1	Thursday, 6 October 2022	1	in this room, sizeable though the day's audience is.
2	(10.00am)	2	Now, in a moment or two, I'm going to ask Sapna to
3	(Proceedings delayed)	3	invite each of you in turn to take the oath, and then
4	(10.58 am)	4	Ms Richards will ask the questions. If at any time you
5	SIR BRIAN LANGSTAFF: Welcome to you all.	5	want a break or you want people to speak more loudly
6	Elisabeth, I think, Brenda and Linda, and that's how	6	because I think, Linda, you may have some difficulties
7	you would wish to be known. Tell me if that's not	7	of hearing on occasions
8	right.	8	MS WOOLLISCROFT: Yes, I've just turned it up a bit.
9	You're nodding, thank you.	9	SIR BRIAN LANGSTAFF: You can hear me all right, can you?
10	Can I first, though, say something to you.	10	MS WOOLLISCROFT: I can hear you better now.
11	Apologies for starting a little bit later this	11	SIR BRIAN LANGSTAFF: All right. Well, we'll take it
12	morning logistical reasons but we have the rest of	12	slowly, I hope, and if I ask anyone to slow down, it is
13	the day to concentrate on what we are about to hear.	13	so that you can follow and have haven't to strain too
14	The last witness today, not on this panel, will be	14	much.
15	anonymous, and in due course I will make an anonymity	15	So Sapna.
16	order. He will be present in this room but, because of	16	ELISABETH MARY BUGGINS (affirmed)
17	the nature of his evidence and the likelihood that he	17	BRENDA HADDOCK (sworn)
18	may mention matters which could potentially identify	18	CHRISTINE LINDA WOOLLISCROFT (sworn)
19	him, there will be no YouTube and there will be no	19	SIR BRIAN LANGSTAFF: Now, we know from what you've just
20	live stream. So those who are watching online, I'm	20	said that your first given name is Christine but you are
21	afraid you will not be able to access that evidence,	21	normally known as Linda?
22	though of course there will in due course be	22	MS WOOLLISCROFT: Linda.
23	a transcript. You will appreciate, those of you who are	23	Questioned by MS RICHARDS
24	here, that I'm saying that for the benefit of others,	24	MS RICHARDS: I'm going to start by asking Elisabeth some
25	but they are likely to number rather more than we have	25	questions.
	1		2
1	Elisabeth, you're here to talk about the treatment	1	I think the second bleed had resulted from a subdural
2	of your three sons at Birmingham Children's Hospital?	2	tap, which they'd done at Alder Hey before moving him to
3	MS BUGGINS: am.	3	Walton Hospital. And it was only two days after that,
4	MS RICHARDS: Your first son, Richard, was born in 1978.	4	when it looked as if it was happening again, that I was
5	MS BUGGINS: He was.	5	told that Richard had been found to have severe
6	MS RICHARDS: How did it come about that Richard was	6	haemophilia and that was the cause of the bleeding. It
7	diagnosed with severe haemophilia A?	7	wasn't an aneurysm that had broken or a cancer which had
8	MS BUGGINS: Richard wasn't diagnosed until the [redacted]	8	tapped into a major blood vessel in his brain.
9	of 1978, so when he was eight months old. He had become	9	MS RICHARDS: And Richard was left with some cognitive and
10	very unwell, and the GP referred him to the local	10	physical difficulties following the events you've
11	hospital, who then shipped him from where we lived, near	11	described?
12	Birmingham, up to Alder Hey Hospital in Liverpool with	12	MS BUGGINS: He was. When he came back from Liverpool,
13	a police escort and staff on board because he was so	13	which was four months later, he had he was more or
14	poorly. And there was something wrong with his brain	14	less paralysed on one side. His sight was very, very
15	but they didn't know what, and it took three days for	15	poor. But he could hear, and the joy for me was that
16	Richard to be scanned, and then they realised that he'd	16	every time I went into a room where he was, he'd put his
	•	17	•
17 10	got a lot of bleeding in his brain and there was so much blood they couldn't see where it came from.		hand up. And he was always pleased to see me. MS RICHARDS: You had two further sons, Jonathan
18 10	•	18	·
19 20	So they operated and excised a large part of his	19	MS BUGGINS: I did. MS BIGHARDS: and Edward Janethan harn in 1090
20	brain and he just about pulled through, and began to get	20	MS RICHARDS: and Edward. Jonathan born in 1980.
21	a little bit better, and then a following week	21	MS BUGGINS: (Witness nodded)
22	I recognised the same look on his face as the week	22	MS RICHARDS: And what year was Edward born in?
23	previously. And so they scanned again and realised that	23	MS BUGGINS: 1981.
24 25	he'd bled again, and took him back to theatre. He was	24	MS RICHARDS: And they too were diagnosed with severe
25	very, very, very ill, obviously, at that point. And	25	haemophilia A. 4
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(1) Pages 1 - 4

1	MS BUGGINS: They were.	1	MS RICHARDS: Thank you, Lawrence.
2	MS RICHARDS: Did you have any family history of haemophilia	2	So the ongoing care of Richard, Jonathan and
3	that you were aware of?	3	Edward's haemophilia took place at Birmingham Children's
4	MS BUGGINS: None. And we can go back many decades, nobody	4	Hospital and the consultant was Dr Frank Hill.
5	has any sign of haemophilia. But once genetics came	5	MS BUGGINS: It was.
6	along, it seems that I'm the start of the tree rather	6	MS RICHARDS: Your husband was working full time, you had
7	than having a history.	7	been working in the Health Service in a managerial role,
8	MS RICHARDS: We've got some photos of the boys that we'll	8	a role you later went back to, but you gave that up to
9	just show at this stage of your evidence.	9	look after the children at this point in time?
10	So if we could have those up on screen, please,	10	MS BUGGINS: I did.
11	Lawrence, Elisabeth's photos.	11	MS RICHARDS: So, as a result, you were dealing with the
12	So	12	vast majority of the hospital appointments and the
13	MS BUGGINS: This was Jonathan sitting on the homemade	13	treatments?
14	truck, and Edward, his younger brother, pulling him.	14	MS BUGGINS: I was.
15	And it's probably about the age Jonathan was when he	15	MS RICHARDS: And so with three children with haemophilia A,
16	acquired HIV.	16	were you at the hospital a lot?
17	And this was Richard, probably about four or	17	MS BUGGINS: A huge amount, yes. I lived there for a month
18	five years into his life, yeah.	18	at a time, because Richard had he was a high
19	And this is the three boys a few months before	19	responder, inhibitors, with Factor VIII, and so and
20	Richard died.	20	the bleeding was very difficult to control.
21	MS RICHARDS: And one more photo, which shows	21	MS RICHARDS: Richard was treated from a very young age with
22	MS BUGGINS: And then after Richard died I had a daughter,	22	Factor VIII concentrates.
23	and she was quite keen that I showed this photo because	23	MS BUGGINS: Yes.
24	it shows how young I was.	24	MS RICHARDS: Do you know, in Richard's case, whether they
25	[Laughter]	25	were commercial concentrates, NHS concentrates, or
	5		6
1	a mix?	1	MS BUGGINS: No, I don't think so. It seemed a much lesser
2	MS BUGGINS: I think they were almost exclusively well,	2	risk, and it wasn't really talked about
3	I know they were almost exclusively American	3	explicitly until, I think, 1985, when the boys were
4	concentrates because he needed so much volume of	4	given hepatitis B vaccine.
5	treatment.	5	MS RICHARDS: Now, Jonathan began to be treated with
6	MS RICHARDS: We'll look shortly at when Jonathan began to	6	concentrates also at a very young age.
7	be treated, but at this point in time, with Richard	7	MS BUGGINS: Yes.
8	being treated and then Jonathan, what, if anything, did	8	MS RICHARDS: We can pick that up from a report from
9	you know at the outset, about risks of transmission of	9	Professor Savidge which details Jonathan's treatment.
10	viruses from the concentrates?	10	Lawrence, could we please have WITN1021004.
11	MS BUGGINS: I don't remember anything from the outset. We	11	If we go to the second page, we can see it's
12	were just hugely relieved that there was something that	12	a report concerning Jonathan's treatment. It's dated
13	could stop this bleeding that was so traumatic for	13	this is on the last page, we don't need to go to it now,
14	Richard.	14	2 June 1992, from Professor Savidge, and is it right to
15	Once we arrived at the Children's Hospital, and	15	understand this was a report prepared in the context of
16	I don't know which year this was it's just too long	16	legal proceedings that you were bringing against the
17	ago but somewhere, I would say, between	17	Health Authority?
18	before 1984, I remember having a conversation about the	18	MS BUGGINS: It was.
19	risks of hepatitis in Factor VIII of and that there	19	MS RICHARDS: We can pick it up towards the bottom of this
20	was a more of a risk with concentrate, although	20	first page on the screen. There's reference to Richard
21	I never remember that being quantified, but that was the	21	and the complications of inhibitors. Then we can see,
22	extent of it, really.	22	the last ten lines or so on the screen, it says in
23	MS RICHARDS: At this point in time, whichever year it was	23	relation to Jonathan:
24	in the first years of the 1980s, were you told anything	24	"The child experienced his first clinically
25	about the seriousness or otherwise of hepatitis?	25	significant haemorrhage on 13.02.81 with a bleed into
	7 REDACTED VE	RSION	8

