patients would be screened and results would be 24 Then there's reference to starting the children 25 passed to patients or parents as soon as possible. 25 on treatment.

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1	And then top of the next page:	1	Medical Director. No appeal by myself or the nursing
2	"Around this time the situation with the	2	staff could assuage him to change his decision. In
3	hospital management deteriorated. This resulted from	3	fact, I was accused of deliberately influencing the
4	one of the boys being acutely admitted to C3 [one of	4	nursing staff to be openly hostile to his decision. I
5	the individual wards] with severe pneumonia as a	5	have never understood why his animosity towards me
6	result of 'full-blown AIDS'. He was 8 years old.	6	manifested itself in such a way, but the nursing staff
7	After his mother made it known to another parent that	7	independently opposed this decision as one might
8	her son was HIV positive there was a distressing	8	expect from professionals who had for years provided
9	moment for all the parents who were very frightened	9	care for this sub-group of children. I appealed
10	and concerned about the infectivity risk and welfare	10	directly to the Hospital Manager who refused to be
11	of their children with cancer. Together with the ward	11	involved in what he determined was a purely clinical
12	senior sister, Doris Hackel, who had nursed these	12	matter.
13	children from diagnosis to adulthood, we met the	13	"The edict didn't stop there as from that moment
	_		
14	parents individually and felt that we had reassured	14 15	all children with haemophilia were no longer to be
15	them not only to safety issues, but also to the	15 16	treated or admitted to ward C3 but would instead be
16	necessity of the child with a highly immune	16	seen on a general paediatric ward, with nurses who had
17	compromised state being cared for in a ward with	17	no experience in the management of immune compromised
18	expertise and surrounded by staff that he knew and	18	children or bleeding disorders. The dismay and
19	trusted."	19	distress caused the parents of these boys was in my
20	And then Dr Ball recounts this:	20	mind then as it is now as being cruel and unnecessary.
21	"I found that without consultation the child	21	The parents asked me to mediate but I was unable to
22	under my care [the eight-year-old child with severe	22	convince my colleague to reverse this decision, but
23	pneumonia and AIDS] was moved to a general paediatric	23	the hospital manager agreed to meet with the
24	medical ward the following morning under the	24	parents"
25	instructions of the acting senior ward consultant and	25	She thinks that was around February 1990, and he
	93		94
1	subsequently agreed to the provision of a dedicated	1	rampant and supportive care requirements were sadly
1 2			rampant and supportive care requirements were sadly lacking."
	subsequently agreed to the provision of a dedicated unit. And that was how the paediatric Haemophilia Centre, she says, was finally established at	1 2 3	
2	unit. And that was how the paediatric Haemophilia	2	lacking."
2	unit. And that was how the paediatric Haemophilia Centre, she says, was finally established at Alder Hey.	2	lacking."  Then she talks about HIV being new and relatively unknown. She talks about the work that was
2 3 4	unit. And that was how the paediatric Haemophilia Centre, she says, was finally established at Alder Hey.  If we go to page 21 sorry, I don't think	2 3 4	lacking."  Then she talks about HIV being new and relatively unknown. She talks about the work that was undertaken at Great Ormond Street. Then she says this
2 3 4 5	unit. And that was how the paediatric Haemophilia Centre, she says, was finally established at Alder Hey.  If we go to page 21 sorry, I don't think I need to go to that.	2 3 4 5	lacking."  Then she talks about HIV being new and relatively unknown. She talks about the work that was
2 3 4 5 6	unit. And that was how the paediatric Haemophilia Centre, she says, was finally established at Alder Hey. If we go to page 21 sorry, I don't think I need to go to that. Yes, if we just go to page 29.	2 3 4 5 6	lacking."  Then she talks about HIV being new and relatively unknown. She talks about the work that was undertaken at Great Ormond Street. Then she says this about Alder Hey:  "Alder Hey failed because there most
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children at Alder Hey Hospital to advise regarding the standard of care current at the hospital and to write to the General Manager at the hospital, which I have done as attached.

"Your clients will be aware of an ongoing dispute that has led to a number of meetings between the parents and the General Manager. The general nature of the complaints are that the children, when requiring in-patient care, are being placed in a general ward together with children with infectious diseases, and no longer, unlike in the past, are being given the support of nursing staff with experience in haemophilia and HIV. Further, they are often passed around 'from pillar to post' at times of bet shortage, with no sense of priority. Finally, and unlike in the past, there is no reserved area to which parents can bring their children for day treatment.

"The above situation is prejudicial to the health of the children in that, whilst immunosuppressed, they are being closely exposed to all manner of infections and in an environment where the nursing staff are untrained and inexperienced to sufficiently identify early signs of damage. My clients are having to suffer the added strain of a constant fear that the lives of their children will

led to the HIV infection. It seems extraordinary that the hospital, seen by the parents as responsible, at least in general terms, for infecting their children, can be so inept at handling the patient relations as to bring about the present situation. It is perhaps significant that at no time has Dr Martin offered any personal sympathy or sense of regret to any of the parents."

I should, I think, make reference to the response -- again, of Ms Saunders, the -- from Alder Hey, responding to the issues raised in Dr Ball's statement.

So if we go back to WITN4194006. I read from parts of her statement previously. I can pick it up at the third page. So, paragraph 11, she's referring to the issues that we have just been discussing by reference to Dr Ball's statement, and the way in which the children with HIV were going to be cared for at the hospital. She says:

"The information provided to me I am afraid, is that this process appears to have happened without appropriate consultation with the families affected or a plan to educate the staff on the General Paediatric ward to which their care was transferred. Members of the Haematology Team welcomed this separation as they

be shortened even further than they can already expect specifically because of the failure at the hospital to take sufficient steps for their protection. Further, the children and the parents alike desperately need to feel some continuity of staff and location and, generally, to know there is a place where they can come to, whether to collect supplies, or generally for help and counselling in their more difficult times, where they will feel known and welcomed."

The second paragraph, on the next page, refers to the parents' request for change being fully supported by Dr Ball, which is consistent with what Dr Ball has said in her statement.

If we can then pick it up in the fourth paragraph:

"I have to say that I am extremely concerned at the conduct, as reported to me, not only of Mr Butler, but of Dr Martin, the paediatric consultant, who formerly cared for these children and whose position, as Head of Medical Directorships, appears to have drawn him into administrative decisions that have led directly to these complaints. This is particularly distressing for the parents when, of course, it was the clinical decisions of Dr Martin that, in many cases, according to the allegations in the pleadings,

Q:

felt that care of children with malignant conditions
took precedence on the Oncology Unit.

"12. I very much regret that I cannot now
explain these apparent failings."

Over the page, top of the page, Ms Saunders says that:

"... Alder Hey had not had the benefit of anyone with [Dr Ball's] knowledge and experience prior to her appointment."

Then this:

"Nor am I able to explain, looking back many years later, why having appointed someone with the degree of knowledge and specialism of this witness, her advice was not initially acted upon. Alder Hey prides itself upon being a learning organisation and we will reflect upon these matters and the lessons they provide even after so many years."

And then paragraph 15:

"Funding in the NHS is often an issue. There is never enough money to provide all of the care and treatments that are possible and that we would wish for our patients. If funding priorities at that time were wrong or lacked insight, I am very sorry and apologise on behalf of the Trust to all those who suffered as a result of those decisions."

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1 She apologises in the next paragraph to Dr Ball. MS RICHARDS: It is right to say, however, that most of 2 And then, paragraph 18, says this: 2 the rest of the centres that I'm proposing or hoping 3 "Most of all, I would like to apologise on 3 still to cover today have far fewer documents to look 4 behalf of the Trust for the distress these 4 at, simply because there are far fewer revelatory or 5 shortcomings must have caused to patients and their 5 informative documents than there were in relation to families who have suffered such trauma and tragedy and 6 6 these two centres we've been looking at this morning. 7 deserved better. I am truly and deeply sorry." 7 So I should still be able to cover a lot this 8 8 So that's the response that we've had from the afternoon but we'll see how we get on. If there isn't 9 9 current -- those in charge at the current Alder Hey enough time to cover all of those, then we will cover 10 10 them on another occasion rather than compress or rush Trust 11 I should say we have, and I'm not going to refer 11 any of them. 12 to it now, but we have, again, statements from parents 12 SIR BRIAN LANGSTAFF: Yes. about the way in which the children were cared for at 13 Can I just recap a little of what we have heard 13 14 Alder Hey at that period of time, and it describes --14 this morning? You've been absolutely right to take 15 well, it describes their experiences in a way which is 15 Alder Hey and, for that matter, to some extent, 16 16 very consistent with what we've seen related by Liverpool, the Royal Liverpool Hospital, at the length Dr Ball and what we saw related by Mr Ross on their 17 17 that you have. behalf in his solicitor's letter. 18 18 As Ms Saunders says, it may be an abject or an 19 Sir, those are the key parts of the material 19 object lesson to be learned from the comparison in 20 relating to Alder Hey that I wanted to refer to. 20 particular between the accounts you have given through 21 I note the time. I wonder if we could take 21 your presentation in respect of Alder Hey, and what we 22 22 lunch now and then we can start with the remaining heard yesterday from you about the Sheffield 23 centres after lunch. I'm not going to rush any of 23 Children's Hospital. 24 24 them They may be separated only by a few miles in the SIR BRIAN LANGSTAFF: No. 25 Pennines, but they're worlds apart in what you have 25 101 102 1 described and, to identify the essential differences, 1 probably one only being -- seroconverting in 2 2 what are they? Are they that the treatment in Sheffield. 3 Sheffield was led by the most up-to-date scientific 3 MS RICHARDS: Yes. There may be some similarities in the 4 knowledge at the time, by somebody expert in the 4 sense of, in terms of the provision of information to 5 field, that that led to a focus upon cryoprecipitate 5 parents about risks, there's no particular evidence in 6 as the treatment of choice, and very great care to 6 relation to Sheffield -- in common with, I think, what 7 7 we've learnt about the majority of places -- there avoid, where possible, treatment with concentrates, 8 8 certainly commercial, in facilities which had the doesn't appear to be evidence of a proactive approach 9 9 additional support staff that you identified in to warning parents or patients about risks. But 10 a dedicated centre, in part, I think in Sheffield. Am 10 certainly what we see from Sheffield appears to have been a relationship between the Children's Hospital 11 I right about that? 11 MS RICHARDS: I can't remember the timings in terms of 12 and the adult Centre, absolutely as we have in 12 13 when the facilities were developed, but certainly 13 Liverpool, so mirrored in that sense, but in Sheffield there was a dedicated paediatric haematologist. it's underpinned by, perhaps no doubt the work of 14 14 SIR BRIAN LANGSTAFF: And with access to, again, a team, 15 Professor Preston, the particular awareness of the 15 16 16 in Sheffield generally, which had shown itself well risks of hepatitis, which led to a focus upon 17 aware of the particular risks of hepatitis 17 cryoprecipitate for children, not exclusively, but at 18 non-A, non-B from an early stage. And plainly having 18 least being a main form of treatment, in marked 19 the support of the hospital management at the time, 19 contrast to the position in Liverpool, where 20 and the region. 20 cryoprecipitate appears to have played little or no 21 Are there any other significant differences that 21 part in treatment, even for those of a very, very 22 22 you would identify? Because the result couldn't be young age. 23 more different, could it? It's 90 per cent, over 23 It is almost entirely commercial concentrates or 24 90 per cent of children, some brothers from the same 24 very substantially commercial concentrates, with no 25 family, dying of infection with HIV in Liverpool, and 25 apparent thought being given to the risk, no