(2) Pages 5 - 8

1 the left ankle joint. He was treated at the hospital 1 There is then a bleed treated with cryoprecipitate 2 2 with 3 packs of cryoprecipitate with good effect. On and then a similar bleed treated with Armour 3 3 27.03.81, the boy sustained an injury to the left leg concentrate, further details of Armour concentrate being 4 with bruising of the upper third and from treatment 4 given, and then further occasions in which Jonathan was 5 records it would seem that the child was given 234 units 5 treated with cryoprecipitate. 6 US commercial factor VIII ..." 6 If we look towards the bottom of the page -- yes, 7 Just pausing there, just to get a sense of it, and 7 I'll pick it up about seven lines from the bottom, 8 without giving details of dates of birth, Jonathan would 8 Professor Savidge says this: 9 have been in the region of a year old at this point in 9 "On many of the occasions when cryoprecipitate was 10 10 given, the patient was not admitted to a ward indicating MS BUGGINS: He was. 11 11 that convenience of administration of factor VIII concentrates over cryoprecipitate possibly obviating 12 MS RICHARDS: So Professor Savidge continues: 12 13 "As cryoprecipitate treatment of infants was the 13 IP admission was not a cogent argument for their usage. 14 recommended policy of the hospital and indeed 14 During 1983, the boy was treated on 26 occasions, 15 nationally, the administration of this large donor pool 15 exclusively with Armour factor VIII ... both as an 16 commercial material in preference of cryoprecipitate or 16 [inpatient] and [outpatient]. During this year, 17 NHS concentrate without authorisation was negligent." 17 9 different batches of the Armour product were used. 18 There's then a reference to a further administration 18 During 1984 the boy was treated on 17 occasions, 19 of Armour Factor VIII concentrate in March '81, another 19 initially until [and then there's a date in May] with 20 one in May '81, and Professor Savidge continues, and 20 ... Armour ... and then exclusively with NHS 21 21 factor VIII ..." this is five lines from the top: 22 "As before, there is no evidence that authorisation 22 And it was suggested that was due to an allergic 23 was given to depart from hospital policy, and it is 23 reach to Armour in May of 1984, and then in 1985 only 24 remarkable that a different batch of US material was 24 NHS material was used. 25 25 given." Come back to the issue of the HTLV-III testing, but 9 10 1 if we just look further down the page, we can see 1 "... and imparted a substantially higher risk of 2 2 Professor Savidge expressing an opinion about the way in hepatitis." 3 which Jonathan had been treated, he says -- just above 3 That's the first observation Professor Savidge 4 the heading, "1. Use of large pool US commercial 4 makes. 5 5 concentrates", we'll see that Professor Savidge says: Over the next page, picking it up about six lines 6 "There are several issues in this case which are 6 down, he says in relation to the administration of 7 Armour Factor VIII in March of 1981: divergent with established clinical practice:-7 8 "1. Use of large donor pool US commercial 8 "No explanation whatsoever was given as to why cryoprecipitate or even NHS factor VIII concentrate were 9 concentrates" 9 10 10 not used or even if they were not available in the And we can see Professor Savidge reiterates that 11 cryoprecipitate would have been the recommended form of 11 hospital at the time. Furthermore, there's no 12 12 documentation as to whether advice in the choice of treatment. 13 And top of the next page he explains why, when he 13 therapeutic product was sought from a senior colleague, 14 14 or whether authorisation was requested or given to says: 15 "Cryoprecipitate was of particular benefit in such 15 administer this US material. Treatment of the child 16 16 cases since it was derived from single voluntary donor with US product, in view of the prevailing 17 17 recommendations and hospital policy, the lack of plasma collections in the UK and thus carried 18 a substantially lower hepatitis B and 18 suitable documentation and in the absence of 19 non-A, non-B hepatitis risk ..." 19 authorisation was negligent." 20 20 And towards the bottom, then, of the next page, I'll He explains then further down, about 12 or so lines 21 down: 21 just pick it up in the last few lines -- having 22 "Factor VIII concentrates, on the other hand, and 22 described the ongoing use of Armour concentrates, 23 23 particularly US commercial material from paid donors, Professor Savidge says this in the last four lines: 24 24 were derived from large donor pools ..." "This policy was pursued, with no reference to the

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Then he gives some figures.

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(3) Pages 9 - 12

availability of NHS concentrate at the hospital in the

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face of growing concern and increasing information in the public and medical press, that AIDS was transmitted by blood products."

Then if we go to page 9 last of all, there is this observation from Professor Savidge:

"It would seem that Armour was the sole supplier of commercial factor VIII to Birmingham Children's Hospital at that time, and Dr Hill was purchasing large amounts ... of low unitage ... vials at any one time. However, instead of allocating an individual small group of patients on any one batch to ensure long-term continuity of management of such cases on the same batch, it would seem that, with a few exceptions, the vast majority of Dr Hill's patients received the same batch over a few months until the batch was used up. This rather bizarre approach to patient management resulted in the child receiving a relatively large number of batches of vials of material containing few units in a remarkably short time.

"The therapeutic management of this child during 1981-1984, but particularly during 1981 and 1982 was negligent, and undoubtedly the ill-conceived use of Armour factor VIII must be held responsible for the infection of the child with the AIDS virus."

So that's Dr Savidge's -- Professor Savidge's

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1 report. And we can see from this that Jonathan was

2 treated sometimes with cryoprecipitate -- it would

appear perfectly satisfactorily; is that your

4 recollection?

5 MS BUGGINS: Yes.

6 MS RICHARDS: But then treated with Armour Factor VIII for

no obvious reason.

MS BUGGINS: Mm-hm, yes. 8

> It's interesting that -- there's one thing in that report which is contrary to what Dr Hill said was his policy -- told to me was his policy, which is that children were kept to the same batch wherever possible. It doesn't seem to have happened in this case. The only way I can explain it to myself is that -- I think it was Sister Marion who consistently gave cryo, although I haven't been back through the records to check, but out-of-hours treatment, the management of junior doctors

18 and their prescription of treatment seems completely

19 random.

20 MS RICHARDS: And we're going to come shortly to a meeting 21 that you attended at the hospital in, I think, 1984, 22 late 1984. But before we get to that, had you at any 23 point during these years been given any advice or 24

information about the possible risks in terms of

25 transmission of AIDS?

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1 MS BUGGINS: No.

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2 MS RICHARDS: Edward's treatment at this time, I think, was 3

with cryoprecipitate; is that correct?

4 MS BUGGINS: It was, although he did have a mix of treatment 5 in his early life too. I have little information about 6 that. Yes, so I don't think there's a different

8 MS RICHARDS: Now -- so a meeting then took place and 9 I think, doing the best you can, you think it was autumn 10 of 1984?

11 MS BUGGINS: Yes.

MS RICHARDS: What can you recall about that meeting? 12

13 MS BUGGINS: Well, I remember there were a lot of parents

there. That was -- it was a -- sort of overwhelming walking into the room and seeing how many people were affected. And I can remember still where I was sitting in relation to the platform. There are some things that are burnt on my mind. And we were told that -- there was sort of preamble about HTLV-III and what it was and what the understanding was, from the -- from Dr Hill, at the time, and I think there were a few others from his

team there, but I can't remember who. And he told us

that they had been testing the stored samples, of which they had many, because they'd been doing research on

other issues to do with immunosuppression, and that they

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knew which boys had acquired HTLV-III and which hadn't.

2 But my memory is quite clear that they didn't -- they

encouraged us not to ask unless they felt we really 3

4 needed to know, because they were worried that we would

treat the boys differently if we knew that they had

6 HTLV-III, and that wouldn't be good for them.

7 MS RICHARDS: So is it right to understand that the message 8

you recall is that, as parents, it would be better not 9 to know?

10 MS BUGGINS: That was what I took away from it.

11 MS RICHARDS: And you put it this way in your statement:

12 "We were invited to ask for a personal meeting with 13 Dr Hill if we wanted to know whether or not our children had HIV. However, we were discouraged from asking as he 14 15 said that he was concerned that our knowing of 16 a positive diagnosis would change our relationship with 17 our child. There was no treatment and nothing could be

18 done about the results." MS BUGGINS: Yes.

20 MS RICHARDS: Now, a few days after that meeting you went into one of the treatment rooms, and you saw a list of

22 names on the refrigerator. What can you tell us about

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24 MS BUGGINS: I'd taken one of the boys in for some 25 treatment, and it was a very small treatment room with

(4) Pages 13 - 16

1	couple of big fridges in my colleagues will	1	MS RICHARDS: Is it right to understand that you hadn't been
2	remember and on the tall fridge door there was a list	2	aware before the October meeting that there was testing
3	pinned to the outside of the fridge door with a list of	3	being undertaken on the boys?
4	boys' names on. And because I had spent so much time in	4	MS BUGGINS: Um, it's a difficult one, that. I don't think
5	the previous few years at the hospital and most of the	5	I knew that there was testing going on. It didn't
6	boys weren't on prophylactic treatment, so they were	6	surprise me when we were told they had been tested,
7	there too, I knew which boys were big users of	7	because there was, you know, frequent blood tests being
8	Factor VIII and which weren't, and I had understood from	8	taken quite often, we didn't know what they were
9	the meeting that Richard would have been infected with	9	being taken for and repeatedly of about 100ml, which
0	HTLV-III, as it was, because of the volume he was	10	out of little boys is quite a lot, because there was
11	getting through. I think he had over	11	research going on in the unit. And I was comfortable
12	450,000 international units during his short time at the	12	with that, because I wanted them to find out how to make
13	Children's Hospital before he died.	13	things better, but we weren't told what they were being
4	So and when his name was there, that sort of	14	tested for.
15	confirmed what that might be. But then I saw Jonathan's	15	MS RICHARDS: So you knew the blood was being taken and yo
16	name, and that was completely unexpected.	16	knew there were a variety of tests but you don't think
17	MS RICHARDS: And you understood this to be a list of the	17	you were specifically told and invited to consent to an
18	boys who had tested HTLV-III	18	HTLV-III test?
19	MS BUGGINS: Who were positive. Yeah, I was pretty certain.	19	MS BUGGINS: No. I'm almost certain of that.
20	So I then asked to see Dr Hill.	20	MS RICHARDS: When you were told this by Dr Hill, do you
21	MS RICHARDS: What did Dr Hill tell you?	21	have any recollection of how the information was
22	MS BUGGINS: He told me that both boys were infected but	22	communicated and the extent to which you were given
23	Edward wasn't.	23	advice or guidance on what to do?
24	MS RICHARDS: And Edward had not	24	MS BUGGINS: In that initial meeting, no. I think the
25	MS BUGGINS: He'd not been on the list.	25	_
J	17	25	emotions just were enough to take out without 18
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4	corning a lot of information out with mo. I don't	4	hoovy bloods, as there would be blood in the home
1	carrying a lot of information out with me. I don't	1	heavy bleeds, so there would be blood in the home
2	think there was much information available at the time.	2	environment?
3	Certainly the only advice we had was at home to wash	3	MS BUGGINS: Almost every morning Richard had had
4	everything in the hottest possible wash and use a 10%	4	a nosebleed overnight and he would wake up with a cowpat
5	bleach solution, which was completely impractical in	5	of blood on his pillow and it would be all matted in his
6	a household setting, because you don't live in	6	hair and face. He used to drink from a feeder beaker
7	a hospital environment at home, and I had little boys	7	and put it down and his smaller brothers would pick it
8	and home furnishings. And I even went back and asked	8	up you know, with blood trickling down his face, from
9	what to do about that, and was told that it wasn't	9	time to time. So we lived in an environment where, if
10	important.	10	HIV was easy to transmit in a family setting, it would
11	MS RICHARDS: You learned from the retrospective testing of	11	be likely to be transmitted in ours.
2	stored samples that were undertaken that Richard was	12	MS RICHARDS: And again, just picking up on the evidence you
13	infected, in all likelihood, between August and November	13	gave a minute or two ago, you say you recall going back
14	of 1983, is that right?	14	to the hospital this is in your statement and
15	MS BUGGINS: Yes.	15	asking if Persil would kill HIV.
6	MS RICHARDS: And that Jonathan was infected between	16	MS BUGGINS: Mm-hm.
7	February 1981 and May 1983?	17	MS RICHARDS: And the nurse said, "There are far more
8	MS BUGGINS: Yes. So that first Armour transfusion may have	18	important things to research than that"?
9	carried the virus, when he was 1.	19	MS BUGGINS: Yes.
20	MS RICHARDS: And as you have described in your statement	20	MS RICHARDS: You said in your statement that the nursing
21	and referred to a moment ago, you had particular	21	sister was very helpful.
22	concerns about how to manage in a home environment with,	22	MS BUGGINS: Yes, Marion Gregory was an absolute treasure
23	at that point, three children, one of whom, of course,	23	and I think I don't know how I would have coped with
24	was not infected with HIV, and in circumstances in	24	these particular three small boys and their difficulties
25	which, is this right, Richard in particular had very	25	had it not been for her. The boys called her

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(5) Pages 17 - 20

1 Aunty Marion. And she had a cupboard full of toys that 1 of attention. 2 were refreshed all the time, so the boys went to the 2 MS RICHARDS: At the end of April 1986 Richard became 3 3 hospital to see what the new toys were rather than for very ill and he was admitted to hospital. MS BUGGINS: Mm-hm. 4 treatment. And in that way just normalised our 4 5 experience to an extent, as well as giving me huge 5 MS RICHARDS: And is it right to understand that the 6 personal support. 6 thinking was that this was HIV and that Richard was 7 MS RICHARDS: And in that time, after you had learnt that 7 dving from AIDS? 8 both Richard and Jonathan had been infected with HIV, so 8 MS BUGGINS: It was, yeah. It was a bit early. They 9 October '84, over the next couple of years, to what 9 couldn't find a reason for his unconscious state, so 10 10 extent did you have ongoing dealings with Dr Hill prior Dr Hill had heard about a patient in France that had to Richard then becoming ill in the last couple of weeks toxoplasmosis of the brain as a result of HIV infection, 11 11 of Richard's life? 12 12 and he -- his theory was, his thesis was that that was 13 MS BUGGINS: Dr Hill was a very assiduous doctor, I would 13 what was happening to Richard. 14 say. We had -- and I used to be annoyed about it at the 14 MS RICHARDS: And Richard was then in hospital for about 15 time. We used to have quarterly outpatient appointments 15 a couple of weeks? MS BUGGINS: Yes. 16 for all three boys that would always run over. And to 16 17 manage three boys in an outpatient clinic setting. 17 MS RICHARDS: And his condition deteriorated? 18 especially one with disabilities who I couldn't keep in 18 MS BUGGINS: It did. 19 his wheelchair, was really hard work. And I thought --19 MS RICHARDS: And then he died mid-May of 1986? 20 because we were being seen at the hospital so often --20 MS BUGGINS: Yes. 21 it was more than necessary to keep a tab on what was 21 MS RICHARDS: You have described how he was during those 22 going on. 22 last couple of weeks in your statement. Is there 23 So we saw him often. And when Richard was at the 23 anything you want to tell us about it? It is entirely 24 hospital, he would be there all hours, round the day and 24 a matter for you the extent to which you want to talk 25 25 night, weekends and weeks. So we didn't have any lack about it. 22 21

MS BUGGINS: It felt very unreal at the time, because
Richard had been so desperately ill through brain bleeds
and encephalitis and so on through his life, that it
wasn't really until some months after he died I'd
emotionally accepted that he wasn't coming back.
But the hospital looked after us really well through
that period. I think he was the first child to die,

that period. I think he was the first child to die, thought to be dying with AIDS in the hospital. And we never felt that there was anything untoward about them caring for him. So gloves and aprons and masks would be worn, but never spacesuits. People would come in and talk to us without gowning up. Yeah, it was exemplary, the way they looked after us.

14 **MS RICHARDS:** The trauma of Richard's death was exacerbated by events in the immediate aftermath of the death.

16 MS BUGGINS: It was.

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17 MS RICHARDS: Can you tell us about that, please?
 18 MS BUGGINS: Well, the Children's Hospital at the time --

it's since moved -- didn't have facilities to do a
postmortem on an infected child, and so they needed to
use the facilities at the coroner's office. Dr Hill got
in touch with the coroner and asked to do the postmortem

there, and the coroner, in Dr Hill's words, became very "excited" at the idea that an HTLV-III positive boy had

died on his patch. And he released a -- Richard died at

8.50 in the morning, and he released a statement to the
 press, the coroner, that morning before the postmortem
 was done to say that a child known to be HTLV-III
 positive had died and thought to have died of AIDS in
 Birmingham Children's Hospital.
 The media loved it at the time because it was still

The media loved it at the time because it was still a very stigma-oriented illness, and so there was a feeding frenzy around the fact. And because Richard --well, boys with haemophilia don't die every day when they are eight, and Richard's age was given, everybody who knew us knew that Richard had HTLV-III.

12 MS RICHARDS: We can see, if we just look at WITN1021009.

If we go to the second page, we can see some examples of press reporting. We don't need to look at the text, but the headlines tell us the story: "Hospital AIDS probe on little boy's death"; "AIDS theory over death". And then there is what effectively is then a correction, "AIDS virus not to blame", because, as I understand it, the postmortem revealed that Richard had died of a bleed on the brain.

21 **MS BUGGINS**: It was a clot down in the stem of his brain, yes.

23 MS RICHARDS: We can take that down. Thank you.
 24 How did the boys' schools react to their infection?
 25 I think you had a range of experiences.

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for him.

MS BUGGINS: I did. All three boys were at different schools. Richard was at a special school, and his headteacher had lost her child at 15, and so phoned, when she heard Richard had died, with severe -- sincere condolences. It was about midday. And then when the first edition of the lunchtime news came out, she phoned me back and was so abusive on the phone that I'd put, you know, everybody's lives at risk in the school because I hadn't told them -- for very good reason, which I do mention in my statement -- and I just had to put the phone down. It was just shocking.

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Then Jonathan's school didn't say anything. But the headmaster asked me some weeks later if Jonathan was all right, and I knew -- I thought I knew what he was asking me, but I answered the question he actually asked, and I said, "Yes, he's fine," because I didn't want to talk about I, and I didn't think it was necessary because he wasn't bleeding at school.

And Edward's school, the headmistress got in touch with me and said the parents had been asking questions and were quite concerned about having Edward in the class, whether it was safe for their children. And she agreed with me what she should say and that she should call a meeting to the parents, and it completely calmed it down. And they wrote to me a lovely composite letter

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1 And, thereafter, we moved the boys' schools to a primary 2 school ten-ish miles away where nobody would recognise 3 our history, and they could carry on their childhood as 4 normal.

MS RICHARDS: And you also observe in your statement that there was -- there were known to be a number of other children treated at Birmingham Children's Hospital also infected with HIV, and obviously we'll be hearing further evidence about that today. And then there would be deaths and funerals.

MS BUGGINS: It sort of increased the -- sort of stepped up the frequency of them. And because we as parents knew each other very well, we went to the funerals, and it just felt like there was this wave of death, and every time I went to funeral, we would all be in tears. And we would be anticipating our children -- our own children dying. But there was quite a lot of mutual support between parents who were in that group, which was very helpful and continued for a while.

20 MS RICHARDS: Just one observation, if I can pick up on in 21 your statement. I'll just read a paragraph from your 22 statement. You say this:

> "One question in my mind is what incentives, if any, doctors were given to limit product use or to use a particular product. On one occasion, I remember a set

1 and sent a donation to Richard's memorial fund, which. 2 you know -- so you couldn't have a wider range of 3 responses, really, in one town. 4

MS RICHARDS: More broadly, how did you, as a family, 5 experience the stigmatising effect of AIDS and HTLV-III? 6 MS BUGGINS: We didn't really feel the stigma too much.

7 I mean it was a frightening thing, and we knew we 8 wouldn't talk about it outside a very, very tight circle 9 when we first heard about it, but it wasn't difficult 10 for the family, really, because our friends were fabulous, until the publicity. And then everything 11 changed because there were no -- the play dates just 12 13 stopped coming for the boys. We'd send invites out for 14 the boys' birthday parties and nobody would turn up, or 15 one or two. The school stopped stimulating Jonathan, 16 and he was a bright, you know, very, very capable boy

> Edward's mental health was really, really badly affected by Richard dying, and there was no help at all for that. And immediately on the death, we -- the media were trying to find out from the hospital who we were, and we got these little boys who were four and six. So we went to friends on the south coast who provided us respite for two weeks while the media frenzy died down.

and was just allowed to daydream because they felt sorry

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1 of white leather suitcases appearing in the treatment 2 room, and someone mentioned that these had been provided

3 by a drug representative. I wondered what really 4 influenced treatment choices."