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1	differentiation between mild, moderate and severe, and	1	(2.03 pm)
2	no alternatives being contemplated, is the picture		SIR BRIAN LANGSTAFF: Yes?
3	which emerges from the documents we've seen.	3	PRESENTATION RE WALTON COMMUNITY HOSPITAL
4	SIR BRIAN LANGSTAFF: Well, there may be and if there		MS RICHARDS: Sir, I'm going to deal briefly now with the
5	are, I can hear about them in submissions in due	5	centre at the Walton Hospital.
6	course other underlying reasons, other than the	6	It was a recognised Haemophilia Centre in the
7	particular personalities or views of those who were	7	sense that they had a UKHCDO number, number 66. It
8	running the centres, which resulted in such	8	was a very small Centre, which we'll see from the
9	differences in outcome and for, as far as I can see,	9	numbers treated. The director in the 1970s was
10	from the witness statements, the degree of parental	10	a Dr Patricia Rob, and then, from 1980, Dr PA
11	satisfaction.	11	Stevenson.
12	MS RICHARDS: Yes.	12	Dr McVerry, whose time in Liverpool was 1980 to
13	SIR BRIAN LANGSTAFF: Yes. Well, thank you for that. If	13	1985, says he had no involvement himself with the
14	you've any more to say about those brief reflections,	14	Walton Hospital and he wasn't even aware that there
15	I couldn't let the Alder Hey presentation go without	15	was such a centre there.
16	making some reflections on it. I shall have to think	16	And it does appear that over the course of the
17	more carefully about quite where it fits into the	17	early eighties there were very few patients treated at
18	overall picture.	18	the Walton and such patients as had been treated there
19	MS RICHARDS: Yes, sir.	19	may have transferred to the Centre in Liverpool.
20	SIR BRIAN LANGSTAFF: But two o'clock.	20	There are no returns after 1985, and by 1990 it's been
21	MS RICHARDS: Thank you.	21	recorded that there is no longer a Haemophilia Centre
22	(1.00 pm)	22	at the Walton.
23	(The luncheon adjournment)	23	There is comparatively little information about
24	(2.00 pm)	24	what the source of products would have been. We know
25	(Proceedings Delayed)	25	that Regional Transfusion Centre in Liverpool provided
	105	20	106
	100		100
1	some blood or blood products, or at least	1	In terms of the annual returns, what they show,
2	cryoprecipitate, in the seventies to the Walton.	2	essentially is 1976, treatment with cryoprecipitate,
3	Dr Stevenson does appear to have attended some	3	in 1977, treatment with cryoprecipitate, and a small
4	of the regional meetings of the Mersey and North Wales	4	amount of NHS factor concentrate. And it would appear
5	haematologists in the course of the 1980s, and there	5	that there was home treatment with cryoprecipitate in
6	is reference to Dr Stevenson raising an issue in	6	1977. That's what the return seems to suggest.
7	November 1985 about difficulties in obtaining supplies	7	Again, 1978, mostly cryoprecipitate with some
8	of fresh frozen plasma.	8	NHS concentrate and a small amount of fresh frozen
9	In terms of treatment, the numbers treated at	9	plasma.
10	the Walton from 1976 onwards were as follows: five	10	The first year in which there's any commercial
11	patients in 1976, five in 1977, four with	11	concentrate recorded is 1979. It's still
12	haemophilia A, one von Willebrand's, four	12	predominantly cryoprecipitate so it's 55,000-odd
13	haemophilia A patients in '78, three patients in '79,	13	units, but 6,000-odd units of commercial concentrate
14	three patients in 1980, two with haemophilia, one	14	Factor VIII.
15	a carrier, two patients with haemophilia A in 1981.	15	In 1980 it's cryoprecipitate.
16	1982, it's not entirely clear but may have been	16	1981, cryoprecipitate.
17	a single haemophilia A carrier patient. No patients	17	1982, it's unclear, but it appears to be NHS
18	treated in 1983 and one patient treated in 1984. But	18	factor concentrate only.
19	someone who was probably a visitor from Edinburgh	19	As I said, no patients in 1983, and then a tiny
20	rather than a registered patient at Walton.	20	amount of cryoprecipitate in 1984.
21	But there are documents that suggest that there	21	So the picture that emerges, therefore, is
22	was a slightly larger number of patients, around nine	22	predominantly the use of cryoprecipitate with one year
23	or so, registered at the Walton in the early part of	23	of a small amount of commercial concentrate.
24	the 1980s, but the number treated, as I say, rather	24	There's little information to reveal what, as
25	smaller.	25	a matter of fact, either Dr Rob or Dr Stevenson's
	107		108 (27) Pages 105 - 108

1	knowledge of the risks of hepatitis or HIV might have	1	Then, following Dr Cook's death, Dr Taylor
2	been.	2	became the director in 1982, 1983.
3	Dr Rob doesn't appear to have attended many	3	Dr William Murray is a consultant haematologist,
4	UKHCDO meetings. The second half of the seventies has	4	involved with the care of patients from '87 until
5	Dr Rob attending the meeting in 1977 only.	5	2010, and the haemophilia service was then taken over
6	Dr Stevenson is not recorded as attending UKHCDO	6	by Dr Craig.
7	meetings in the 1980s.	7	In terms of facilities, we have a description
8	And there is no information to suggest patients	8	from a witness treated at the Centre in the early
9	were infected with HIV at the Walton Centre.	9	1980s describing a lack of facilities, children dealt
10	In relation to hepatitis, the evidence the	10	together with adults, as the Haematology Centre was
11	Inquiry has received is in relation to patients	11	essentially a tiny room.
12	infected with hepatitis C following a blood	12	As was common in Scotland, there were close
13	transfusion.	13	links between the Blood Transfusion Service and the
14	So that, sir, is the position in relation to	14	provision of haemophilia care, and Dr Cook, as
15	Walton.	15	Director of the Centre, was also the regional director
16	PRESENTATION RE INVERNESS, SCOTLAND	16	of the north of Scotland Blood Transfusion Service,
17	MS RICHARDS: Can we move then to Scotland and to	17	from 1960 to 1982.
18	Inverness.	18	We've put a little bit of information in our
19	So the Haemophilia Centre in Scotland described	19	written note about the Transfusion Service but we're
20	by its director in the late seventies as the smallest	20	going to be looking in more detail at hearings later
21	centre in the UK was located at the Raigmore Hospital	21	in the year in relation to the blood services across
22	in Inverness.	22	the United Kingdom so we'll no doubt come back to
23	Dr Cook was the director through the seventies	23	those issues.
24	until his death in 1982, and he is minuted as having	24	In terms of the numbers of patients registered
25	attended UKHCDO meetings from 1968 onwards.	25	or treated at the Centre, in the seventies, the
	109	20	110
	109		110
1	figures seemed to be between 14 and 18 patients on an	1	a separate form in relation to home treatment, and the
2	annual basis. And the returns indicate that the	2	figure there given is 35,270 units of
3	treatment provided was almost exclusively Edinburgh	3	Edinburgh Factor VIII for home treatment and, if we
4	Factor VIII and IX and that commercial products were	4	look at the comment below, we can see it said:
5	not used.	5	"It is our intention to increase the number of
6	I'll just look at a couple of returns by way of	6	patients on home treatment in the next five-year
7	example.	7	period in view of the difficult problems occurring
8	So if we go to HCDO00002503, please, Soumik.	8	[from] long distances to this Centre in a scattered
9	I've given you too many zeroes	9	community."
10	SIR BRIAN LANGSTAFF: There are three zeroes, it must	10	Then it's really a similar pattern as we go
11	be	11	through the years.
12	MS RICHARDS: HCDO0002503, my apologies.	12	So HCDO000205. So 18 haemophilic patients
13	So we can see here the annual return for 1976,	13	treated. No haemophilia B patients treated that year.
14	the director lain Cook, 20 patients treated during the	14	There's one patient with Factor VIII antibodies.
15	year, and then we can see, in terms of usage: 10,720	15	If we go to the bottom, we'll see the sole
16	units of cryoprecipitate, but the bulk of the	16	product identified there is the Edinburgh Factor VIII,
17	treatment is with Scottish NHS concentrate, 182,950.	17	165,690 units.
18	That's pretty much the pattern we see if we then	18	There are, in relation to that year, identified
19	look at the 1977 return, HCDO0002504. We can see	19	on the various forms that are attached, I think two
20	19 patients treated, presumably haemophilia A patients	20	patients on regular home therapy.
21	treated, and one Christmas Disease patient treated.	21	If we go to the return for 1979, HCDO0002506, we
22	If we look towards the bottom of the entry, so	22	can see 20 patients, haemophilic patients, treated
23	no cryoprecipitate usage recorded, "Other Materials"	23	during the year. One haemophilia B patient treated.
24	identified as "Factor VIII Edinburgh", 144,780 units.	24	And then we can see, again, it's Edinburgh
25	If we look over the page, please, we can see	25	concentrates being you'd for Factor VIII, 151,210, and
	111		112 (28) Pages 109 - 112
			• • •

1	then Factor IX, 5,100 units approximately.	1	of the Laboratory, and that all these 5 were on home
2	And that's really the pattern that continues so	2	treatment, and a total of 1357 bottles of Factor 8
3	I won't go through all the rest of the returns, but,	3	concentrate, all from Edinburgh, were used.
4	again, 1980, it's 15 patients with haemophilia A	4	"So far I have founding no evidence that
5	treated, one haemophilia B. Only Edinburgh factor	5	Factor 9 Concentrate has been used for haemophilia B,
6	concentrates recorded.	6	and as yet we have not verified. The data enquired
7	The same is true for 1981, when there's	7	about a presence of inhibitors, but as far as I can
8	12 haemophilia A patients, one haemophilia B patient.	8	see none of the patients have acquired one.
9	Again. Only Edinburgh Factor VIII concentrates	9	"We are doing our best to acquire the
10	recorded.	10	appropriate information"
11	If we go then, in relation to 1982, to	11	That would probably appear to be something,
12	HCDO002509, we see a letter from Dr Discombe, a local	12	probably, of an underestimate in terms of the number
13	consultant haematologist, to Ms Spooner at Oxford, and	13	of patients treated, but that represents a snapshot at
14	•	13	the time.
	it records that he's having a certain amount of		
15 16	trouble in compiling the data requested because	15 16	If we go to the second page of this document,
16	Dr Cook died in August.	16	it's a follow-up letter in July 1983 from the
17	" I arrived (so that's 1982) in late November	17	Transfusion Service, to Ms Spooner. And if we look at
18	and there has been considerable difficulty with some	18	the last paragraph, it says:
19	of our out-stations, which appear to be unable to	19	"I regret the records are far from complete or
20	maintain the desired records."	20	guaranteed but when we get ourselves sorted out with
21	Dr Discombe refers to trying to get the	21	a proper filing system in respect of the Haemophilia
22	information in a reasonable pattern. He says in the	22	Centre the statistics will again be accurate."
23	next paragraph:	23	Then if we just look at 1983, which is
24	"Preliminary studies suggest that 5	24	HCDO0002510, and we go to page 4, we can see there
25	haemophilia A patients were treated under the control	25	Dr Taylor now identified as the director,
	113		114
1	13 haemophilia A patients, one von Willebrand's. Then	1	to an enquiry about Factor VIII concentrate, June 1973
2	we have the figures, NHS Factor VIII concentrate no	2	and Dr Cook writes to Dr Watt saying:
3	reason to think that's anything other than Edinburgh	3	"Although I'm in charge of the 'Haemophilia
4	concentrate and the figures given for inpatient and	4	Centre' here, the number of Haemophiliacs I have is
5	home therapy, so 183,360 hospital treatment, 176,580	5	only 16. It's just not possible to undertake any
6	home treatment, and then some cryoprecipitate and some	6	research into a new product as these people are so
7	NHS concentrate used for the treatment of patients	7	
8	·		scattered and one cannot optain the required specimens
9	with yon Willebrand's		scattered and one cannot obtain the required specimens or the follow-up needed. The main decisions about
	with von Willebrand's.  And the same pattern, 1984 and 1985: 16	8	or the follow-up needed. The main decisions about
	And the same pattern, 1984 and 1985: 16	8 9	or the follow-up needed. The main decisions about this material will obviously [need] to be taken in
10	And the same pattern, 1984 and 1985: 16 haemophilia A patients, two haemophilia B for 1984,	8 9 10	or the follow-up needed. The main decisions about this material will obviously [need] to be taken in Glasgow and Edinburgh and I'll be interested to hear
10 11	And the same pattern, 1984 and 1985: 16 haemophilia A patients, two haemophilia B for 1984, only Edinburgh factor concentrates recorded. 1985	8 9 10 11	or the follow-up needed. The main decisions about this material will obviously [need] to be taken in Glasgow and Edinburgh and I'll be interested to hear what is decided in due course."
10 11 12	And the same pattern, 1984 and 1985: 16 haemophilia A patients, two haemophilia B for 1984, only Edinburgh factor concentrates recorded. 1985 records the treatment of ten haemophilia A and one	8 9 10 11 12	or the follow-up needed. The main decisions about this material will obviously [need] to be taken in Glasgow and Edinburgh and I'll be interested to hear what is decided in due course."  So it sounds like an invitation to participate
10 11 12 13	And the same pattern, 1984 and 1985: 16 haemophilia A patients, two haemophilia B for 1984, only Edinburgh factor concentrates recorded. 1985 records the treatment of ten haemophilia A and one haemophilia B patient. Again, only the NHS Edinburgh	8 9 10 11 12 13	or the follow-up needed. The main decisions about this material will obviously [need] to be taken in Glasgow and Edinburgh and I'll be interested to hear what is decided in due course."  So it sounds like an invitation to participate in some form of trial or study in relation to a new
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10 11 12 13 14 15	And the same pattern, 1984 and 1985: 16 haemophilia A patients, two haemophilia B for 1984, only Edinburgh factor concentrates recorded. 1985 records the treatment of ten haemophilia A and one haemophilia B patient. Again, only the NHS Edinburgh factor concentrates recorded.  We see, when we look at 1986, which is	8 9 10 11 12 13 14	or the follow-up needed. The main decisions about this material will obviously [need] to be taken in Glasgow and Edinburgh and I'll be interested to hear what is decided in due course."  So it sounds like an invitation to participate in some form of trial or study in relation to a new SNBTS PFC product.  Then if we look at SBTS0000309_159, we'll see
10 11 12 13 14 15	And the same pattern, 1984 and 1985: 16 haemophilia A patients, two haemophilia B for 1984, only Edinburgh factor concentrates recorded. 1985 records the treatment of ten haemophilia A and one haemophilia B patient. Again, only the NHS Edinburgh factor concentrates recorded.  We see, when we look at 1986, which is HCDO0002513, the recording of at the bottom of the	8 9 10 11 12 13 14 15	or the follow-up needed. The main decisions about this material will obviously [need] to be taken in Glasgow and Edinburgh and I'll be interested to hear what is decided in due course."  So it sounds like an invitation to participate in some form of trial or study in relation to a new SNBTS PFC product.  Then if we look at SBTS0000309_159, we'll see again a letter from Dr Cook to Dr Watt. This is
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10 11 12 13 14 15 16 17 18 19 20 21 22 23	And the same pattern, 1984 and 1985: 16 haemophilia A patients, two haemophilia B for 1984, only Edinburgh factor concentrates recorded. 1985 records the treatment of ten haemophilia A and one haemophilia B patient. Again, only the NHS Edinburgh factor concentrates recorded.  We see, when we look at 1986, which is HCDO0002513, the recording of at the bottom of the page, sorry the recording of DDAVP the first time.  But again, the main product used is the Edinburgh concentrates.  Then if we just look at a handful of bits and pieces of correspondence, we can see that there is correspondence between Dr Cook and John Watt at the PFC. And indeed correspondence with Dr Cook and	8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23	or the follow-up needed. The main decisions about this material will obviously [need] to be taken in Glasgow and Edinburgh and I'll be interested to hear what is decided in due course."  So it sounds like an invitation to participate in some form of trial or study in relation to a new SNBTS PFC product.  Then if we look at SBTS0000309_159, we'll see again a letter from Dr Cook to Dr Watt. This is 23 September 1975, and it gives an indication of what Dr Cook's approach to treatment may have been.  If we go further down the page, we can see halfway down that paragraph beginning "This is not a quibble", he says this:  "It did seem from last week's meeting that the really severe haemophiliacs might well need a dose

them. This is no doubt being very greedy at the start and I feel they are extremely fortunate to be given even one dose on a regular basis but I would like to hear whether it is possible that the amount to Inverness might be increased from twelve to eighteen and if so at what future date. No doubt my plan is too ambitious at this stage but you will, I am sure, appreciate that these demanding patients and their relatives do like to know where they stand ..."