5 MS BUGGINS: Mm. It's still a question. I don't know the 6 answer

7 MS RICHARDS: Now, Jonathan, at this point in time when 8 Richard died, didn't know his own diagnosis.

9 MS BUGGINS: No.

10 MS RICHARDS: And it was a few years later, I think, when 11 Jonathan was about ten, that you decided that he should 12 he told

13 MS BUGGINS: Mm-hm.

MS RICHARDS: And your husband told Jonathan the position. 14

15 MS BUGGINS: Mm (Witness nodded).

MS RICHARDS: You described that in your statement as 16 17 watching your husband and Jonathan in the garden --

18 MS BUGGINS: Yeah.

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MS RICHARDS: -- how agonising that discussion was. 19

20 MS BUGGINS: Yes. Jonathan had started to ask for grown-up 21 conversations, and we knew we needed to tell him at some 22 point, and there was stuff around in the media that 23 Jonathan was picking up, so we decided it was probably the best time to tell him before he got into

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adolescence. And so, as one of these sort of man-to-man

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1	conversations he was asking for, Phil took him into the	1	a small house of his own. So I decided I'd achieved my
2	garden and had a chat about it.	2	objective, and because we were so hugely dependent on
3	MS RICHARDS: Before I ask you a little more about Jonathan	3	the Children's Hospital for treatment, and I respected
4	and Edward, you brought litigation on Jonathan's behalf	4	Dr Hill at that time, and I didn't want him to be
5	against the Health Authority, and that went the	5	cross-questioned I wanted to protect that
6	global HIV Haemophilia Litigation having settled, and	6	relationship I decided that we should settle. And so
7	the Inquiry has heard evidence about that, the	7	he was never cross-questioned in the High Court.
8	individual case against the Health Authority actually	8	MS RICHARDS: We'll look in a moment at the statement he
9	went to court.	9	provided for that litigation. Just before we do that,
10	MS BUGGINS: It did.	10	however, can I ask you about something, again, you say
11	MS RICHARDS: And you gave evidence to the court on the	11	in your statement. It was a time later you or the
12	second day of the hearing.	12	family encountered someone who had also worked at the
13	MS BUGGINS: Yes.	13	Children's Hospital in a more junior capacity.
14	MS RICHARDS: And on the third day of the hearing, Dr Hill	14	MS BUGGINS: Yes. Well, it was my father-in-law. He used
15	was due to give evidence. What happened before Dr Hill	15	to repair antique clocks as a hobby after he retired,
16	gave evidence?	16	and he went to a house near to where he lives, and the
17	MS BUGGINS: Well, first thing in the morning, my QC	17	owner of the clock said to him, "Are you related to
18	approached me and said that they'd had an offer to	18	Elisabeth Buggins?" And so he said, "Yes." He said,
19	settle with the children's hospital. And he said it was	19	"I was a junior doctor at the hospital when Elisabeth
20	a total gamble because he had no idea how Dr Hill would	20	took the court case, and she should never have settled."
21	respond to questions. And the settlement that they'd	21	Now, I only have that from my father-in-law, so it's
22	offered was £75,000, and my intent in taking the action	22	secondhand information, and I tried to find the doctor
23	was really to make sure that Jonathan could have a home	23	concerned, who I think has retired since, but he told my
24	if he was to be lucky enough to grow up, and at that	24	father-in-law, so I understand that he went abroad to
25	point, £75,000 would have been enough to have bought him	25	work because he felt so uncomfortable about the way
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1	treatment was managed.	1	Dr Hill. And there's a letter back from me following

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1 treatment was managed. 2 MS RICHARDS: And the reason he thought that you shouldn't 3 have settled was -- shouldn't have settled for that sum 4 because, in reality, Jonathan should have been awarded 5 a much greater --6 MS BUGGINS: Substantially more, yes. 7 MS RICHARDS: And then, again, just before we look at the 8 statement from Dr Hill, not long after, so 1993, you've 9 told us you -- one of the reasons you also thought 10 favourably of the settlement offer was you didn't want 11 to impair the relationship with Dr Hill because you had 12 two children who continued to be treated under Dr Hill. 13 MS BUGGINS: Yes. Yes. MS RICHARDS: But you then got a letter from Dr Hill 14 15 refusing to continue to treat the children. MS BUGGINS: Yes. It was early in -- very early in 1993, so 16 17 the year after the court case, and he asked us to take 18 our children for treatment to another centre. MS RICHARDS: And did he explain why? 19 20 MS BUGGINS: I have copies of the letters at home which 21 I could supply, but I don't have that in my mind. 22 I know there was some allegation made, I think, by my 23 lawyers that there was a note in Jonathan's notes, 24 a handwritten note, that looked as if it may have not 25 been added contemporaneously, and that really upset

Dr Hill. And there's a letter back from me following Dr Hill's letter saying, "I'm really sorry that that allegation was made."

Then I spent the next year trying to persuade him that we still did trust him, because it was -- it turned into an issue of how much did we trust him to treat the boys and, I think, how much he trusted us. And I involved a huge range of people, because I -- having worked in the Health Service, I knew how the structures hung together.

So I went first to the hospital management and asked them to intervene and mediate. I then went to the local Area Health Authority. Dr Bernard Crump was the lead there. He refused to get involved. The Children's Hospital supported Dr Hill and said, "No, you have to find somewhere else". I went to Professor Rod Griffiths, who was the regional director of public health, and I think the regional arrangements held the doctors' -- consultants' contracts at that time. And he worked with us really hard to try to mediate and make arrangements. But by Christmas of that year, so a whole year, we hadn't had outpatient appointments for the boys. We had emergency treatment only. And I'd arranged, through my professional contacts, for the HIV specialist at Heartlands Hospital

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to do blood tests on Jonathan so that we could keep track of how HIV was affecting him under a pseudonym so that it wouldn't be recognised.

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Yes, so it was a hugely difficult time. And because we weren't on prophylaxis, we were at the hospital every few days. And I couldn't imagine with three children -because Rosie had been born by that time -- how we could manage going to Liverpool or Oxford, which was where we were trying to be persuaded to go, and still manage any sort of life or any sort of education for the children, and so I felt completely stuck.

And because Dr Hill had done -- Dr Savidge had done the expert report, and we came across the clinical nurse specialist from there at a Haemophilia Society conference, it was suggested that we should go and see Dr Savidge, which we did.

And I thought it was going to be really, really hard to manage life like that and we would probably need to move house, and in actual fact, because they had prophylaxis, because the factor was delivered to our house, because they only wanted to see them every six months, life became substantially easier and much less painful and traumatic for the children.

24 MS RICHARDS: I'm going to look now at the statement that Dr Hill provided in Jonathan's litigation. And as well

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as dealing with aspects of Jonathan's care, it is Dr Hill's perspective on his approach to treatment and therefore of wider interest and importance as well for those children who were treated at the Children's Hospital.

Lawrence, could we have WITN1021024.

We can see it's a statement from Dr Hill. The date of the statement is 11 April 1992. That's later in the document. He gives some background about the paediatric centre. Paragraph 2 refers to it being the largest paediatric centre for haemophiliacs in the country, between 50 and 70 severe haemophiliacs registered. And then he describes regular medical cover being provided by senior house officers in paragraph 3.

Then if we go to the top of the next page, there is reference at the top of the page to the quarterly assessments that you have referred to, Elisabeth. Then he says this:

"The treatment policy of the unit was to provide a treatment service that allowed replacement therapy to be given as early as possible to treat spontaneous haemorrhages so that the potential short term and long term damage to joints and muscles could be minimised. Our means to do this was dependent on supplies of Factor concentrates. With regard to

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haemophilia A the Factor concentrates available for the 1 2 use were cryoprecipitate, NHS or commercial Factor VIII concentrates. The amounts of these available at any 3 point in the time was variable with supplies of NHS 4 5 Factor VIII being the least available. Cryoprecipitate is a product that was suitable for use in the 6 haemophilia unit but not faced for use at home because 7 many patients, particularly children, can have 8 anaphylactic reactions to this product. Cryoprecipitate 9 10 was therefore used only for treatment on demand in the haemophilia unit particularly for newly presented 11 patients until it was clear whether or not they would 12 require regular treatment, as it was known that 13 infrequently treated or mildly affected haemophiliacs 14 were more at risk of contracting hepatitis B and 15 16 becoming hepatitis B carriers if treated with Factor VIII concentrates rather than cryoprecipitate. 17 Patients of younger age prior to training for home 18 therapy were therefore likely to be treated more 19 frequently with cryoprecipitate. However, if 20 cryoprecipitate of an appropriate ABO blood group or if 21 the patient had had reactions to cryoprecipitate or one 22 23 was treating a major bleed or required a smaller volume product, Factor VIII concentrates were more likely to be 24

used. The type of concentrate would be determined by

availability but the unit tried if possible to maintain a given patient on either NHS or commercial concentrate. In late 1976 in an attempt to control haemophilia bleeds and to give patients a better quality of life home therapy programmes were introduced. This therefore required increased amounts of Factor concentrate and commercial concentrates were more available than NHS concentrates."

Then he says this about his knowledge of risk:

"I was well aware of the existence of viruses causing serum hepatitis from the time that I came to the Birmingham Children's Hospital."

That was in 1976, he says elsewhere in the statement.

"I was aware that concentrates made from pooled plasma carried a greater risk of hepatitis than blood products made from single donors and we closely monitored our patients for jaundice. Tests for screening for hepatitis B were introduced in the UK in the mid-1970s and these tests were conducted on our patients.

"7. I was aware of the AIDS syndrome in homosexuals from 1979/1980. From my dealings with other patients, I became aware of the possibility of AIDS being a condition encountered in haemophiliacs in early 1983

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but I had no knowledge of whether the condition was associated with a virus infection or could be associated with imported Factor VIII concentrates. I was certainly conscious that there was a similarity between haemophiliacs and homosexuals in that both had an increased risk of hepatitis but there were many theories about its cause including that it might be related to an increased antigen load. It was not thought that there was any call for any treatment alteration because of the association between haemophilia and AIDS based on information available in 1983 and to withhold treatment of acute haemorrhages was considered more dangerous."

There's then a reference in the next paragraph to a tuberculosis outbreak in the Children's Hospital. I'm not going to read through that.

Last paragraph. He says this:

"The treatment policy that I had in the Unit for severe haemophiliacs was to treat newly diagnosed infants initially with cryoprecipitate."

If we go to the bottom of the next page, please.

Then he refers to what he'd set out above.

Then top of the next page he makes this statement:

"Cryoprecipitate was not appropriate for use at home

because it had to be stored under strict temperature conditions in a deep freeze or it would be dangerous to

to cryoprecipitate that cannot be controlled.

If we then go over the page he then details
Jonathan's treatment and puts forward thoughts about the treatment. If we pick up -- I'm not going to read it all but we can see, about eight lines into this paragraph, eight or nine lines, he refers to Jonathan being given Factor VIII, Armour Factorate, on 27 March 1981, and he says this:

"I cannot decipher the signature of the SHO who treated the Plaintiff and there is no indication on the note as to why Factor VIII concentrate was given on this occasion. It could have been that no cryoprecipitate was available or it was felt more convenient to give Factor VIII concentrate or to ensure a predicted therapeutic response."

Then he looks at a number of other occasions upon which Jonathan had been given Armour Factor VIII.

If we then go over to the bottom of -- I think it's page 8, Lawrence, please -- he makes this assertion, again going to the generalities of the approach to treatment:

"The Birmingham Children's Hospital never had sufficient supplies of NHS Factor VIII concentrate to meet its needs. The supply position for the hospital in relation to blood products between 1981 and 1985

immediate medical help. These risks outweigh the advantage of cryoprecipitate of reduced donor exposure and making Factor VIII concentrate the treatment of choice for children once they were on home treatment. Factor VIII concentrate was also the treatment of choice if a patient had any anaphylactic reaction to cryoprecipitate or when one wished to be certain of a definite rather than expected rise in Factor VIII units."

use and the risk of anaphylaxis occurring without

Then paragraph 14 tells us that:

"Normally we would consider a patient for home therapy at about 3 years of age although it was not uncommon for it to be earlier particularly as our unit was very skillful at training patients and their parents to be able to administer Factor VIII at home."

He then refers in the next paragraph to on-the-job training for senior house officers and a written instruction on protocol, and he refers to attaching that document. And indeed we have that document, which we'll look at in a moment

He asserts that it, the document, sets out the fact that cryoprecipitate is the most frequently used material and that freeze-dried Factor VIII is reserved for patients who have had severe anaphylactic reactions

was ..."

Then he refers to an attached schedule. Then he says this:

"It was my view at the time that the NHS material was safer because of the lower transmission rate of hepatitis. It was a product I would have preferred for all my patients if I could have received enough. Given the difficulty in supply, I made efforts to ensure that the commercial product which we received limited potential exposure from hepatitis infected donors to the patients. I attempted to purchase entire batches of concentrate so that the batches could last much longer and I also aimed for bottles with smaller numbers of units which were better for the size of our patients."

Then he refers to setting up a priority system for the use of the very limited supplies of NHS concentrate that he says he had available. And it seems essentially to be if there was an anaphylactic reaction to concentrate.

We then have a heading "Advice to Parents of the Risk", and he says this, and obviously we'll be picking this up with Brenda and Linda in due course as well:

"It was always my practice to keep parents informed of risks as we knew them. As stated earlier in this statement however, we had no reason to suppose that the

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1	treatment being given exposed the patients to an AIDS	1	showed that in 1981 the product mainly used for
2	risk at the relevant time. However, we were aware of	2	inpatients was mainly NHS product with some Factor VIII,
3	the potential risk of the transmission of hepatitis	3	and home treatment was mainly commercial.
4	virus by all blood products. This risk had to be set	4	1982, it was mainly Factorate, Armour product, some
5	against the risk of leaving the Haemophiliac bleeds	5	NHS, and a little cryoprecipitate. Those who were home
6	untreated."	6	were mainly on Factorate.
7	Then he refers to aspects of Richard's treatment.	7	1983, some cryoprecipitate, some more NHS, but
8	Then if we go over the page, the assertion in the	8	mainly Factorate.
9	second line is:	9	And in 1984 there was somewhere between 20 % and 25%
10	"The risks of treatment and balancing these risks	10	of the total product used was NHS, 70-75% was
11	against not managing the haemophilia bleed by treatment	11	commercial, and about less than 1/16th was
12	with concentrate was always discussed."	12	cryoprecipitate.
13	Then he refers later to meetings, including,	13	In 1985, the what you observed at the time, there
14	I think, possibly the 1984 meeting that we've already	14	was never enough NHS Factor VIII for all the patients.
15	referred to.	15	1985, the Armour supplies were said to be steady.
16	Can we then go to the next page briefly. I don't	16	There was some unheated National Health Service product,
17	propose to read this out but, if we could just turn it	17	but the demand for cryoprecipitate had then increased.
18	round, this is the schedule that Dr Hill refers to. And	18	That's what I was told.
19	it gives the product usage.	19	MS RICHARDS: Yes, and that was information drawn from the
20	Sir, I haven't had an opportunity yet to match that	20	annual returns.
			SIR BRIAN LANGSTAFF: Yes.
21	up against information in the annual returns but we'll	21	MS RICHARDS: So what we'll need to do Elisabeth having
22	certainly do that.	22	
23	SIR BRIAN LANGSTAFF: Well, the the presentation which	23	very kindly been able to provide us with this
24	you provided on the Birmingham Children's Hospital,	24	document is to see whether the information that
25	amongst the well, of the two Birmingham hospitals, 41	25	Dr Hill was giving the court matches up with what was in 42
	71		42
1	the annual returns.	1	SIR BRIAN LANGSTAFF: He may be wrong.
2	Then just briefly, if we go to the next page, we see	2	MS RICHARDS: He may be wrong.
3	the written protocol which his statement says was	3	SIR BRIAN LANGSTAFF: But that's what he says.
4	a document issued to senior house officers.	4	MS RICHARDS: Yes, it is.
5	I'm not going to go through the detail of it, but it	5	So our thanks, Elisabeth, to you and to Jonathan for
6	may be that in terms of it's undated, but it may be	6	providing us with that information, which is of great
	describing a state of affairs in the 1970s rather	7	assistance as we didn't have a full statement from
7	than 1980s. I say that because, if we go to the next		Dr Hill.
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9	page, please, under the heading "Dose of Replacement		Can I just ask you a little, then, about
10	Therapy", paragraph 3 says:	10	hepatitis C. You didn't recall discussions with Dr Hill
11	"Type of therapeutic material available:-	11	about hepatitis C. You told us in your statement
12	"(a) Cryoprecipitate - most frequently used	12	Jonathan asked himself to be tested in around 1994,
13	material.	13	1995, and learnt he was hepatitis C positive.
14	"(b) Freeze-dried preparations of Factor VIII -	14	In relation to Edward, at the time you drafted your
15	small amounts only available"	15	statement you couldn't recall being told by Dr Hill that
16	So that certainly isn't the position either	16	Edward had tested positive for hepatitis C, but as
17	described by any of the witnesses we'll hear from today	17	I understand it, in the course of preparing for your
18	by the time we get beyond the second half of the 1970s,	18	evidence today, you found some material which suggests
19	nor is it the position that the annual returns reveal.	19	that you may have been told?
20	So although it is an undated protocol, it really does	20	MS BUGGINS: Yes, and this is the difficulties of memories
21	look as though it must be referring to the position in	21	over so many decades, and the fact that HIV was the big
22	the 1970s.	22	worry and hepatitis was always presented as something
23	SIR BRIAN LANGSTAFF: Yes, Dr Hill suggested it was the	23	not to worry about at the moment, I think.
24	relevant protocol at the time, in his statement.	24	But yes, there were letters in Edward's treatment
25	MS RICHARDS: He does, yes.	25	record of certainly letters to the GP that explain

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1	that he has discussed hepatitis with me, because Rich	1	heard the conversation. And what do you do in that
2	Edward let's get the name right Edward had periods	2	situation?
3	where he was really lethargic and not very well for some	3	So I confirmed that he was correct. I think he
4	weeks and I was quite concerned about that and talked	4	couldn't understand why Jonathan had got HIV and not
5	Dr Hill about that, and he had abnormal liver function	5	hepatitis C as well, and yet Edward had hepatitis C.
6	test results. And so it was likely that it was	6	Then after we'd had the consultation, I went out and
7	non-A, non-B, and then he we were told before he left	7	found the doctor and explained to him that Edward hadn't
8	the Children's Hospital that he was HCV positive,	8	known before. And he was profoundly sorry. I mean, it
9	I think in 1992.	9	was just one of those things: he was thinking hard and
10	MS RICHARDS: Now you hadn't told Edward, who had been	10	not thinking straight, I think, yeah.
11	profoundly distressed by Richard's death	11	But I think it helped us because it breached that
12	MS BUGGINS: Yes.	12	difficult decision about when to tell, and Edward was
13	MS RICHARDS: you hadn't told him that Jonathan was HIV	13	old enough at that time to be able to keep a secret and
14	positive.	14	to have a conversation with.
15	MS BUGGINS: No.	15	MS RICHARDS: Jonathan, in terms of his own health, suffered
16	MS RICHARDS: How did Edward learn of Jonathan's diagnosis?	16	PCP in 1987
17	MS BUGGINS: It's very difficult to know what to say when,	17	MS BUGGINS: Yes.
18	but we went to St Thomas's Hospital for treatment	18	MS RICHARDS: pneumocystis carinii pneumonia. You,
19	following eviction from the Children's Hospital. And it	19	because not least, I think, of having lost Richard, you
20	wasn't our first clinic there, it was some months in.	20	feared that was the end for Jonathan?
21	We went I took them to a clinic. And a new doctor	21	MS BUGGINS: Yes. I know there's number of people here who
22	appeared and he walked in the room with both sets of	22	have lost more than one child, and I just can't imagine
23	notes and he said to me, "Let me get this straight:	23	how they deal with that. I listened to Sue last week,
24	Jonathan has HIV and Edward has hepatitis C?" In front	24	from Alder Hey, and my heart went out to her, because
25	of Edward. I think Jonathan was sitting outside, but	25	the second time it's happening it sort of reawakens all
	45		46
1	of the emotion of the first time. And it was me who	1	MS RICHARDS: to enable you and your family
2	needed to go and see him at St Thomas' when he was	2	MS BUGGINS: Particularly for Edward, who was just
3	admitted for PCP, it wasn't him that needed me. But	3	devastated. He wouldn't leave my side after Richard
4	I just had to get the train straight down and be there.	4	died. He wouldn't go to school, he just wanted to take
5	And I just kept going for walks along the Thames to cry,	5	some toys and play with Richard in his box, his coffin,
6	because I didn't want to cry in front of Jonathan.	6	because at four you don't have a concept of death,
7	But we were very fortunate in that in a couple of	7	really, and he was the one who always tried to make
8	weeks he was well enough to come home and we he is	8	Richard feel better. They were similar mental age,
9	still here.	9	I think. And from being a happy-go-lucky little boy who
10	MS RICHARDS: You described in your statement your focus	10	was always sunshine, Edward became morose, difficult,
11	throughout these years was trying to focus on the	11	depressed. He started wetting the bed again at night,
12	positive, trying to keep life normal, and you said in	12	which distressed him for years afterwards. And I tried
13	your statement, looking back now, you don't think you	13	very hard to get help for him. In fact, one of the
14	realised the full extent of the emotional and physical	14	letters from Dr Hill in the notes talks about me asking
15	impact on you all?	15	for psychiatric help, and he didn't think that was
16	MS BUGGINS: I don't think we could have coped or had any	16	appropriate, and he wrote to the GP and told her and
17	sort of sensible life if we'd have "wallowed" is the	17	said that he'd discussed some strategies with me and
			_
18	wrong word, but if we'd have spent too much time	18	he gave me a chart to a sort of gold star chart for
18 19		18 19	5
	wrong word, but if we'd have spent too much time thinking about the difficulties. And I've been a very optimistic person all my life and, I think because I had		when Edward was dry at night and things like that, to try to encourage him.
19	thinking about the difficulties. And I've been a very	19	when Edward was dry at night and things like that, to
19 20	thinking about the difficulties. And I've been a very optimistic person all my life and, I think because I had	19 20	when Edward was dry at night and things like that, to try to encourage him.