It appears that Dr Cook was keen on being able to provide a greater amount and more regular treatment

There are then various letters -- I'm not proposing to go through them in any detail -- in 1975 showing a degree of fluctuating availability of product. So in October 1975 Dr Cook wrote saying:

to some, at least, of the more severely affected

"We've got a shortfall of Factor VIII, we've had to return to making more cryoprecipitate."

However, by the end of that year he says:

"Well, we're getting the lion's share of Factor VIII over the last three months, this is unfair, we're going to return to using cryoprecipitate and restrict our Factor VIII to a couple of severe

haemophiliacs to restore the balance of fair play", as 117

of patient.

patients.

There's also little information about either Dr Cook's or Dr Taylor's knowledge of non-A, non-B hepatitis. They did, however, attend a number of UKHCDO meetings, and also local meetings, meetings of Scottish directors, at which there were discussions about the hepatitis risks.

Of course, Dr Cook in his role within the Transfusion Service was part of decision making in Scotland about the screening of blood donors for hepatitis in the early 1970s and, again, we'll no doubt come back to this when we look at the blood services later in the year, but we've identified in our note some correspondence from Dr Cook in relation to the introduction of hepatitis screening in the early 1970s. He is said, by 1975, to be testing every specimen for hepatitis B and there's, again, an interesting exchange of letters between Dr Cook and Dr Cash that we may want to look at in more detail when we examine the role of the blood services.

In terms of knowledge of risk of AIDS and response to risk, as we've heard, Dr Cook died in, I think, August 1982. The first meeting I have identified Dr Taylor attending, where issues relating to AIDS were discussed, was a meeting in January 1983.

he puts it, between the smaller centres.

He raised concerns about supply of Factor VIII in 1977 and talked about having to rely again on cryoprecipitate.

By June 1979 there's correspondence suggesting that there were three haemophiliacs at that stage at the centre on home treatment. Dr Cook is there now saying he's got an excess of Factor VIII stock. In 1981 he offered to reduce his Factor VIII allocation, and says:

"I'll be the first to shout if I think my 16 haemophiliac patients are being inadequately treated in the long term."

The conclusions of the Penrose Inquiry, in terms of the factual position in relation to this centre, was that between 1981 and 1985 almost no cryoprecipitate was used, that appears to be broadly consistent with the returns, and that only SNBTS products were used at the centre from 1974 onwards, and that heat-treated products were supplied to the Centre in December 1984.

That's the position in relation to what products were used as a matter of fact. There's no particular documentation casting any light on the policies or approaches towards treatment of different categories

That is at PRSE001736, we can see it's a meeting of the directors of the Scottish National Blood
Transfusion Service and Haemophilia Directors held in St Andrew's House, Friday, 21 January 1983 and we can see present, towards the bottom of the list of attendees, Dr Taylor.

Then if we go to the last page, no, the seventh page, please Soumik, we can see item 6, about halfway down the page, is headed "Acquired Immune Deficiency Syndrome (AIDS)":

"Dr Cash drew members attention to recent articles in the United States and also in the Observer and the Lancet, about this problem. An MMWR extract ... had been circulated with his paper."

It seemed likely, given the timing, to be the December 1982 MMWR:

"Dr Ludlam informed members that in the UK a letter and questionnaire had been sent to haemophilia directors."

In fact, I think the position is there was a plan to send that letter out and it was actually sent out in March 1983 but, in any event, there is Dr Taylor receiving, in January 1983 what appears to be an update of the factual position in terms of those infected.

(30) Pages 117 - 120

1	SIR BRIAN LANGSTAFF: Do we actually have a date for the	1	the treatment of children at present, because of the
2	time in January?	2	new danger of AIDS. Dr Hann concurred. A policy
3	MS RICHARDS: The meeting is 21 January.	3	seemed to be emerging however to use less cryo for
4	SIR BRIAN LANGSTAFF: Thank you.	4	haemophilia A patients. It was agreed that a certain
5	MS RICHARDS: Of course, we have present, amongst others,	5	minimal amount of cryo was required and Dr Cash
6	Dr Forbes and Dr Ludlam. We've explored with	6	pointed out that TDs could produce it in emergencies."
7	Dr Ludlam obviously directly his knowledge and	7	Then there's a reference to the phasing in of
8	involvement in matters at the time. We've got the	8	heat-treated Factor VIII.
9	Immuno meeting taking place at London Airport in the	9	Again, Dr Taylor present at that meeting and for
10	same month, and so on. We know there were Reference	10	that discussion.
11	Centre Director meetings going on in February 1983, so	11	In terms, then, of the arrangements for patients
12	no reason to think that kind of information wouldn't	12	to be tested for HTLV-III and informed of their
13	be communicated to the directors of the smaller	13	diagnosis, Professor Ludlam told us he sent out
14	centres and this seems to be precisely what this	14	invitations to a range of centres, or patients at
15	minute of the meeting was doing.	15	centres, in respect of that group meeting that was
16	We can see that Dr Taylor also attended a later	16	held in Edinburgh in December 1984. There's no
17	meeting in February 1984 of the same group.		evidence, we've detected, of Inverness patients
18		17	•
	PRSE0001556. So 2 February 1984, Dr Taylor is in the	18	attending that.
19	list of attendees. If we go to the second page,	19	However, we then have a template letter signed
20	I think this is a document we looked at with	20	by Dr Taylor in February 1985, which is at
21	Professor Ludlam, but just a little further down, so	21	HIGH0000011. So we can see it's a draft dated
22	the paragraph (ii):	22	12 February 1985, "Dear" and then it presumably
23	"Members discussed the suggestion that the	23	intended to be sent to the patients of the Centre:
24	production of cryoprecipitate could now be reduced.	24	"As you are no doubt aware, there is
25	Dr Ludlam said that cryoprecipitate was preferred in	25	considerable disquiet among people with Haemophilia
	121		122
1	throughout the country, about the subject of AIDS and	1	tested, there's a second template draft letter of the
1	throughout the country, about the subject of AIDS and	1	tested, there's a second template draft letter of the
2	we have had several enquiries from patients. Reports	2	same date, 12 February 1985, at HIGH0000012:
2	we have had several enquiries from patients. Reports in the Press and on Television are often biased and	2	same date, 12 February 1985, at HIGH0000012: "Dear [blank]
2 3 4	we have had several enquiries from patients. Reports in the Press and on Television are often biased and may be misleading. For this reason I am enclosing	2 3 4	same date, 12 February 1985, at HIGH0000012: "Dear [blank] "Because of the recent problems with AIDS, we
2 3 4 5	we have had several enquiries from patients. Reports in the Press and on Television are often biased and may be misleading. For this reason I am enclosing some notes which we have compiled in the hope that we	2 3 4 5	same date, 12 February 1985, at HIGH0000012:  "Dear [blank]  "Because of the recent problems with AIDS, we are now producing new types of Coagulation Factors.
2 3 4 5 6	we have had several enquiries from patients. Reports in the Press and on Television are often biased and may be misleading. For this reason I am enclosing some notes which we have compiled in the hope that we can answer the questions most commonly asked. It is	2 3 4 5 6	same date, 12 February 1985, at HIGH0000012:  "Dear [blank]  "Because of the recent problems with AIDS, we are now producing new types of Coagulation Factors.  "Before this can be issued, we need to do
2 3 4 5 6 7	we have had several enquiries from patients. Reports in the Press and on Television are often biased and may be misleading. For this reason I am enclosing some notes which we have compiled in the hope that we can answer the questions most commonly asked. It is simply a Summary of what we know at present about this	2 3 4 5 6 7	same date, 12 February 1985, at HIGH0000012:  "Dear [blank]  "Because of the recent problems with AIDS, we are now producing new types of Coagulation Factors.  "Before this can be issued, we need to do a blood test on each of our patients. Could you
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1 received mainly commercial Factor VIII concentrate, 2 had been tested, or their stored samples had been 3 tested by Dr Follett and found to be HTLV-III positive, and Dr Pettigrew says: 4 5 "... I thought you ought to be informed so that 6 you can arrange for appropriate measures to be taken." 7 Now, the Inquiry has evidence from the patient 8 who is the subject of the letter, whose recollection 9 is of their parents being told of the HIV infection in 10 around 1987, 1988 so two, possibly three years on from 11 this, being told by Dr Taylor. 12 13 14

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That witness's account is when his parents asked why they'd not been told earlier, but doctors said that it was not hospital policy to tell patients.

That issue appears to have triggered a letter from The Haemophilia Society, which is at LOTH0000006\_028.

It's a letter from Mr Watters and it's to Dr Rizza, 22 May 1989, but it concerns patients at Inverness and Aberdeen:

"I have learnt recently that patients with haemophilia attending Raigmore Hospital in Inverness and Aberdeen Royal Infirmary are not necessarily being advised of their HIV status. This came to light recently when a boy of 14 was suddenly told of his HIV

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have received the above document from the General Medical Council. Sufficient concern has been expressed by individual members of the profession in Ayrshire and Arran to warrant discussion by the Area Medical Committee

"Following this discussion, I have been asked to write to you to express our unanimous view that, while we will of course abide by the advice given, we disagree with the requirements imposed on the medical profession.

"We object to the advice on two grounds. Firstly, we do not feel that AIDS should not be treated differently to any other disease, and we would hope that we would extend the same standard of care and compassion to a patient with AIDS as to a patient with any other potentially fatal disease. We have all taken blood for wassermann reaction, for example, on antenatal patients, and never have sought patient consent or explained the catastrophic social consequences if a test were to prove to be positive.

"Secondly, your stress on confidentiality towards patients is irrational when, in the same paper, you insist that a doctor counselling a colleague who is HIV positive must 'inform' on that colleague should he or she not accept the advice on

antibody status -- his parents having assumed, and the lack of any information to the contrary, that he was negative. I also understand that there were two patients at Aberdeen Royal Infirmary where there was a long delay in giving the information to the patients or their families."

Mr Watters is asking Dr Rizza if UKHCDO has some policy on this which could be circulated.

Certainly, the evidence that the Inquiry has received from some witnesses is to the effect that patients were seen from their medical records that they were being tested for HTLV-III but they were not told at the time that they were being tested.

There's another letter from Dr Taylor in October 1988 which may cast some further light upon that. It's at HIGH -- let me just find it -- 0000020. It starts with a letter dated 6 September 1988 addressed to the registrar of the General Medical Council and it's from a Dr McClure, described as the honorary secretary of the Area Medical Committee of the Ayrshire & Arran Health Board, and it refers to a publication from the GMC entitled HIV Infection and AIDS: The Ethical Considerations, which I think we looked at in a presentation a few weeks ago:

"Doctors in this Area, as doctors elsewhere,

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changing practice offered.

"We would respectfully suggest that the General Medical Council reconsiders the advice to the profession. It is our view that, if the legal advice used by the GMC is valid in law, then the law requires amendment."

So that's the view being expressed by the Area Medical Committee. If we go over the page, we see then a supporting letter from Dr Taylor at Inverness:

"Thank you for forwarding the correspondence on this subject. Our department would give the strongest possible support to the views expressed by Dr McClure in his letter to Dr Paterson ..."

Now whether that is referring to the same letter or not is unclear but we've received these documents together, but the issue, is clear from the remainder of the sentence:

"... ie we feel it inappropriate, unethical and illogical that we have to seek patient consent before testing for HIV."

That would appear to be a pretty clear expression of Dr Taylor's views as at 1988, that it was positively inappropriate, unethical and illogical to seek patient consent before undertaking HIV testing.

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In terms of the numbers infected with HIV in Inverness, the conclusion, as we understand it, of the Penrose Inquiry, although it was told by the director of the Centre in 2011 that there were no haemophilia patients considered to have been infected with HIV as a result of treatment in Inverness, the Penrose Inquiry's conclusion was that there were two patients, and that's consistent with the provisional data that we have received from the UKHCDO.

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So if we go to INQY0000250, and we go to the last page. This is the table the Inquiry has put together from the data it has received from UKHCDO. Inverness is the last hospital, last Centre identified, and it records there, according, as we understand it, to the information held on the National Haemophilia Database, two patients testing positive in 1985.

In terms of the arrangements in relation to hepatitis C, we've little by way of documentary evidence. There's evidence the Inquiry has received from patients about being informed about hepatitis C diagnosis at routine appointments, which is a not unfamiliar story.

The Penrose Inquiry's conclusion, again in relation to patients with hepatitis C, was that, as at

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a nurse at the Aberdeen Royal Infirmary and working there in relation to the care of patients with bleeding disorders from 1985 to 1987. She has provided us with a description of the facilities in terms of haematology beds, based in ward 41 in the Royal Infirmary about nine beds and then it split off to ward 16 in around 1987 and then ward 112.

As with Inverness, there's a close relationship between the Blood Transfusion Service and the Haemophilia Centre, so the Aberdeen and North East of Scotland Blood Transfusion Service was also based at the Aberdeen Royal Infirmary. The director of that service was Dr Brodie Lewis in the 1970s, and then Dr Stan Urbaniak became the regional director in 1982.

Again, their role and policies and decision making will be explored in more detail in later hearings.

Dr Dawson in her statement to the Inquiry talks about the relationship between the Haemophilia Centre and the Blood Transfusion Service, explaining that the Haemophilia Centre received concentrates from the blood bank in the local Blood Transfusion Service, mostly SNBTS concentrates. She describes the blood bank staff keeping details of the amount of products used issued to each patient throughout the year.

2011, there were 26 living patients infected with 2 hepatitis C at Inverness. 3 Sir, that's the position in relation to 4 Inverness 5 Just forgive me for a moment while I rearrange

bundles, I'm going to turn to Aberdeen.

PRESENTATION RE ABERDEEN HAEMOPHILIA CENTRE MS RICHARDS: So Aberdeen, Aberdeen Haemophilia Centre, located at the Aberdeen Royal Infirmary. Director was 10 Dr Audrey Dawson from 1967 to 1996. She has provided 11 a statement to the Inquiry which says she shared 12 responsibilities as a team with Dr King, who was 13 a paediatric haematologist, and Dr Bennett, who was 14 a consultant haematologist.

> Dr Dawson says that she spent much of her time developing the service for leukaemia and lymphoma and other malignant haematology services and that Dr Bennett was effectively the person with expertise in bleeding conditions, but she was officially the haemophilia director from that period, 1967 to 1996.

Dr King has also provided a statement to the Inquiry about his role at the Royal Aberdeen Children's Hospital and his role as a paediatric haematologist.

We've also a statement from Gina Andrew, who was

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She says there was a good relationship with the Blood Transfusion Service, that the Transfusion Service played a key role in maintaining records of treatment use. She says there were many discussions between the Scottish National Blood Transfusion Service and the Regional Transfusion Service about risk of infection from blood and blood products. She savs:

"These weren't informal meetings but we tried to make the best decisions that we could based on what was known at the time."

If we go to STHB0000568, we can see a letter Dr Dawson wrote to the -- or wrote around the time of the Penrose Inquiry. If we just pick it up where she says, "We would like to make the following comments", paragraph 1. I should say she explains that this is following discussions she'd had with Dr Bennett. She says:

"We had several patients whose exposure to commercial concentrates before arrival was not accurately known to us. Aberdeen and North-East Scotland in the 1970s-80s were experiencing an economic boom related to North Sea oil, and we had many incomers, often transient. One man I remember treating was French, working off-shore on a Total rig,

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1	having not admitted to his French employers that he	1	Dr Dawson there identified as director, haemophilic
2	had haemophilia There were also other	2	patients treated during the year, nine. Then, in
3	haemophiliacs, who were transient in Grampian, either	3	terms of the products used, 49,630 units of
4	working or on holiday. Also, our 'native' patients,	4	cryoprecipitate, 818,450, it looks like, units of
5	even though treated probably exclusively with NEBTS	5	Edinburgh Factor VIII concentrate.
6	material in Aberdeen, would have been exposed to	6	Then really it's a similar position in 1977,
7	commercial products when away from North-East	7	I won't go to that return, 14 haemophilia A, five
8	Scotland."	8	von Willebrand's patients treated, treatment is
9	Then she says in paragraph 2:	9	cryoprecipitate and Edinburgh NHS Factor VIII.
10	"With regard to the records of material which	10	If we go to the return for 1978, HCDO0002431, we
11	were used in treatment, the North-East Blood	11	can see 16 patients, haemophilic patients treated
12	Transfusion Service actually obtained the material for	12	during the year, one with antibodies, and then, in
13	us, and kept detailed records of batch numbers, etc;	13	terms of the treatment, 77,760 units of cryo, 96,370
14	while we (ie Haemophilia Centre) kept only minimal	14	units of Edinburgh Factor VIII, but then a small
15	records of this in the clinic/ward, and this mainly	15	amount of commercial product, so Hemofil, being
16	related to the amount of and type of material. Even	16	used it looks like 4,590 for the first time in
17	these latter records would have fallen victim to the	17	the returns that we have.
18	Grampian clinical records system, where material which	18	There's a similar picture, again I won't go
19	was considered transitory was culled in the 1980s, in	19	through each of the documents on the screen, but
20	order to try to contain the bulk of the clinical	20	there's a similar picture for 1979: cryoprecipitate,
21	notes."	21	Edinburgh factor concentrates, and then a similar
22	So that was her recollection as set out in	22	amount of Hemofil being used, also FEIBA for the first
23	a letter to the Penrose Inquiry.	23	time recorded for 1979.
24	If we then look at the annual returns, we can	24	Then we see FEIBA being recorded in 1980 and
25	pick it up with 1976, HCDO0002429. We can see	25	1981 and 1982, as well as cryoprecipitate in Edinburgh
	133		134
1	NHS factor products. We don't see Hemofil or any	1	the bulk of the treatment is with the NHS concentrate.
2	other commercial concentrate recorded after 1979.	2	Again, presumably, I think, Edinburgh concentrate.
3	If we then pick matters up in 1983, HCDO0002436.	3	And there's a reference there to material sent to the
4	We can see the directors identified as Dr Bennett and	4	islands.
5	Dr Dawson jointly.	5	And then a small amount of cryoprecipitate used
6	Twelve haemophilia A patients, one carrier,	6	for carriers of haemophilia A and von Willebrand's,
7	eight von Willebrand's patients treated.	7	and reference there to Factor IX being used again in
8	We can see the bulk of the treatment for home	8	a small quantity.
9	treatment, in fact exclusively, is the NHS Factor VIII	9	Then it's a similar picture in relation to 1985,
10	concentrates again, presumably, Edinburgh	10	I wouldn't go to the return itself. We have
11	concentrate 255,908 units. 87,000-odd units being	11	18 haemophilia A, two von Willebrand's patients
12	used in hospital. Cryoprecipitate being used only for	12	treated that year, one haemophilia B patient. Cryo,
13	the treatment of von Willebrand's patients, and	13	Edinburgh NHS products, FEIBA and plasma recorded.
14	a small amount of NHS concentrate being used for the	14	In terms of paediatric patients, Dr King has
15	same purpose, and then we can see, bottom of the page,	15	indicated in his statement to the Inquiry, in terms of
16	a small amount of porcine Factor VIII concentrate and	16	figures of patients, that as at 1985 he thinks there
17	then a much larger quantity, 246,000 units, of FEIBA.	17	were three severe haemophilia A patients, four
18	And then I don't think we have the return in	18	haemophilia A patients who were mild or moderate, no
19	terms of haemophilia B but the pattern, as far as we	19	haemophilia B patients and five with von Willebrand's
20	can see, is Edinburgh concentrates only.	20	disease.
21	Then 1984 is a similar picture, HCDO0002437.	21	Dr Dawson in her statement has said that, due to
22	We can see 16 haemophilia A patients, two	22	the passage of time, she has little or no recall of
23	carriers, nine von Willebrand's patients.	23	the processes in place for ordering factor
24	A very small amount of cryoprecipitate being	24	concentrates. Her recollection is that they were
25	used for the treatment of haemophilia A patients, but	25	sourced from the PFC or the blood products were
	135		136 (34) Pages 133 - 136
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1	sourced from the PFC in Edinburgh, and she says:	1	MS RICHARDS: Yes. We don't know whether that relates to
2	"When we didn't have enough of a product we	2	a longer time period or we don't know what the
3	would have used commercial factor, although I think in	3	explanation for that is.
4	Aberdeen that was rarely the case."	4	SIR BRIAN LANGSTAFF: Because, well, if it's the two added
5	And that appears to be borne out by the returns.	5	together, because there's no Hemofil after 1979, the
6	There is one additional document which indicates	6	first bit of tiny Hemofil was in '78 2431. That's
7	the purchase of Hemofil in 1979. That is at	7	0002431, HCDO.
8	SBTS0000233_008 I think I said it wrong,	8	MS RICHARDS: It's not far off the amounts recorded
9	SBTS0000223_008.	9	for (overspeaking)
10	It's headed "Purchase of commercial blood	10	SIR BRIAN LANGSTAFF: Well, it's exactly the same, pretty
11	products as reported by transfusion directors". For	11	much
12	Aberdeen Royal Infirmary, we see there recorded	12	MS RICHARDS: It's about 30 units out, I think, on my
13	Hemofil. It's a larger number of units than appears	13	quick mental arithmetic.
14	on the annual return: 9,780 units the year to	14	SIR BRIAN LANGSTAFF: So it doesn't add up, not exactly.
15	31 August '79, FEIBA, and then Buminate, which I think	15	MS RICHARDS: No
16	is albumin, there recorded.	16	SIR BRIAN LANGSTAFF: And yet the figures are quite
17	SIR BRIAN LANGSTAFF: Can we just go back to 2432?	17	specific.
18	HCDO0002432. Scroll down a bit, please.	18	MS RICHARDS: Yes. That's the data that we have.
19	Yes, that's what I thought. The number of units	19	The conclusion of the Penrose Inquiry in terms
20	there is 4,860.	20	of what was being done at Aberdeen was that the use of
21	MS RICHARDS: Yes.	21	imported commercial concentrates was very infrequent
22	SIR BRIAN LANGSTAFF: If we go back to what we've just	22	throughout the material time. That at least appears
23	been looking at, SBTS000223_008.	23	to be borne out by the returns that we have.
24	MS RICHARDS: It's 9,000, I think, yes.	24	In terms of the approach to treatment, Dr Dawson
25	SIR BRIAN LANGSTAFF: Yes, double, almost.	25	has said in her statement to the Inquiry that:
	137		138
1	"Most of the boys and men that we treated that	1	and Dr Dawson, along with other directors,
2	severe haemophilia and so had no alternative to factor	2	participating in the UKHCDO's hepatitis survey.
3	concentrates."	3	Dr Dawson attended a number of UKHCDO meetings
4	So that was her perspective.	4	in the 1970s, so she was there in 1971 where Dr Biggs
5	Her view was that home therapy with	5	summarised her report on the incidence of jaundice and
6	cryoprecipitate wasn't much of an option.	6	inhibitors.
7	Gina Andrew, the nurse, recalls Dr Dawson and	7	Dr Dawson and Dr Bennett both attended the 1972
8	Dr Bennett as being keen to get as many patients as	8	UKHCDO meeting. Again, there was a discussion about
9	possible onto home treatment, and she describes	9	jaundice. Dr Dawson was there in November 1974, when
10	this is the nurse describes how once most of the	10	not only was there a further update from Dr Biggs
11	patients were on home treatment the numbers coming	11	about the jaundice survey but Dr Craske discussed the
12	into the ward decreased dramatically as they no longer	12	epidemic or outbreak of hepatitis in Bournemouth from
13	required admission.	13	commercial products.
14	Dr Dawson's recollection is that for mild	14	She attended in 1975, where there was again
15	haemophiliacs DDAVP would have been used. We don't	15	a discussion about hepatitis and, in 1979, when
16	see it recorded on the annual returns, but then that's	16	Dr Craske presented material about non-A, non-B
17	been quite a common feature in different parts of the	17	hepatitis.

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seventies:

treatment."

the early 1970s that hepatitis B could be transmitted by blood. She has told the Inquiry that in the 1970s she became aware of non-A, non-B hepatitis. In

Dr Dawson has told the Inquiry that she was aware in

In terms of knowledge of risk, of hepatitis,

sne became aware of non-A, non-B nepatitis. In common, again, with other centres, we see data being

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United Kingdom.

provided to Oxford which recorded cases of jaundice, 139

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became aware of non-A, non-B hepatitis in the

What she said to the Inquiry was that when she

"It did not change treatment much, as it did not

appear to be a progressive condition, and none of the

patients were dying of liver disease but would have

suffered seriously if we'd stopped their Factor VIII

In terms of knowledge of AIDS, again, Dr Dawson, as a Centre Director, would have had access to the minutes of the UKHCDO meetings or such meetings as she was herself unable to attend.

She has said in her statement that the risk of AIDS was highlighted in meetings of the Scottish Haemophilia Centre Directors. She wasn't at that January 1983 meeting that we looked at a few minutes ago. But she was -- I think Dr Bennett -- I'll double check, I think Dr Bennett was in attendance at that meeting.

There are various Scottish meetings, 1985, 1986, and UKHCDO meetings where either Dr Dawson or Dr Bennett attend. So while there were no particular documents to refer you to, no reason to think that they would have been any less equipped to follow reports in the medical press and what was being discussed at meetings than anyone else.

In terms of the process of testing, we have relatively little information about the process itself, but in terms of patients being told of their diagnosis, Dr Dawson says patients would not have been told as a group, but in individual appointments.

There is one patient who has told the Inquiry that he was informed of his HIV infection face-to-face

what he's saying.

We looked a few minutes ago, in the context of Inverness, at that letter from David Watters of The Haemophilia Society May 1989 to Dr Rizza. I wouldn't go back to it, but you'll recall from it that, as well as referring to an Inverness patient not being advised of HIV status, the letter referred to two patients at Aberdeen where there was a long delay in the diagnosis being provided to the patient or families.

In terms of numbers affected with HIV, Dr Dawson's recollection was that there were three patients at the centre infected with HIV, all of whom had severe haemophilia A. The evidence provided by the subsequent director, Dr Henry Watson, to the Penrose Inquiry, again was of three patients. That evidence suggested two had severe haemophilia A, one had moderate haemophilia A. The Penrose Inquiry then received information from UKHCDO to suggest that there were seven patients associated with Aberdeen who tested positive for HIV, and that's consistent, again, with the date the UKHCDO has supplied to the Inquiry at INQY0000250.

Then if we go to the last page, we can see Aberdeen is Centre 160, and there is identified a total of seven HIV cases to 1988. by Dr Bennett in a side room, recalls no real information being provided.