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MS RICHARDS: You also observe in your statement you wish

there'd been access to professional help --

25 MS BUGGINS: Absolutely, yes.

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him, because at 4 you don't have the language to

describe how you're feeling. And she spent quite some

time with him over a period of months, taking him for

1	walks in the park and playing games with him and trying	1	"He died last year and Dr Acland kindly let me have
2	to get him to talk. And she said to me, "This isn't	2	the brain as I understand he was HIV Positive. I have
3	I can't do this". She said, "I've been trained to work	3	got sections which are really quite interesting but
4	with adults on a lay basis, and I don't think I'm making	4	difficult to interpret and I wondered if it is possible
5	any progress."	5	to have a look at the notes as I have only a scanty
6	So I went back to the hospital and asked for some	6	clinical history."
7	help. But there was just none available. And we saw	7	Now you'd given consent for there to be a limited
8	Edward from being this confident little boy just fluff	8	post-mortem.
9	nearly all of his exams, his piano exams as well as	9	MS BUGGINS: Yes.
10	school things, because as soon as there was any sort of	10	MS RICHARDS: But is it right you did not know that there
11	test, he froze. He just couldn't do it. He wasn't	11	were organs or tissue elsewhere?
12	confident. And he took that into his adolescent years,	12	MS BUGGINS: We thought, because the coroner wanted a more
13	which, you know, were then compounded by treatment for	13	extensive postmortem, and we wanted to support the
14	hepatitis C and so on. And I don't think he's now the	14	learning about what this disease was, thinking it was
15	same person that he would be had that not had he had	15	HIV at the time, I don't think we would have objected.
16	the help that he needed at that point.	16	But not knowing that his whole brain went somewhere
17	MS RICHARDS: You've told us about Richard's post-mortem and	17	else, particularly to the place where the consultant
	•		
18	the consequences in terms of the media activity and so	18	paediatrician in [redacted] wouldn't send Richard when
19	on. But you've also recently seen a letter in Richard's	19	he first had a brain problem he sent him to
20	medical notes. Are you content for us to look at that?	20	Alder Hey, which was hundred miles away, instead,
21	MS BUGGINS: Yes.	21	because he hadn't got confidence in their capability of
22	MS RICHARDS: It's WITN1021012. Second page, please.	22	neurology in children, it just jumped out at me when
23	It's from a neuropathologist, May 1987, to Dr Hill,	23	I saw it in the notes.
24	refers to the Home Office pathologist, Dr Acland, and	24	MS RICHARDS: And it's the lack of consent?
25	says in relation to Richard:	25	MS BUGGINS: It's the lack of consent, it's the lack of
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1	knowing, and having understood from the Bristol Inquiry	1	about, for present purposes, was about an issue relating
2	the consequences of samples being everywhere. I guess	2	to the Skipton Fund and Richard.
3	it's no longer there, but I don't know.	3	You made an application to the Skipton Fund,
4	MS RICHARDS: Elisabeth, I'm not going to ask you in detail	4	obviously a number of years after Richard's death, which
5	about matters relating to Jonathan and Edward's ongoing	5	was turned down
6	health. They are both, I think, going to be able to	6	MS BUGGINS: It was.
7	provide their own statements to the Inquiry, and we have	7	MS RICHARDS: because having died such at a young age and
8	a statement from your daughter too	8	before tests were available for hepatitis C, you
9	MS BUGGINS: Mm.	9	couldn't prove that he had been infected with
10	MS RICHARDS: which describes the impact upon the family	10	hepatitis C.
11	from her perspective. I just wanted to pick up on	11	MS BUGGINS: Mm.
12	a couple of points, though, if I may.	12	MS RICHARDS: You then, I think, after you heard some of the
13	The first is, in your statement you've referred to	13	evidence given to this Inquiry about the Skipton and
14	your guilt at giving the boys haemophilia.	14	EIBSS from Nick Fish and from Professor Thomas, you made
15	MS BUGGINS: Mm. I don't think I'm alone in that with	15	a further application. Can you just tell us about that?
16	carriers of haemophilia. Not that I could do anything	16	MS BUGGINS: Yes. I applied in 2011, when it became
17	about it. But it is you would never wish something	17	possible to apply for people who'd deceased, and that
18	like that on your children, particularly because	18	was turned down, as you say. And I was so upset when it
19	I wasn't certain I was a carrier until I'd had the	19	was turned down, I can remember scrumpling all the paper
20	two you know, I couldn't have prevented it. And	20	up and putting it on the fire because it was just like
21	Edward I felt very embarrassed about when he was	21	you sort of raise your expectations, and then swipe,
22	diagnosed with it. But yes. So I felt an added	22	that's it. And I didn't know what more I could do
23	responsibility, I think, to try to make life as good as	23	because the evidence isn't there. And yet it had been
24 24	I could for them, despite that.	24	presented to me as: if they were HCV positive or had
	room for from, adopte that.	4	processed to the do. It they were now positive or ridu

REDACTED VERSION

25 MS RICHARDS: Then the final point I just wanted to ask

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been exposed to HCV, then you were eligible for the

1 20,000, not that you had to have evidence of chronic 1 forward. They won't consider it until there's further 2 2 evidence. There is no further evidence to have. And illness 3 So I thought, "Oh, that's it." You know, didn't pay 3 yet Richard, through his life just at Birmingham 4 any more attention to it until I heard the evidence that 4 Children's Hospital -- so this isn't around the brain 5 you mentioned. And then I thought, "Well, this isn't 5 operations -- had, I reckon, from my best translation of 6 right." So I got the information again that I -- that's 6 the medical notes, at least 104 units of blood in his 7 right. I'd applied for the notes, Richard's medical 7 life through the period where hepatitis C was being 8 records, and I saw copies of the application in 8 acquired through blood transfusions, not blood products, 9 Richard's notes, and Dr Williams' letter to Skipton on 9 as well as all of this commercial Factor VIII. From the 10 10 my behalf that you had to supply as part of the pack evidence that you mentioned, it's a hundred per cent originally. So I thought I would write to Mr Fish and likely he would have had HCV. And I feel guilty again 11 11 say, "You said this to the Infected Blood Inquiry, and because I'm not desperately poor, and I don't need the 12 12 13 this is the application that I made, and please will you 13 20,000 to be able to get by next week, but it's just 14 reconsider?" 14 this -- it's a sense of injustice, you know. If they 15 And I had a letter back from the support scheme 15 were clear about that. 16 saying, "You need to fill in a new form, and you need to 16 And I only found out about the ability to apply 17 send it to the Children's Hospital, and they need to 17 because other mothers had said they'd all applied, and 18 write to us again, otherwise we can't consider it; we 18 I didn't know about it until I heard from them. So 19 can't deal with it as an appeal." 19 I actually applied late in the first place. It was just 20 And so I didn't want to trouble the Children's 20 really poorly managed. 21 21 Hospital again. We were in the middle of Covid, and MS RICHARDS: And so that others follow, the evidence that 22 they were far too busy anyway, and there was no new 22 you refer to from Mr Fish and from Professor Thomas was 23 information because I'd had a look at the records by 23 evidence to the effect that the approach taken by 24 then, so I couldn't see any point in reapplying. So it 24 Skipton was: if you were a haemophiliac who had been sort of sits like that, really, in that I'm no further treated with factor concentrates, certainly for any 25 25 53 54 doctor, and he sent us to the Children's Hospital to 1 prolonged period of time, they worked on the assumption 1 2 that you would have been infected with hepatitis C. 2 have some blood tests taken because my theory was, if he 3 MS BUGGINS: Mm. 3 is a haemophiliac, I want him to have records. So if he 4 MS RICHARDS: And yet Richard, having been treated with very 4 needs treatment, there's going to be no delay; he can 5 significant quantities as well as the blood transfusions 5 have the treatment. So that was when we found out, when 6 during his short life, they have rejected the 6 he was six to seven months old 7 7 application. MS RICHARDS: And he was under the care of Birmingham 8 MS BUGGINS: Yes. 8 Children's Hospital, and Dr Frank Hill was the MS RICHARDS: Thank you, Elisabeth. 9 9 consultant. 10 I'm going to turn next to Brenda and ask Brenda to 10 MS HADDOCK: Yes. Yes. 11 tell us about Andrew. 11 MS RICHARDS: Now, to start with in the 1970s, Andrew was 12 So Andrew was born in 1972; is that right? 12 treated with cryoprecipitate. 13 MS HADDOCK: That's right, yes. 13 MS HADDOCK: He was -- yes. He had the cryo when he was MS RICHARDS: Diagnosed with severe haemophilia A from a baby for so long. I'm not sure whether that was 14 14 15 birth 15 before the Factor VIII was so readily available. MS HADDOCK: Not from birth; from around six months old. 16 Because I do remember the Factor VIII becoming a thing, 16 17 I've got haemophilia in my family. My grandfather was 17 and we all thought, "Oh, this is wonderful," you know. 18 a haemophiliac. My brother, two cousins. So I knew the 18 "A breakthrough treatment. We're all going to be able 19 likelihood of me being a carrier, although it had never 19 to live a more normal life." 20 been confirmed, because I don't think in those days 20 But mainly I remember Andrew having Factor VIII 21 there were any tests to tell you whether you were 21 rather than the cryo. So I think -- I don't think he

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a carrier or not.

So when Andrew became six months and he started to

move around a bit more, rolling on the floor and things

like that, I wanted to know. So I went to a family

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had the cryo for that long before he was changed on to

the Factor VIII. And in the beginning, he was given the

the one day we went for treatment, and he was given this

NHS Factor VIII for quite a while, I believe. And then

1	Armour Factor VIII. And I remember the doctor on	1	came into our lives after the HIV, you know, quite a few
2	duty I think it was an out-of-hours doctor, because	2	years after.
3	we'd be there day or night any time, really. And the	3	MS RICHARDS: And what, if anything, were you told about the
4	doctor said, "This is something new. This Factor VIII	4	risks of transmission leading to AIDS?
5	is new, and some of the boys have had a reaction to it.	5	MS HADDOCK: Nothing, really, that I can remember. When it
6	And if he gets a slight reaction, don't worry; it's	6	all started to blow up, there were two meetings that
7	nothing to worry about."	7	Dr Hill called at the hospital. We could only attend
8	So that sort of sticks in our mind, that that was	8	one because we were on holiday for the second one.
9	when changed over. And I think after that, I think he	9	I think it was in the autumn, but we always used to go
10	was mainly given the Armour, the Armour Factor VIII,	10	away in the October half term, and I think the second
11	but, I mean, I can't say for sure about that.	11	one was then. So we went to the first meeting, which
12	But when it comes to batch numbers, I don't think	12	I remember Dr Hill stressing that it's in the boys' best
13	they ever seemed to take any care about giving the same	13	interests to carry on with the treatment. And in those
14	batch numbers. You were just given what was in the	14	days we all you know, we believed doctors. We'd put
15	fridge, weren't you, really, as far as I could remember.	15	our faith in doctors. We'd got a child with an ongoing
16	I don't remember them trying to keep them on the same	16	account, we followed what the doctors said. So, you
17	batch numbers.	17	know, we blindly carried on giving the treatment.
18	MS RICHARDS: And what, if anything, were you told by	18	But I do wonder, afterwards, why couldn't they just
19	Dr Hill or anyone else at the hospital about risks of	19	temporarily stop the Factor VIII treatment while they
20	hepatitis from concentrates?	20	investigated exactly what was going on, and give us some
21	MS HADDOCK: I don't remember hepatitis being mentioned at	21	more information? You know, why did we have to sort of
22	all, to be quite honest, when Andrew was a small child.	22	blindly carry on?
23	I honestly don't remember that being mentioned. I was	23	And, I mean, Elisabeth was talking about the guilt
24	quite shocked to hear that they knew about it, back	24	as well. There's also the guilt of having home
25	then. That, to me, was something that came after	25	treatment and me giving Andrew the Factor VIII at home.
	57		58
	-		
1	Did I actually administer the dose that infected him?	1	you feel that you were ever given a choice of what
2	It's quite possible. So as well as the guilt of being	2	treatment to have?
2	It's quite possible. So as well as the guilt of being the carrier that gave him haemophilia in the first	2	treatment to have? MS HADDOCK: No, I don't believe we did ever have a choice.
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1 1 And all of a sudden Andrew's behaviour changed, and Dr Hill that he was HIV positive without you knowing, 2 2 and without you being there, what did you think of that? he started becoming really sort of depressed and -- his 3 3 MS HADDOCK: Well, I was disgusted, to be guite honest, behaviour changed completely, and he started losing 4 interest in school. I think it was in his probably 4 because Andrew had -- he became very, very depressed. 5 second year at secondary school, and we couldn't 5 He lost interest in everything. 6 understand why this change in him. But it turned out 6 When he started secondary school, we were -- at the 7 that Dr Hill had told him his HIV status at one of these 7 first parents evening we were told that he was a very 8 meetings that we weren't there -- you know, one of the 8 intelligent boy, great academic future, you know, he 9 clinic meetings that we weren't there. And Andrew 9 could do really well. And then all of a sudden he could 10 10 didn't tell us what he'd been told for quite a while. see no point in working hard at school because he 11 So we didn't know 11 thought he was going to die. He wasn't going to have 12 But I found out because when Andrew was an 12 a future, "So what's the point in me working hard?" 13 inpatient, I can't remember exactly how long after he 13 And he stopped going to school. I didn't even 14 was an inpatient in hospital, probably overnight couple 14 realise he wasn't going to school -- he was being taken 15 of nights, I think it was dental. Sitting by the bed, 15 to school, and apparently coming out of school and 16 you just look through the notes, you know, to see what's 16 hanging round the streets in the daytime, which we 17 going on. And there it was written at the top of the 17 didn't know about for so long. 18 page: "HIV positive". And that was the first official 18 MS RICHARDS: And I think it must follow from what you've 19 thing that I'd seen on, you know, or been told about it. 19 told us that you didn't know that he was being tested 20 MS RICHARDS: So you learnt that your child had been 20 for HIV? infected with HIV accidentally --MS HADDOCK: No. 21 21 22 MS HADDOCK: Yes, yes. 22 MS RICHARDS: You didn't consent for him being tested 23 MS RICHARDS: -- because you were looking through the notes? 23 for HIV? 24 MS HADDOCK: Yes. 24 MS HADDOCK: No. Well, they were always taking blood for MS RICHARDS: When you learnt that Andrew had been told by 25 25 various reasons. When we went for treatment, you know, 61 62 they were always taking blood samples. So, you know. 1 MS RICHARDS: You're at risk yourself? 2 obviously Elisabeth said they probably had blood stored, 2 MS HADDOCK: Mm-hm. which apparently they did. 3 3 MS RICHARDS: And you didn't know that? 4 And I think they were conducting some kind of test 4 MS HADDOCK: No. Well, when we started on home treatment 5 5 at the hospital, and looking into families with they automatically give you some plastic gloves to 6 haemophilia [... redacted ...]. I can't remember the 6 handle the Factor VIII and, I mean, I was always under 7 dates and how it all fits together, it's just such 7 the impression that that was to protect Andrew from 8 a long time ago. 8 germs from me, really. Because, you know, you are 9 9 So, you know, they had blood from the whole family, punching in their skin, you don't want to pass anything 10 because they were looking at the connections of, like, 10 on to them. I never even dreamt that it would work the 11 the family relationships and -- I'm not sure exactly 11 other way around. MS RICHARDS: You touched on the impact on Andrew, now in 12 what it was for, but I wasn't surprised that they got 12 13 blood samples because, as I say, they were always taking 13 his early teens, from what you describe --MS HADDOCK: Mm-hm. 14 it for one purpose or another. 14 15 MS RICHARDS: And I think it must also follow from your 15 MS RICHARDS: -- withdrawn, stopping trying at school and so 16 evidence that there was a period of time when the 16 17 hospital knew that Andrew was HIV positive. 17 MS HADDOCK: Mm, mm. 18 MS HADDOCK: Mm-hm. 18 MS RICHARDS: In terms of hepatitis C, how did that 19 MS RICHARDS: You didn't? 19 diagnosis come about? MS HADDOCK: No. 20 MS HADDOCK: Well, that -- by the time we knew about the 20 21 MS RICHARDS: Were you still involved in his home treatment? 21 hepatitis C, Andrew had moved on to the Queen Elizabeth MS HADDOCK: Oh, yes, yes. 22 Hospital, so he was no longer under the care of the

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Children's Hospital, and life was quite difficult

because it was a time that all the stories were in

Eastenders and one thing and another, about AIDS, and

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MS RICHARDS: So you have a son who is a haemophiliac,

you're administering treatment?

MS HADDOCK: Mm-hm.

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the -- you know, the news, the information on the television and everything. So Andrew found that quite difficult to cope with.

And then, because he was at the Queen Elizabeth, he was considered an adult now, so, as parents, we weren't involved at all, really. And one morning a letter came for Andrew from the Queen Elizabeth, and I passed it over to him, thinking it was an appointment or something, and it was a letter stating that he was positive for hepatitis. I mean, that just came off like a time bomb, really. It just went -- it exploded. We just -- you know, we just couldn't believe that someone would just be told like that, in a letter, without any face-to-face.

MS RICHARDS: And you went to the appointment because Andrewnow could no longer face going to the hospital?

MS HADDOCK: No, he became very withdrawn. He didn't want to mix with people. And he did start -- for a time he refused to go to the hospital, and he had an appointment with some liver specialists at the hospital and he just -- he just wouldn't go. So I went to this appointment, because I wanted them to know what was happening: that he wasn't just not turning up, you know,

that -- just what had happened to him.

I mean, they were very nice and they listened to me

but obviously they didn't divulge any medical
 information or anything. But I just felt it was
 something that I had to do, so that they knew exactly - or tried to tell them exactly what was happening.
 MS RICHARDS: Sir, I'm conscious of the time. I'm very

MS RICHARDS: Sir, I'm conscious of the time. I'm very
 happy to continue but I know the stenographers require
 breaks from time to time. So I'm in your hands.

8 SIR BRIAN LANGSTAFF: Well, I think I'm going to ask the 9 stenographers to bear with this evidence. It's not 10 being given at a very fast speed so we'll go on until 11 the usual time for breaking, I think.

> Let me just say that if the stenographers take a different view, they should indicate through the usual channels.

MS RICHARDS: You have told us in your statement that there
 was a complete change in Andrew. He went from your
 sociable, funny boy to someone who was withdrawn and
 depressed?

19 MS HADDOCK: Yes, yes.

20 MS RICHARDS: He didn't want to talk to people?

21 MS HADDOCK: No.

22 MS RICHARDS: He had mood swings?

23 MS HADDOCK: Yes.

24 MS RICHARDS: He became paranoid?

25 MS HADDOCK: Hm-mm.

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    MS RICHARDS: And you and your family felt as though you
    were walking on eggshells, you don't know what would set
    him off?
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4 MS HADDOCK: Yeah, that's right.