Dr Dawson doesn't think the testing of family members was offered as a matter of routine but said it would have been available if the request was made. In terms of the treatment of patients with HIV, she said there would have been referral to colleagues in the infection unit locally.

Then if we look at -- I think I've got the right note here, SBTS0000652\_083. This is a 1990 letter from Dr Dawson to Professor Cash, referring to a letter she has received from a lawyer representing a haemophiliac with inhibitors who'd -- well, who was known to be HIV positive in October 1985. That is the first test which was performed that we have records of, and there's no blood stored before that time, so that might assist in giving some indication about the timings for the undertaking of HTLV-III tests in relation to Aberdeen patients.

Dr Cash's response is at SBTS0000635\_069, 11 January 1991. He refers to how Dr Urbaniak will provide the details he requires but his observations: "It should be a fascinating investigation. My

money would be on the FEIBA!"

Presumably as the source of the infection, is

The data there would suggest that UKHCDO holds some records that would indicate tests being carried out on broad samples, because we have one test attributed to 1982 -- or one result, I should say, attributed to 1982, one 1984, four 1985, and one in 1986, giving a total of seven HIV cases.

**SIR BRIAN LANGSTAFF:** Seems a strange discrepancy, the three as against the seven.

MS RICHARDS: Yes. And it may be a matter we'll need to try to investigate more. But as I say, it did come up following -- the Penrose Inquiry report set out its analysis of those three cases, and then there was later information received by the Penrose Inquiry to suggest seven. So what the difference is between, on the one hand, Dr Dawson's recollection, which may, for all we know, be not an independent recollection but based upon what she understands was said to be the Penrose Inquiry, or may indeed be her own independent recollection, what explains that on the one hand as against the UKHCDO data that it then supplied to Penrose and has supplied to us, we don't know.

In terms of testing for hepatitis C, Dr Dawson's evidence to the Inquiry says that, upon the advent of hepatitis C testing, the Centre tested some of the patients but she says:

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1 "We didn't know what to tell the patients doctor said I had hepatitis C." 2 because we were not sure how the virus behaved and 2 Similarly, there are concerns expressed by 3 3 whether having it meant that the patients would go on witnesses that they were not given clear information 4 to have liver disease or be able to transmit it or 4 about what hepatitis C was or how they should 5 not." 5 understand its implications. 6 6 She said in the statement there was a policy of Dr King has indicated that one paediatric 7 offering hepatitis C testing to all patients who came 7 patient was infected with hepatitis C. In terms of 8 8 to attention, and who'd had treatment with factor treatment for hepatitis C, Dr Dawson has referred to 9 9 concentrates in the seventies and eighties. the use of interferon. She recalls telling patients 10 It's not entirely clear what's meant by "came to 10 that the most common side effect was feeling as if you attention". It may be that that's patients as and 11 11 had flu. Again, others have recorded doctors giving 12 when they presented to the Centre on a routine 12 that as the indication but the real experience being appointment were tested, rather than a proactive 13 13 very different. 14 reaching out to patients. 14 Sir, that's the picture in relation to Aberdeen. 15 Again, not dissimilar to accounts we've heard in 15 The third Scottish Centre I'm going to turn to 16 relation to other centres across the United Kingdom. 16 is Dundee. It might be sensible if we could take The Inquiry's received statements from individuals or 17 a short break now because, although it's relatively 17 their families critical about how the information 18 18 short, I won't complete it in five minutes. 19 about hepatitis C was provided to them. 19 SIR BRIAN LANGSTAFF: Yes, well, we will take a break for 20 There's one witness, for example, who describes 20 just over 20 minutes, and come back at half past. 21 following -- finding out about her infection when 21 MS RICHARDS: Yes, sir, I should say it's apparent that 22 22 Dr Dawson walked into the room, and said, "Make sure I'm not going to get through all of the rest of the 23 you put the tissues in the red bin, we don't want to 23 centres today without doing an injustice to the 24 catch anything from you". And it was only when the 24 individual centres. So I'm certainly not going to get 25 patient asked about it that, she says, "The 25 to Cambridge or Norfolk and Norwich. I'll be able to 145 146 complete Dundee and Bristol, possibly also Truro, and 1 who was a consultant haematologist, was given 1 2 2 we'll have to see where we get to with Southampton as effectively the title of Haemophiliac Director and was 3 to whether we're able to do that appropriately or not. 3 in charge of the care of adult patients until 1991, SIR BRIAN LANGSTAFF: East Anglia will have to wait. 4 4 but his successor, who was Dr Philip Cachia, who took 5 MS RICHARDS: It might have to wait, and I apologise to 5 over in 1992, has said that Dr Heppleston wasn't 6 those who had any particular interest in hearing that 6 a haemophilia specialist and had a very heavy clinical 7 7 evidence. load looking after patients with haematological 8 8 (3.09 pm) malignancies. 9 9 Then Dr Cachia was --(A short break) 10 (3.30 pm) 10 SIR BRIAN LANGSTAFF: Dr Heppleston, you mean? PRESENTATION RE DUNDEE MS RICHARDS: No, sorry, so that was Dr Heppleston 11 11 MS RICHARDS: Sir, the third Scottish centre or source of 12 until 1991 --12 13 provision of haemophilia care is relating to Dundee. 13 SIR BRIAN LANGSTAFF: Dr Cachia? It wasn't a formal Haemophilia Centre in the MS RICHARDS: Dr Cachia took over in 1992 until 2004, 14 14 1970s. From 1972, however, adult haemophiliacs in 15 formally established the Tayside Haemophilia Centre 15 Dundee were under the care of Dr Tudhope. He was 16 16 in 1992. We've a statement from him to the Inquiry. 17 based, from 1975, in ward 5 and 6 at Ninewells 17 Then Dr Ron Kerr, who took over effectively as a locum 18 Hospital in Dundee. 18 and then as the consultant haematologist and director 19 In terms of paediatric provision from the 1970s 19 in around 2004, has also provided a statement to the 20 or late 1970s, Dr Sydney Wilson was in charge of 20 Inquiry, although obviously his evidence is focused 21 paediatric patients based at ward 30 in Ninewells 21 very much more on the modern position. 22 22 Hospital. There's evidence to suggest that Dr Wilson At the time that the Tayside Centre was formally 23 and Dr Tudhope held joint clinics during parts of the 23 established in 1992 by Dr Cachia there were around 24 1980s. 24 25 patients with severe haemophilia. 25 Dr Tudhope retired around 1986. Dr Heppleston, 25 We've got a description from Dr Cachia of the

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1 picture he identified when he arrived in around 1992: inconsistently recorded in the relevant patients' 2 no specific centre or dedicated location for 2 medical records." 3 3 haemophilia care, patients seen on the general And he says this: 4 4 haematology ward or day unit. He says: "The situation was in part due to the 5 "It was essentially a crisis intervention 5 underdeveloped haemophilia service and in part due to the unusual circumstance of a regional SNBTS service 6 service. There was no managed or organised system of 6 7 routine or prospective review of patients with 7 situated in the main hospital and providing services 8 8 clotting disorders, in terms of their general health, of both a regional transfusion centre and the local 9 9 joint disease, or any of the complications of hospital transfusion and cross matching services." 10 10 haemophilia or its treatment. Adults on home therapy So, as alluded to by Dr Cachia, there were close obtained supplies by contacting a technician from the 11 11 links in the years before that between the haemophilia 12 SNBTS laboratory and were issued with the required 12 service and the local transfusion service. product without regular medical supervision or formal 13 13 Dr Charles Cameron was the director of the East 14 review of their treatment." 14 of Scotland Blood Transfusion Service until 1981, and 15 He says there were no formal liaisons between 15 he was then succeeded by Dr Brookes in 1981, and there 16 the haematology department and key specialist services 16 are close links between the two. essential for the provision of comprehensive 17 17 So we see, for example, Dr Brookes representing haemophilia care, including the HIV service and 18 Dr Tudhope at a Haemophilia Centre Directors meeting 18 19 19 in October '83. hepatology. 20 He has also told the Inquiry that when he 20 That's the meeting at which the issue of 21 arrived in 1992: 21 reversion to cryoprecipitate and AIDS was discussed. 22 22 "The haematology department did not keep records And Dr Cachia himself says there was a close 23 of factor concentrate stocks, batch numbers, issues to 23 working relationship with the director and staff of 24 patients or home treatment use. Details of factor 24 the regional Scottish National Blood Transfusion concentrates given in Ninewells Hospital were 25 25 Service based in Ninewells Hospital and, again, no 149 150 1 doubt, we will explore later in the year, when we look 1 Christmas disease patients. 2 at the blood services in detail, more about the Blood 2 Then we can see, in terms of the units, 3 Service. 3 cryoprecipitate looks like 9,860 units, NHS 4 I will just note, however, in light of those 4 concentrate, it looks like there's -- it's, I think, 5 close working relationships, there's an interesting 5 a combination of 61,000 and 51,000 used, although it's 6 exchange of correspondence which, as I say, we will no 6 not entirely clear. Then there's a reference to 7 7 doubt look at later in the year, between Dr Brookes Factor IX concentrate further down. 8 8 and Dr Cash and others where Dr Brookes is raising Again, no reason to think that's anything other 9 9 concerns about the collection of blood in prisons and than local, as in from Edinburgh rather than from BPL. 10 borstals in Scotland, and she provided a witness 10 We can see that from the 1977 return, 11 statement to the Penrose Inquiry when she explained 11 HCDO0002445, where Edinburgh is specified as the 12 that her concerns about the use of blood in prisons 12 source of the concentrate. So that year we have ten 13 was based on her experience in the seventies working 13 patients treated, identified as haemophilic patients, six haemophilia B patients. We can see 14 in London. 14 15 15 cryoprecipitate still being used to a significant Again, that's in issue we'll clearly want to 16 extent, 77,360 units, and then Edinburgh Factor VIII 16 pick up on, but it's relevant, obviously, to the 17 question of local products, Scottish product, and the 17 concentrate, 89,400 units. And Edinburgh Factor IX 18 potential risk of transmission of viral infection. 18 concentrate, 38,100 units. 19 If we then look at numbers of patients treated, 19 And that's the pattern that follows over the 20 we won't look at all the returns, but a sample of 20 years. If we go briefly to 1978, HCDO0002446, we can 21 them. We can pick it up in 1976 at HCDO003224. 21 see the amount of concentrate in relative terms 22 22 Sir, this is the 1976 return. It's described reducing, and more treatments being by reference to 23 23

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here as the "East of Scotland Haemophilia Centre".

during the year, one with Factor VIII antibodies, six

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It's Dr Tudhope identified as director. 12 treated

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the Edinburgh concentrate. So it's 46,960 cryo and

86,000 Edinburgh Factor VIII concentrate and then,

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again, Factor IX concentrate, 61,800.

1 If we then look at 1980, HCDO0002448, Again, we see it's cryoprecipitate, and NHS 2 It's not entirely easy to read. We can see it's 2 concentrate. And then the only other product is 3 3 Hyate:C, purchased from Speywood, 22,750 units. nine haemophilia A patients, three von Willebrand's, 4 Then the remaining returns, for '83, '84, show 4 and the reason for going to this is that we can see 5 it's broken down into hospital and home treatment, the 5 only the use of Scottish concentrates and 6 6 forms now. Again, cryoprecipitate in use, 35,120, but cryoprecipitate. 7 solely hospital, not for home treatment. 7 From '85 shows only Scottish concentrates, no 8 8 And then two figures given. The main figure is cryoprecipitate. 9 9 188,940. That's described as "Total used for all And the number of patients treated ranges 10 10 patients". And then we have a rather more indistinct from: 14 haemophilia A, six haemophilia B, two 11 breakdown between hospital and home treatment, 11 von Willebrand's in 1983; ten haemophilia A, four with 12 I think. 12 haemophilia B, in 1984; twelve haemophilia A, seven 13 If we go to 1981, HCDO0002449, we can see -- we 13 haemophilia B in 1985. So that gives a flavour of the 14 don't have clear records of the number of patients 14 kind of numbers of patients treated. 15 treated but if we look at the products used, again, 15 Dr Cachia told the Penrose Inquiry that only 16 we've got cryoprecipitate in hospital, looks like 16 SNBTS products were used at Ninewells, and with that 17 45,440, and then factor concentrate, a much larger 17 limited exception of the purchase of Hyate:C from Speywood, that's borne out by the UKHCDO annual amount now being used: 300,000 odd -- or 308,000, 18 18 19 rather, concentrate for hospital, and 204,100 units 19 returns. 20 for home treatment. We can see the return expressly 20 The Penrose Inquiry's conclusion is that, in 21 says in relation to the commercial concentrates and 21 relation to Dundee, the picture was clearly one of 22 22 a preference for NHS products, and the use of imported other materials, "None purchased or used". 23 And that's the pattern over the following years. 23 commercial concentrates was very infrequent throughout 24 24 the material time. So that we get, I think, to 1982 before we see 25 anything else. That is at HCDO0002450. 25 And the Hyate: C appears to be in relation 153 154 1 specifically to a patient who had developed an 1 which there were presentations on hepatitis. 2 2 inhibitor. The Penrose Inquiry also found, and again He didn't attend the '72 meeting, but he was 3 it's borne out by the returns, that although 3 represented by a Dr Todd in 1974 and 1979, and it may 4 cryoprecipitate was a feature of treatment, it 4 not be unreasonable to assume that he would have 5 accounted for a relatively small proportion of total 5 received the minutes of the UKHCDO meetings that he 6 therapy, which was based predominantly on the use of 6 didn't attend. Likewise, there's nothing specific 7 7 the Edinburgh Factor VIII. that casts any light on his developing knowledge or 8 8 In terms of home treatment it's not clear understanding of the risk of AIDS. 9 9 precisely how many patients were on home treatment. He was not in attendance at that January 1983 10 There's a letter in January 1983 from Dr Brookes to 10 meeting that we looked at in relation to Inverness, 11 Dr Watt saying that there had been, over the previous 11 where Dr Cash drew attention to recent articles in the 12 two years, several patients established on home 12 US and in The Observer and in The Lancet. 13 treatment. So some at least receiving home therapy 13 However, again, it may be reasonable to assume but the precise number is unclear. that Dr Tudhope would have received the communications 14 14 15 15 sent to directors from UKHCDO as well as copies of Other than that, we've no particular indication 16 16 as to the approach to treatment, or particular minutes, so, one would expect, perhaps, him to have 17 approaches in relation to patients, for example, with 17 received the March and June 1983 letters in relation 18 mild haemophilia as opposed to severe haemophilia. 18 to the risk of AIDS. 19 In terms of knowledge of risk, there's no 19 The Penrose report references to Dr Peter Foster 20 specific documentary evidence which casts any light on 20 of the PFC, giving presentations in March 1983 to 21 Dr Tudhope's knowledge of or response to the risk of 21 clinicians and haematologists in Edinburgh and Dundee 22 22 hepatitis. He did attend a number of UKHCDO meetings on the issue of AIDS, and you may be able to hear 23 23 at which there were discussions or presentations about about that at later hearings firsthand from Dr Foster. 24 hepatitis. So he attended the meeting in April '71, 24 In terms of the process for undertaking tests 25 in September '75, in January '77 and October '81, in 25 for HTLV-III, again, there's not very much, I'm

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afraid, documentary information that we have.

The medical records of one patient refer to him attending a special clinic for haemophiliacs on 11 January 1985, arranged along with Dr Tudhope, so that the problem of AIDS could be explained, with blood being taken for testing and the samples sent to Edinburgh along with others obtained at the same time from other haemophiliacs.

That was a witness who was a child at the time.

The witness's evidence to the Inquiry is that his parents have no recollection of either attending that clinic or receiving the results of that test.

The evidence given to the Penrose Inquiry was to the effect that no patients with bleeding disorders appear to have been infected with HIV as a result of treatment at Dundee. That reflects also the material which UKHCDO has provided to us. So if we go back to INQY0000250, and go to the last page, we can see five lines up from the bottom, centre 161: Dundee. And the figure that UKHCDO have provided to the Inquiry is zero cases.

Dr Cachia in his statement has explained that during his time as director the Centre did care for one haemophilia patient with HIV. That was a patient who'd been treated and diagnosed with -- treated for

review and to counsel for blood-borne virus infections."

He says that for each of the patients who had been tested for HCV, he explained to them what had happened and requested their consent to repeat the hepatitis C testing on a fresh blood sample and then, if there was a confirmatory HCV test, he met the patients' partners if appropriate to explain the diagnosis and implications.

It's not entirely clear, I think, when that process or how long that process took. Again, there are accounts given by individuals to the Inquiry about there being delays between what their records showed was the date of them being tested and the date upon which they were informed and that may, at least in part indeed, entirely be explained about what Dr Cachia has explained in his statement was the position he inherited.

So by way of example, we have a witness whose records show first testing positive in November 1992, being told of the infection in January of 1995.

Another being told of their infection in 1998.

Another describing her father being given a diagnosis around 1995 when attending a routine haemophilia appointment and having been unaware that they'd been

haemophilia and diagnosed with HIV at a different Centre before transferring to Dundee.

Dr Cachia's provided the Inquiry, however, with information about the process for testing for hepatitis C. So he has said that when he arrived at Ninewells Hospital in 1992, Dr Heppleston:

"... provided me with a box of file cards containing the name and details of all patients with inherited bleeding disorders who had attended or been registered with the department. Dr Heppleston also had a list of around 30 of these patients whose stored serum had been tested for HCV antigen when the first test was introduced in 1991. From memory, around 25 of these patients had tested positive."

So the evidence would suggest that there were stored samples, that those stored samples have then been tested in 1991. It doesn't appear that that was something known to the patients.

Dr Cachia's own conclusion following discussions internally within the hospital was that the samples had been analysed without any patients' consent. He did not know whether the patients had consented to having their serum samples stored in the first place. He then says in his statement that:

"Appointments were arranged to undertake a full

tested.

In terms of numbers, Dr Cachia's understanding, as told to us, is that around 25 patients were infected with hepatitis C at Ninewells.

The data gathered by the Penrose Inquiry as at 2011 recorded 21 living patients and nine patients who had died as at 2011. So there's a slight difference between those figures, or a not insignificant difference, I should say, between those two figures.

Dr Cachia, and then, in terms of the current position, Dr Kerr, have provided information in their statements about the process of treatment for hepatitis C, treatment with interferon and ribavirin in the early years, and then Dr Kerr has talked about how the Centre has more recently been able to treat patients with the modern hepatitis C treatments.

Sir, that's the position, then, in relation to

18 Dundee

## 19 PRESENTATION RE BRISTOL HAEMOPHILIA CENTRE

20 MS RICHARDS: I'm going to move next to Bristol. In light
21 of the time, I think it's reasonable to complete
22 Bristol, but to continue then to look at Truro and
23 Southampton will result either in sitting very late or
24 compressing both of those centres into a speedier
25 presentation than they merit. So it might be wise,

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1	sir, to finish at Bristol today and then, I'm	1	Dr Raper was director from 1968 to 1976, and he was
2	afraid and again apologies to anyone listening with	2	then succeeded by Dr Scott, who held that position
3	a particular interest in those centres that Truro,	3	until 2000. At the Children's Hospital, Dr David
4	and Southampton, along with Cambridge, Norfolk and	4	Berman was in post from 1978 until 1987, and both Dr
5	Norwich, may have to await a later hearing.	5	Scott and Dr Berman were invited to UKHCDO meetings,
6	SIR BRIAN LANGSTAFF: I think it is only right that we	6	although looking at the minutes it appears in practice
7	should hear about them in appropriate detail, and we	7	it was usually one or the other who would attend
8	don't want to rush that. That would be far greater	8	rather than both.
9	an insult to those who have been waiting to hear today	9	Then Dr Helena Daly was senior registrar in the
10	than it would be for them to have to wait, in my	10	haematology department at the Bristol Royal Infirmary
11	judgment. So that's what we'll do.	11	from 1979 to 1985, and we have couple of witness
12	MS RICHARDS: Sir, certainly the presentation notes	12	statements from Dr Daly, whose evidence will also be
13	themselves have been disclosed to at least the Core	13	relevant when we look at the later hearing at Truro.
14	Participants and legal representatives, so that the	14	So Bristol sat within the Oxford Haemophilia
15	information in them is already available.	15	Centre supra-region, and there are minutes of the
16	SIR BRIAN LANGSTAFF: Yes.	16	supra-region Haemophilia Centre Directors and Blood
17	MS RICHARDS: So Bristol, then. So the Bristol	17	Transfusion Centre directors meeting, for example, in
18	Haemophilia Centre effectively covers straddles two	18	June 1978 when both Dr Berman and Dr Scott attended.
19	hospitals, two haemophilia departments the Bristol	19	We have a description from Dr Daly of the
20	Children's Hospital and Bristol Royal Infirmary,	20	facilities at the haematology department at the Royal
21	sometimes they're collectively referred to as the	21	Infirmary during her time there from 1979 to 1985.
22	Bristol Centre, sometimes they're talked about as the	22	She describes a comprehensive clinical and laboratory
23	Children's Hospital being an associate centre of the	23	haematology service, so that's overall haematology not
24	Royal Infirmary.	24	uniquely haemophilia service. She says there was
25	In terms of directors, the Royal Infirmary,	25	a well-equipped laboratory, a designated haematology
	161		162
1	day unit, and inpatients cared for in a ward shared,	1	Welsh donors which were fractionated at the
2	within what she describes as the professorial unit.	2	NHS-managed blood products laboratory at Elstree, in
3	She has given information about the haematology	3	preference to commercial products. (Scotland had its
4	staff, so as well as Dr Scott as consultant, there	4	own blood transfusion and blood products service). My
5	were two senior registrars, of which she was one, one	5	belief was that the NHS products carried less risk of
6	registrar, rotating senior house officers, and various	6	infection, particularly hepatitis and HIV than
7	nurses. But again, those do not appear to have been	7	commercially derived products from the USA.
8	dedicated to haemophilia but to haematology services	8	Allocation of these products was determined by the
9	more generally.	9	amount of plasma which was collected by each regional
10	In terms of decisions about treatment policies,	10	blood transfusion centre, and as the Bristol centre
11	Dr Daly's recollection was that Dr Scott was	11	serving the South West Regional Health Authority had
12	responsible for product selection both at the Royal	12	a very good record for plasma collection our
13	Infirmary and effectively at the Children's Hospital.	13	allocation was above average. Nevertheless it was not
14	If we go to WITN4685002, we can see it's a letter from	14	sufficient to cover our needs and therefore commercial

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Bristol Haemophilia Centre based at the Bristol Royal Infirmary and Bristol Children's Hospital in 1984 and I remain in this post at the present time. I was not and never have been a Director of the Blood Transfusion Service at Bristol. It was always my

policy to use plasma-derived products from English and

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Dr Scott to Dr Daly, who was going to be giving

evidence to the Lindsay Tribunal. If we go over the

page, we can see Dr Scott setting out his recollection

"I confirm that I was the Director of the

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there. He says:

became available but not in sufficient supply to provide our needs. The first heat treated products

"In late 1984 heat treated commercial products

blood products had to be purchased to make up the

children and adults who had previously received little

treatment and were known to be hepatitis and HIV

negative. I think that my decision was justified by

the fact that the incidence of HIV infection amongst

parts of the country.

haemophiliacs in Bristol was lower than in many other

deficit. Priority for NHS products was given to

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were received in the Bristol Haemophilia Centre in December 1984. There was discussion amongst haemophilia centre directors and also by the Haemophilia Society although I do not have documentary proof available about whether heat treated commercial products were preferable to NHS products. The efficacy of heat treatment had not been fully established and it was believed by many physicians dealing with haemophilia that NHS concentrates although not heated were preferable.

"Heat treated NHS Factor VIII became available in March 1985 although our quota was not sufficient to meet our needs. It was the policy to give heat treated NHS concentrates to children and mildly affected adults who had not received much treatment previously. We continued to use non heat treated NHS product and also heat treated commercial product.

"In August 1985 all the NHS product was heat treated. We were asked to return all non heat treated product. We did not keep a large stock nor did any patients but all the patients were asked to return their non heat treated product and it was replaced. The non heat treated product was returned to Elstree. Our allocation was still not enough to meet our needs and therefore commercial heat treated product was used

"As I told you during our telephone conversation the other morning, we are encountering difficulties over supply of Factor VIII material for the treatment offer our patients with haemophilia. There are fifteen patients with severe haemophilia registered at this Centre and a number of others who attend infrequently for treatment."

Then, if we go towards the bottom of the page, he says about ten lines up from the bottom:

"I have reviewed the treatment of each patient, and I am sure that the current usage of Factor VIII is justified, and that if it was to be reduced, then the standard of patient care would be seriously affected."

Then if we go over the page, he says:

"Our current usage of Cryoprecipitate is running at approximately 1,000 units (ie material obtained from single donations) per month, and this is being provided by the Regional Blood Transfusion Centre at Southmead. In addition, we have been purchasing between 6 and 7 thousand units of Factor VIII in the form of concentrates from commercial sources, namely Hyland, and Immuno Products, and this has been used for home treatment programmes and to cover minor surgery. The current cost of this is in the region of 7 to 8 hundred pounds monthly, which is going to mean

as well. In October 1985 the new NHS intermediate purity heat treated product VIIIY was introduced and from that time it became our major treatment product and commercial Factor VIII was gradually withdrawn."

Top of the next page:

"NHS Factor IX has always been used in the Centre and the supply has always been adequate so that there has been no necessity to purchase commercial product. At the ending of October 1985 heat treated Factor IX became available from Elstree, all non heat treated was withdrawn and patients were asked to return their non heat treated material."

So that's Dr Scott's account as at June 2000. Dr Daly, who was involved in discussions about product choices with Dr Scott in the first half of the 1980s recalls similarly that selection was based on a preference for UK donor plasma, single donor products for mild/moderately affected individuals or with no previous exposure, and heat-treated concentrates from 1984.

Going back a little further in time, we can see Dr Scott voicing concerns about the supply of products in 1975. That's CBLA0005695, please. Sir, this is a letter from Dr Scott to Dr Maycock at BPL, 2 July 1975:

an increase in the drug bill to the District of between 8 and 9 thousand pounds in the current year." Then he says:

"I have been able to maintain a high standard of patient care, only to the efforts of the Regional Blood Transfusion Centre in meeting our demands for cryoprecipitate and to the understanding of the District Administrators who have allowed me so far to purchase commercial Factor VIII without question."

Then he goes on in the next paragraph to explain that the Regional Blood Transfusion Centre can't guarantee more than 800 units of cryoprecipitate each month:

"... they are faced with the dilemma of processing increased amounts of plasma to produce Cryoprecipitate or supplying more plasma for fractionation by your Department."

He refers also to there having been depletion of the stock of cryoprecipitate previously held for emergency demands and he asks as to whether it is possible to have a regular supply of Elstree Factor VIII concentrate.

In terms of a response, I'm not sure that we traced one. But we can see if we then look at CBLA0009063, later that same month, Dr Tovey of the

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Regional Transfusion Centre wrote to Dr Maycock referring to a letter from Dr Maycock and says:

"Dr Scott has undertaken to restrict the amount of cryoprecipitate being transfused to haemophiliacs at the Bristol Royal Infirmary to a lower figure and to use more Hemofil in an emergency. As a result of this we are planning to step up the amount of fresh frozen plasma we send you to about 100-120 packs per quarter."

So it doesn't appear as though Dr Scott's request resulted in his desired answer. It seems to have resulted in less use of cryoprecipitate and then the plasma was going to be used, then, to try to provide -- well, to enable the Transfusion Centre to send more plasma to BPL but, in terms of treatment for those with haemophilia, the gap was going to be filled with Hemofil.

In late 1976, Dr Maycock wrote to Dr Scott saying "BPL concentrate, can you now please obtain it from the Regional Transfusion Centre?" and that appears to have been the practice thereafter, and that's Dr Daly's recollection too, that commercial concentrates would be purchased by the Bristol Royal Infirmary's hospital pharmacy, but that the BPL products would be distributed via the Regional

concentrate featuring significantly.

If we just look at page 2, we can see in the forms that we're no doubt now familiar with, patients receiving more than one type of commercial concentrate, or receiving Elstree and one or more types of commercial concentrate. So there's no obvious indication, at this stage at least, of any adherence to a policy of restricting patients to one type of product.

In 1978, if we go to BPLL0009270\_006, Dr Scott wrote to Dr Tovey in February 1978 at the Regional Transfusion Centre complaining about the solubility or effectiveness of the Elstree Factor VIII product and, picking it up about halfway down that paragraph, he says:

"Because of its insolubility ..."

Sorry, two-thirds of the way down:
"... I feel that I cannot use this material for
home treatment any longer and this will mean
a considerable increase in the amount of commercial
Factor VIII which has to be purchased. I thought
I ought to let you know so that you could perhaps pass
on my comments to Elstree. Talking to other
Haemophilia Centre Directors I do not think that I am

Transfusion Centre.

Dr Daly also recalls there being a close relationship between the Bristol Royal Infirmary and the Blood Transfusion Service.

If we then look at annual returns, and we pick the picture up in 1976, at HCDO0000023\_002, we can see number of patients treated, 39 haemophilic, seven Christmas Disease. Then we can see substantial usage of cryoprecipitate, 442,680 units; NHS concentrate, 132,500 it looks like that might be, but then a range of different commercial products being used, Profilate, Factorate, Koate, Hemofil and Kryobulin all being purchased in the quantities there set out.

That's the picture which, to some extent, continues. So if we look at the return for 1978, HCDO0001238, I think. I may have misread my handwriting there, Soumik, so I apologise.

If we go to page 6, we can see there annual return for 1978, 36 haemophilic patients, six Christmas Disease patients. The usage of cryoprecipitate is now 158,480. There's 269,000 units of NHS concentrate; and then a much larger figure for the Armour product, 462,800; 110,520 units of Koate; 74,600 units of Hemofil. So again, commercial concentrates and more than one type of commercial

unsatisfactory."

If we then go to 1979, we see an increase in that year of cryoprecipitate usage.

HCDO0001307.

Sir, we can see cryoprecipitate, 258,970 units, NHS concentrate, 171,720. And again, we see a range of commercial concentrates being used, Profilate, Factor VIII, Koate and Hemofil, in relatively large quantities, in particular the Koate, 247,870.

Then again, I think if we look at page 7 we can see there an indication that there are some patients, and it's not true by any stretch of the imagination, for all the patients receiving a range of more than one type of concentrate. In fact we've got one patient there we can see being treated with cryoprecipitate Elstree Factor VIII, Profilate, Factorate, Koate and Hemofil in the course of one year.

Around this time, and according to Dr Daly, home therapy was being commenced at the children's hospital by Dr Berman for children with severe haemophilia and regular bleeds, from about the age of four. The indication is that that was using BPL products.

Cryoprecipitate, Dr Daly says, was considered impractical for home therapy.

alone in finding the Elstree concentrate

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And then if we go to 1982, HCDO0001603, we can 1 If we then go to the return for 1980, which is 2 at HCDO0001402, of the numbers of patients treated, 31 2 see that figures in terms of usage there set out. So, 3 3 haemophilia A, four von Willebrand's, and then if we again, there's an increase in the amount of zoom in a little closer to the figures we can see 4 4 NHS concentrate being used: 562,956 for home 5 cryoprecipitate still in usage in hospital, 250,400. 5 treatment. But still reasonably significant amounts of commercial concentrate, particularly Koate, being 6 6 And NHS concentrate, an increase, and so a significant 7 amount being used for home treatment, 227,550. But 7 used. So 246,590 units of Koate. And then a smaller 8 8 then again, a range of commercial concentrates in use amount of Kryobulin, and 65,000 plus units of 9 9 for home treatment. So Profilate, 179,000 plus. Profilate being used. 10 10 Factor VIII, just under 60,000. Koate, 66,990. We don't see any reference there to DDAVP, and 11 Kryobulin, just under 50,000. And 72,000 units of 11 Dr Daly's recollection is that DDAVP became available 12 Speywood's Humanate. 12 in 1983, and that cryoprecipitate was used for the 13 Then in relation to 1981, which is HCDO0001500. 13 treatment of patients with mild and moderate 14 again we can see, number of patients: 35 14 haemophilia as well as the treatment of patients with 15 haemophilia A, six von Willebrand's, and in terms of 15 von Willebrand's disease. 16 the figures we again see a range of different 16 You'll recall, sir, the evidence of Mr and 17 Mrs Turton about the treatment of their son, Lee, 17 commercial products, not perhaps as many as the previous year. So there's still significant usage of 18 18 being switched from cryoprecipitate to NHS factor 19 cryoprecipitate in hospital and a small amount for 19 concentrate in 1982, apparently because 20 home treatment, you'll note. 20 cryoprecipitate was not available, but it is apparent 21 A significant amount or larger amount of NHS 21 that there were substantial quantities of 22 22 concentrate used for home treatment, so 452,647. But cryoprecipitate available to the Centre. 23 also significant amounts of Profilate, Koate being 23 If we look at DHSC0001313, these are notes made 24 used for home treatment, and then Kryobulin and 24 by Mr Milne of The Haemophilia Society 1982 following 25 Humanate also being used for home treatment. 25 the meeting of UKHCDO directors in September 1982, and 173 174 1 if we go to the third page, he reports a conversation 1 there, on the screen. 2 2 MS RICHARDS: We were. Let me just find the reference to with Dr Daly, and says: 3 "Dr Daly ... was representing Dr Scott. She 3 1983. Can we try HCDO0001603. SIR BRIAN LANGSTAFF: No. that's '82. 4 stated that special arrangements had been made to 4 5 supply cryo to three patients who particularly 5 MS RICHARDS: Is it? Let me try 1699 then. Here we are. 6 requested it, but that it might not be possible to 6 Thank you, sir. 7 7 continue the arrangement indefinitely." 48 haemophilia A patients. So we can see this 8 8 We don't get any further insight into that from is representing both the Royal Infirmary and the 9 9 the document, unfortunately. Children's Hospital, 48 haemophilia A patients,nine 10 Then if we look at 1983, HCDO0001795. 10 von Willebrand's. And there we have cryoprecipitate, 11 We can see cryoprecipitate used in hospital, and 11 NHS and Koate as the three products used in that year. 12 an amount being used for home treatment. So 21,800 12 Now that records a significant amount of 13 units used in home treatment, 160,000 plus units in 13 cryoprecipitate use for home treatment, so nearly hospital. The bulk of home treatment is with NHS 14 119,000 units, as well as usage of cryo in hospital. 14 concentrate, over 500,000, but also a significant 15 The main product for home treatment is the NHS 15 16 16 volume of Koate being used, 173,980 units for home concentrate, nearly 438,000, but also significant 17 treatment, as well as some usage of Koate and Hemofil 17 usage in hospital, and then also a substantial volume 18 in hospital. 18 of Koate, 155,000 used for home treatment. 19 So that's 1984. Then if we just finally look 19 And then I should say the picture in relation to 20 at 1985. HCDO --20 von Willebrand's is fairly consistent across the SIR BRIAN LANGSTAFF: Sorry, have we missed one? We've 21 years. It's cryo and/or NHS concentrate. 21 22 22 done '83, so we now want to look at '84. I haven't looked at the haemophilia B figures MS RICHARDS: I'm so sorry, I think I've gone ahead of 23 but, again, it's NHS Factor IX concentrate that we see 23 24 myself in my own --24 being used. SIR BRIAN LANGSTAFF: In fact, we just were looking at '84 25 So, sorry, that's 1984. 175 176

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SIR BRIAN LANGSTAFF: No. that's 1983. SIR BRIAN LANGSTAFF: Well, as you've been setting out the MS RICHARDS: 1983. figures, I've been drawing up a very rough, and it may SIR BRIAN LANGSTAFF: Then we had 1984. not be entirely accurate because it's been done pretty MS RICHARDS: Then if we just go, to complete the picture, quickly, idea of the proportion of the -- when to 1985, HCDO0001887. And of course we know that Factor VIII concentrate has been used, the proportion heat-treated products became available at various which is NHS and the proportion which is commercial. stages in the course of the year. We've got there the And it has been pretty well throughout, until 1981, numbers treated: 47 haemophilia A, six three times as much commercial as NHS. And then the von Willebrand's. NHS starts off to be a slightly higher proportion, two parts to three. And then, 1982, the NHS is in greater Then we can see limited use of cryoprecipitate for home treatment, still used in hospital. And then quantity than the commercial. Which may fit with what the main sources of product for home treatment are you've just described from the literature. 1983, the NHS concentrate and Koate, but also Profilate and high point I think, roughly three times as much NHS as Factor VIII to some extent. And then there's a small commercial. '84, I make it about five to two in amount of Scottish product referred to as being used. favour of NHS. '85 dropping off a bit. And there's evidence also of use there, in that But that's the rough proportions. If someone year, of Koate to treat patients with can check those, because they may not be accurate -von Willebrand's. MS RICHARDS: We will, sir. We'll look at the articles that were authored by SIR BRIAN LANGSTAFF: They're very broad, to get an idea Dr Daly and Dr Scott in a moment, but in one of -- in of the proportion which was used, which may be an a 1985-article authored by Dr Daly and Dr Scott, they easier way of looking at it at the moment than simply refer to a growing reluctance by patients in 1983 to trying to remember figures.

be tied in with what we know about the Bristol

patient, which I'll come on to shortly.

use commercial concentrate. And of course, that may

## MS RICHARDS: We will.

I should, sir, just say, in relation to use of DDAVP, there is some contemporaneous documentary evidence to support Dr Daly's recollection of DDAVP being used from 1983, because there's -- she wrote to Dr Bloom about DDAVP and received a response in July of 1983 encouraging its usage.

There's also some evidence in relation to heat-treated products to show that Dr Scott entered the trial of heat-treated Factor VIII in the spring of 1984.

If we then turn to the issue of knowledge of risk, Dr Scott was a regular attender of UKHCDO meetings, not every meeting, but attended a number of them in the 1970s and in the 1980s, and indeed into the 1990s. So -- and would presumably also have received the minutes, so would have been aware of the discussions taking place.

There is also evidence, unsurprisingly, of Dr Scott participating in the hepatitis survey, reporting cases of jaundice to Oxford. And there is, for example, communications in the 1970s between Dr Scott and Dr Maycock about haemophiliacs developing serum hepatitis. And indeed, communications between Dr Tovey of the Transfusion Service and Dr Maycock

referring to reports from Dr Scott about the development of serum hepatitis.

you're going to provide this graphically.

MS RICHARDS: Yes.

So a fairly familiar picture that emerges from the contemporaneous documents. There's no particular evidence one way or another in terms of documents about the provision of information about risks but the picture that emerges from the evidence given by witnesses who were patients or their family members to the Inquiry is to the effect that they were not informed about the risks associated with the blood products that they were given.

SIR BRIAN LANGSTAFF: In due course, as you've said,

In terms of the knowledge of risk of AIDS, again, it would be the expectation of Dr Scott and, indeed, Dr Berman being familiar with what was being discussed at UKHCDO meetings, either through attendance or through the receipt of minutes, and what was being reported in the medical literature. But there's then a particular issue in relation to the knowledge of the risks from AIDS associated with Bristol, because one of the first patients to die from AIDS in the United Kingdom was a Bristol patient, who died in August of 1983.

If we just pick matters up in Dr Daly's witness statement, WITN4685001, and if we go to page 32, Dr Daly says:

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1	"I first heard of AIDS in the (MMWR) reports	1	were HIV positive."
2	in late 1982. I followed the USA and UK literature	2	And there were two publications to look at. If
3	over the following years.	3	we look, first of all, at an application(?) relating
4	"32.2. Following the death from AIDS of one of	4	to that specific patient, it is at PRSE0004509. It's
5	our haemophilia patients in August 1983, 18 months	5	the top left thank you.
6	after intensive treatment with commercial concentrate	6	So we've looked at this before.
7	of US origin, I believed that there was a definite	7	"Fatal AIDS in a haemophiliac in the UK."
8	risk that this was in some way due to factor	8	And we can see it being reported in the last
9	concentrate."	9	sentence of the first paragraph:
10	Then she tells us a little more about that	10	"We report here a fatal case of AIDS in the
11	patient.	11	haemophiliac who received intensive treatment with
12	"At the time of his acute illness in	12	factor VIII concentrate of US origin."
13	[January] 1981, having excluded other causes,	13	And there is then documented the development of
14	I thought it was an 'acute viral infection ? related	14	that patient's condition, so admission to hospital in
15	to factor concentrate'. In May 1983 we suspected	15	January 1982, in the third paragraph.
16	AIDS. My consultant identified a histopathologist who	16	February 1982, he was still unwell, lethargic
17			and irritable. Reference to a diagnosis being made of
18	was immune to hepatitis B and who kindly agreed to do	17	•
	a post mortem which confirmed the diagnosis.	18	non-A, non-B hepatitis in the last sentence of that
19	Subsequently my consultant had to insist on the report	19	paragraph. If we then go back to the main text of the
20	being published in the Lancet after it was initially	20	letter, we can see March 1982 and July 1982, up to
21	rejected."	21	August October 1982, updates being provided.
22	And:	22	February 1982, admitted again. And May 1982 records
23	"By the end of 1984 we had results of HIV tests	23	various opportunistic infections.
24	on patients at the BRI and learned that many of our	24	If we go back to the full page, we can see, top
25	patients, mainly those who had been heavily treated,	25	of the page, they say, "At this time AIDS was
	181		182
1	cucnected"	1	hecause it is plainly the same nationt
1	suspected".	1	because it is plainly the same patient.
2	And then we can see below the table an account	2	MS RICHARDS: Yes.
2 3	And then we can see below the table an account of the patient's illness and deterioration in the	2	MS RICHARDS: Yes. SIR BRIAN LANGSTAFF: And so it must be January '82.
2 3 4	And then we can see below the table an account of the patient's illness and deterioration in the course of August of 1983, resulting in the patient's	2 3 4	MS RICHARDS: Yes.  SIR BRIAN LANGSTAFF: And so it must be January '82.  MS RICHARDS: Yes, I think so.
2 3 4 5	And then we can see below the table an account of the patient's illness and deterioration in the course of August of 1983, resulting in the patient's death.	2 3 4 5	MS RICHARDS: Yes.  SIR BRIAN LANGSTAFF: And so it must be January '82.  MS RICHARDS: Yes, I think so.  And then we can see, if we look at a second
2 3 4 5 6	And then we can see below the table an account of the patient's illness and deterioration in the course of August of 1983, resulting in the patient's death.  If we look then towards the bottom of the page,	2 3 4 5 6	MS RICHARDS: Yes.  SIR BRIAN LANGSTAFF: And so it must be January '82.  MS RICHARDS: Yes, I think so.  And then we can see, if we look at a second publication, later in time, but it tells us about what
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patients, which continues over the page. In fact, actually we should pick it up -- I don't want to skate over that too quickly. Bottom of the previous page, sorry, Soumik.

So if we go to the analysis for severe and moderate haemophilia A and von Willebrand's disease, which accounted for 28 of these 43 patients, was receipt of cryo, NHS concentrate and Factor VIII concentrates, an average amount of treatment of 48,000 per patient per year.

It says the patient who died of AIDS was in this group but was unusual in that his average amount of treatment was 5,000 units per year. So that's the first category analysed.

The second was of those with mild haemophilia A and moderate von Willebrand's, ten patients had received cryoprecipitate only, many treated on one occasion only. And then, haemophilia B, five patients who were treated exclusively with NHS Factor IX concentrate.

So it would appear that their experience with this individual patient led to the particular study of these 43 patients.

If we look to the third page, we can see that there were analyses undertaken of hepatitis status and

"The first death from AIDS of a haemophiliac in this country caused considerable anxiety among patients attending the Centre. The total amount of treatment used at this Centre decreased in 1983. This is due to a growing reluctance by patients to use commercial concentrate."

So those were the findings of the study of the 43 patients in those categories at the Bristol Centre undertaken in 1983.

There's also a letter sent by Dr Scott in October 1983 to a patient and his wife, HSOC0003486. It's dated 3 October. It's not clear whether this was simply sent to these recipients because of concerns they'd expressed or whether it was a wider communication, but it says:

"As I am sure you know one of the patients attending the Bristol Haemophilia Centre has recently died of AIDS. The cause of this condition is still unknown but there is evidence to suggest that it is due to an infection which can be transmitted by blood or blood products. There is reason to believe that the source of the infection in this case was imported Factor VIII concentrates but this is not proven and it cannot be said with certainty that these were the source of infection. I can understand that you are

T4/T8 ratios.

And if we go to page 6, there's then a discussion -- sir, just pausing there, I should say what's not clear is the extent to which any of these patients were aware of any of these studies being undertaken.

So there's a discussion then on page 6, continuing over to page 7. So it sets out details in relation to T-cell findings, lymphopenia and other immunological abnormalities. We can see from the date this is a point in time at which the testing for HTLV-III was not available.

And then if we look on page 7, the last main paragraph:

"Thirteen other patients received treatment from the same batches of concentrate as the index case ... So far none of these patients has developed AIDS although three have suspicious features."

Then there's, again, a reference to the first case in developing non-A, non-B hepatitis:

"We think the important reasons why our patient developed AIDS were the administration of a large volume of a contaminated batch of concentrate, and possibly lack of immunity to hepatitis B."

Then the last paragraph:

extremely worried that you have contracted a similar condition by using imported blood products. However, I would like to make it clear that the risk of this is extremely small. Thousands of Haemophiliacs in Europe and America have been treated with Factor VIII concentrates for over ten years and the number of reports of AIDS have been extremely small.

"As far as possible we are avoiding the use of imported Factor VIII concentrates but there is not enough NHS produced Factor VIII available at the moment to meet our needs so we will have to continue to use some commercial Factor VIII for the time being. The production of NHS concentrate is being increased and hopefully we shall be self-sufficient in the not too distant future. In the meantime I think that the dangers of refusing treatment if only commercial concentrate is available is greater than the danger of contracting AIDS. It is also the opinion of The Haemophilia Society which is set out in their latest bulletin.

"I hope that this allays your fears but if you have any further problems please feel free to discuss it with me or any of the other Medical Staff."

This is a rare example in the material we have seen, and this is across the United Kingdom, not

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1	related simply to Bristol, of written information	1	details of the Bristol AIDS case to his fellow
2	about the risk of AIDS being provided by a haemophilia	2	directors, following a presentation by Dr Craske.
3	director to an individual patient. But there is then	3	In terms of testing, there is little by way of
4	the question as to the terms in which it is expressed	4	documentary evidence as to the process that was
5	and whether the intention really was to, as is said at	5	undertaken. Dr Daly's recollection is that there was
6	the end, allay fears by saying, ultimately, this isn't	6	not formal pre-test counselling. She thought she
7	something we should worry about.	7	spoke to patients as she was monitoring them,
8	SIR BRIAN LANGSTAFF: Well, I'm afraid it appears, at	8	explained that sera was being stored. She says this:
9	least as I understand matters at the moment, it	9	"Later, after I received the results of the
10	appears to confuse risk with observed incidence.	10	initial tests and when testing further patients, I did
11	MS RICHARDS: Yes, which is an issue	11	provide a form of pre-test counselling. I can't
12	SIR BRIAN LANGSTAFF: We have explored before.	12	remember for certain if I recorded that in the
13	MS RICHARDS: something of a theme over the last	13	clinical records."
14	months.	14	She does say, in terms of the communication of
15	SIR BRIAN LANGSTAFF: The advice is based upon her	15	results:
16	perception of the risk that is the incidence. She	16	"Patients were informed in person, in private
	•		
17	doesn't	17 18	and usually by me, initially."
18	MS RICHARDS: It's him. It's Dr Scott, not		She also says that:
19	SIR BRIAN LANGSTAFF: Sorry, Dr Scott not Dr Daly. Yes,	19	"Until 1986 or 1987, patients were given
20	it's him. His perception is based upon the numbers	20	an uncertain prognosis as doctors were still
21	that had been affect, as opposed to the risk that	21	optimistic that seropositivity would not necessarily
22	a greater number might be in the future.	22	lead to AIDS."
23	MS RICHARDS: Yes. It's also relevant to note	23	Again, you'll recall, although this is in
24	October 1983, it's on the 17 October 1983, that the	24	relation to the Children's Hospital and Dr Berman
25	UKHCDO meeting takes place at which Dr Scott gave	25	rather than Dr Scott specifically, that Mr and
	189		190
1	Mrs Turton, Colin and Denise, gave evidence in	1	In terms of the numbers infected if we go to
1 2	Mrs Turton, Colin and Denise, gave evidence in relation to Lee, under the care of the Children's	1 2	In terms of the numbers infected, if we go to
2	relation to Lee, under the care of the Children's	2	INQY0000250 again, and we go to I can't find
2	relation to Lee, under the care of the Children's Hospital, that he was tested for HIV and found to be	2	INQY0000250 again, and we go to I can't find Bristol when I need it page 2, so Centre 13 Bristol
2 3 4	relation to Lee, under the care of the Children's Hospital, that he was tested for HIV and found to be positive in March 1985 in circumstances where they	2 3 4	INQY0000250 again, and we go to I can't find Bristol when I need it page 2, so Centre 13 Bristol Infirmary and Children's, so you'll see there again
2 3 4 5	relation to Lee, under the care of the Children's Hospital, that he was tested for HIV and found to be positive in March 1985 in circumstances where they were unaware of the test being undertaken and they	2 3 4 5	INQY0000250 again, and we go to I can't find Bristol when I need it page 2, so Centre 13 Bristol Infirmary and Children's, so you'll see there again the two hospitals being essentially identified as
2 3 4 5 6	relation to Lee, under the care of the Children's Hospital, that he was tested for HIV and found to be positive in March 1985 in circumstances where they were unaware of the test being undertaken and they were not informed of the diagnosis until June 1985.	2 3 4 5	INQY0000250 again, and we go to I can't find Bristol when I need it page 2, so Centre 13 Bristol Infirmary and Children's, so you'll see there again the two hospitals being essentially identified as a single Centre, and the figure given provisionally by
2 3 4 5 6 7	relation to Lee, under the care of the Children's Hospital, that he was tested for HIV and found to be positive in March 1985 in circumstances where they were unaware of the test being undertaken and they were not informed of the diagnosis until June 1985. We looked at some letters from Dr Daly to	2 3 4 5 6 7	INQY0000250 again, and we go to I can't find Bristol when I need it page 2, so Centre 13 Bristol Infirmary and Children's, so you'll see there again the two hospitals being essentially identified as a single Centre, and the figure given provisionally by UKHCDO to the Inquiry is 13. Again, the spread of
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2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23	relation to Lee, under the care of the Children's Hospital, that he was tested for HIV and found to be positive in March 1985 in circumstances where they were unaware of the test being undertaken and they were not informed of the diagnosis until June 1985.  We looked at some letters from Dr Daly to Dr Berman, and then on behalf of Dr Berman to Lee's GP, in the course of their evidence, and we have set those out in our notes but, again, on the theme of the letter we just looked at, it might be useful to look at one of them.  WITN1575010. You may recall this letter, sir. So it's from Dr Donaldson, senior registrar to Dr Berman, dated 14th June 1985 to the GP. It refers to having seen Lee's parents following a report from the laboratory that he was HTLV-III positive, and if we look at the fourth paragraph it says:  "The chance of Lee developing AIDS is therefore extremely small and I stressed this to his parents."  So again, we have Dr Scott's letter where it might be said to be over-optimistic in terms of the risk of being infected and then here what might be	2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23	INQY0000250 again, and we go to I can't find Bristol when I need it page 2, so Centre 13 Bristol Infirmary and Children's, so you'll see there again the two hospitals being essentially identified as a single Centre, and the figure given provisionally by UKHCDO to the Inquiry is 13. Again, the spread of years would tend to suggest stored sera samples and retrospective testing, because we are given two for 1981, one for 1982, two for 1983, two for 1984, four for 1985, two for 1986. So that's the apparently available evidence in relation to HIV infections. In relation to the testing for hepatitis C, Dr Daly has said that samples were stored in the hope of a future test for non-A, non-B hepatitis, and she says: "That was part of the hepatitis monitoring, serum stored in the public health laboratory in Bristol and the microbiology department at RCH-T because at the time we did not know the cause of the abnormal LFTs and there was a lot of research going on to determine this."

1	because she subsequently became director in Truro.	1	going to be woven in and out of the oral evidence in
2	In terms of hepatitis C, again the Inquiry has	2	the course of the week.
3	received evidence expressing concern about the	3	SIR BRIAN LANGSTAFF: Yes.
4	circumstances in which the diagnosis was communicated	4	MS RICHARDS: So we will then hear from a number of oral
5	and the extent to which proper information was	5	witnesses, Monday, Tuesday and Wednesday, those who
6	provided.	6	were pupils at Treloars and, in one instance, the
7	Again, more broadly on the issue of consent, the	7	father of two pupils from Treloars. Then on Thursday,
8	Inquiry has received evidence from individuals treated	8	we're going to hear from the former headteacher at
9	at Bristol to indicate that they were tested without	9	Treloars, and then we'll conclude the presentation
10	their knowledge or consent.	10	we're currently timetabled to conclude that on Friday.
11	Sir, that's a summary of the evidence in	11	It's possible we might complete it on Thursday, but
12	relation to Bristol. As I said earlier, it being	12	it's probably more realistic to think it will run into
13	quarter to five, it's probably not helpful to anyone	13	Friday and be a full week.
14	to embark upon Southampton or Truro now.	14	Again, we don't want to rush any part of the
15	SIR BRIAN LANGSTAFF: No, that's enough, I think, for	15	evidence.
16	today.	16	SIR BRIAN LANGSTAFF: No.
17	Well, we now have a break until Monday, do we?	17	So next Monday, ten o'clock, to start our
18	MS RICHARDS: We do.	18	Treloars week.
19	SIR BRIAN LANGSTAFF: We have a full week next week?	19	MS RICHARDS: Yes.
20	MS RICHARDS: We have a full week. I'm afraid I haven't	20	SIR BRIAN LANGSTAFF: Thank you.
21	got, unless I turn on my phone, the patient names, the	21	(4.46 pm)
22	pupils from Treloars giving evidence, some, in any	22	(Adjourned until 10.00 am on Monday, 21 June 2021)
23	event, are anonymous. But we start on Monday with	23	
24	we'll start with effectively a presentation on	24	
25	Treloars and the idea is that the presentation is	25	
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