MS RICHARDS: And of course you had your daughter who was
 also affected by this.
 HEATHER: Well we tried to protect *Iredacted1* as much as we

HEATHER: Well, we tried to protect [redacted] as much as we could, because she was [redacted] younger than Andrew, and I didn't want this tragedy to affect two children's lives, so we would encouraged her to do normal things, and, to be perfectly honest, we didn't tell her about Andrew's HIV status or the hepatitis. But obviously she must have picked up that something was going on because it was not sort of a normal behaviour in the household. But we did try to keep her, you know, protected as much as we could

But with Andrew he wouldn't even tell anyone he was a haemophiliac, because he didn't want it associated with the HIV, and he thought if anyone knew he was a haemophiliac they would automatically think he was affected with the stigma that was attached to it. So he just would not make any firm friendships. He'd got lots of sort of friends but they weren't close friends, because he was frightened of everyone sort of finding out, you know. And he wouldn't let us tell any of our

friends. So we had no support, we had to pretend everything was all right with our friends, you know, and put on a happy smile.

My mother knew because she is the daughter of a haemophiliac and she was of great support to me. But my husband's family didn't knows all the full facts, again because Andrew didn't want them to know. So we were living in, like, this isolated world with this volatile -- well, not a child but he was a teenager, he was a big -- a big -- big teenager. And we didn't know who we were going to get when he came in the door, how he would be. When he got up in the morning we didn't know how he would be. Sometimes he'd get so pent up and frustrated that he'd punch the doors and punch the wall, put his fist through plasterboard and door panels, just out of sheer frustration of the situation that he was in.

Towards his latter years he was an inpatient in the QE, and he became really agitated in the ward, and he had a drip into his arm, and he was just so agitated and -- because his mental state was terrible -- and he'd pull the drip down, but he'd left the -- the needle was in his arm and the -- you know, it was hanging out, and he'd just got up and marched out of the ward. You know, he just -- "I'm going, I'm going, I've got to get out of

, REDACTED VERSION

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1 here, I'm going". He marched out of the hospital and 1 was sort of seeing things. I think it was all to do 2 security people were following him, and I was following 2 with his liver. He just totally unpredictable, really, 3 3 them, we were all following him down the road trying to of what, you know ... it was just really difficult. 4 keep him safe. And he went down to the bottom of the 4 Really difficult. He also started having really bad 5 road, and he was walking up and down. 5 nosebleeds as well towards the end. And I mean really, 6 Eventually managed to get him back into the 6 really bad nosebleeds. 7 hospital. And they couldn't calm him down at all. He 7 MS RICHARDS: And there came a point when he was under the 8 was just totally, totally, distressed and disturbed, 8 care of the Queen Elizabeth Hospital, and you were 9 that he was taken from the ward to the psychiatric unit 9 called to the hospital, and you were told he was 10 of the Queen Elizabeth Hospital, where he was forcibly 10 terminally ill. kept overnight to -- for his own safety, I think, to MS HADDOCK: We weren't actually told he was terminally ill 11 11 12 just sort of try to calm him down. 12 by the hospital. That was a bit weird. We had a 13 And the next morning I had to go and -- they did let 13 meeting at the QE, where our GP was invited to, and 14 me -- he'd calmed down and they did let me bring him 14 everyone else in his care -- myself and my husband, and 15 15 our GP. And it was our GP that referred to him as being terminally ill. And that was the first time we'd heard 16 MS RICHARDS: You told us in your statement that from around 16 17 the late teens, his physical health started to 17 it, you know, put into those words. And I always 18 deteriorate. 18 thought that was a bit strange, really. 19 MS HADDOCK: Yes, yes. 19 MS RICHARDS: And then you weren't actually able to see 20 MS RICHARDS: He became very fatigued. 20 Andrew the day that he died because you tell us in your 21 21 MS HADDOCK: Yes, yes. statement you're not -- concerned you weren't given the 22 MS RICHARDS: He would experience hallucinations? 22 most accurate and up-to-date information by the 23 MS HADDOCK: Yes, yes, he did have hallucinations. We'd be 23 hospital, so you weren't able to get there to be with 24 in the car, he'd be sitting the back of the car and 24 25 suddenly, "Oh, what's that?" You know, he 25 MS HADDOCK: I wasn't with him at the end because I didn't 69 70 1 realise how things actually were. I mean, I rang up on 1 and it's not really appropriate," and there was nothing. 2 the morning, and I was just told, "Oh, you can go easy. 2 MS RICHARDS: What can you tell us about the longer term 3 He's had a comfortable night." And so I said, "Oh, 3 impact on you, as Andrew's mum, of what happened? 4 right. I'll be coming up." 4 MS HADDOCK: Well, you'll never get over what we've been 5 5 And I went and picked my mother up. If I'd have through. And I think, you know, we could all probably 6 known it was so close to the end. I would have just gone 6 say we're a different person to what we would have been. 7 7 straight there. And I went and picked my mother up, and I think I've sort of lived my life since Andrew died, 8 she came with me, and when we got to the hospital, we 8 um -- I've sort of compartmentalised it, and I've just were too late. But I didn't realise from what they'd 9 9 got on with things because I was always frightened that 10 told me that I was actually going -- you know, it was 10 if I thought about it too much, the floodgates would 11 going to be so close to the end. 11 open, and I'd never shut them. MS RICHARDS: And how old was Andrew when he died? 12 So you try to just carry on. I mean, I had 12 MS HADDOCK: Twenty-four. 13 a 15-year-old daughter. Wanted her life -- I wanted her MS RICHARDS: He didn't, as I understand it from your 14 to enjoy her life and live her life and not be -- you 14 15 statement, receive treatment for HIV or HCV. 15 know, have her life spoilt. So we concentrated on her. MS HADDOCK: No. I think it was a little bit before the It has all been bottled up inside, but I just didn't 16 16 17 anti-virals became, you know, in use, so there was no 17 know what else to do. 18 treatment. 18 MS RICHARDS: And we've got some photos of Andrew. Is it MS RICHARDS: Did he ever receive any counselling? 19 okay if we look at those? 19 20 MS HADDOCK: Yes. Yes. 20 Psychological support?

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MS RICHARDS: Lawrence, could we have those photos, please.

MS HADDOCK: That's us when we were happy, Boxing Day, at

Nan's. Andrew smiling. Michelle -- there's eight years difference between them. But that was before

And just tell us about them. So what's this one?

REDACTED VERSION

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MS HADDOCK: No. No.

MS RICHARDS: And what about you and the rest of the family?

MS HADDOCK: No. No. I did ask my GP, a while after Andrew

died, that I felt I could do with some counselling. But

he just sort of, "Well, you know, time's gone by now,

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1 everything -- you know, everything. Life was great. 1 Sir, we now have the evidence from Linda. What 2 2 Everything was -- everyone was happy. A nice little would you wish to do? 3 3 SIR BRIAN LANGSTAFF: Well, let me ask Linda. We can take happy family. 4 And that, again, is holiday. We were on holiday, 4 a break now and come back at 1.45, if you'd like, and 5 happy. Michelle a toddler; Andrew eight, nine years 5 then hear your evidence then, or you can start now if 6 old, enjoying himself and just living a lovely life. 6 vou want. 7 That was Andrew, his first year at secondary 7 MS WOOLLISCROFT: I don't mind carrying on. I was just 8 school -- again, just before everything started to blow 8 getting a bit upset listening to them, sorry. 9 up -- in his school uniform, all proud and, you know, 9 SIR BRIAN LANGSTAFF: Well, I wondered. MS WOOLLISCROFT: But I'd rather carry on, I think. 10 the whole future in front of him. 10 SIR BRIAN LANGSTAFF: Okay. We will be taking a break in 11 Now, that's later on, when Andrew had started to 11 become ill. I think if you look at his face, you can the middle, that's the only thing. Are you happy about 12 12 13 see that he is -- you know, he is quite ill there. And 13 that? 14 that was the day when we'd gone down to visit Grandad 14 MS WOOLLISCROFT: Taking a break? 15 who was staying in a caravan, so we went for the day. SIR BRIAN LANGSTAFF: In the middle of your evidence. 15 16 And it was on the way back from there that he started MS WOOLLISCROFT: Right. 16 17 having hallucinations in the car as we were driving home 17 SIR BRIAN LANGSTAFF: So you might prefer to have it all in 18 which were really quite frightening. And as you can 18 one go. 19 see, he was quite a big chap and could be quite sort of 19 MS WOOLLISCROFT: I'd rather do it all in one. 20 frightening, you know, when he started having these 20 SIR BRIAN LANGSTAFF: If you'd rather do it all in one go, 21 episodes. 21 we'll take a break now. 22 But that's -- I don't really like to look at that 22 MS WOOLLISCROFT: I'd rather just carry on and get it over 23 photograph because, to me, he just looks so ill on there 23 with, if I can. 24 and not like himself. 24 SIR BRIAN LANGSTAFF: Yes, well, I think that would eat into 25 25 MS RICHARDS: Thank you. everyone's lunch hour. 73 74 MS RICHARDS: I'm told the stenographers need a break, I'm 1 1 Hospital. So Michael was born in 1969; is that right? 2 2 MS WOOLLISCROFT: Yes, that's right. 3 SIR BRIAN LANGSTAFF: Well, that determines it, then. May 3 MS RICHARDS: And he was diagnosed with severe haemophilia A 4 I thank the stenographers for going on to make sure that 4 when he was about 3 years old? MS WOOLLISCROFT: No. 2. About 2. 5 they captured all of Brenda's evidence. So we'll start 5 6 at 1.45, and then you have a free run through, right 6 MS RICHARDS: What can you tell us about that? 7 MS WOOLLISCROFT: Um, well, you know when they start to 7 until you finish. 8 MS RICHARDS: Just to say, I'll be inviting, obviously, 8 crawl when they're little and everything, he was getting Elisabeth to return and sit with Linda, and once we've 9 these bad bruises with lumps and things. Well, our GP 9 10 10 who I took him to see, he'd been a family doctor and

heard from Linda, I'll just want to pick up some general 11 issues about the Birmingham Children's Hospital with all 12 three of you. 13 SIR BRIAN LANGSTAFF: Yes. I was going to say, there are

general themes which Ms Richards is likely to pick up 14 15 with and take the views of the three of you. It's one 16 of the great advantages of having three people who have 17 such similar experiences, although there will be slight 18 differences between them. So 1.45.

19 (12.44 pm)

(The Luncheon Adjournment)

21 (1.45 pm)

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22 MS RICHARDS: Linda, can you hear me okay?

23 MS WOOLLISCROFT: Yes.

MS RICHARDS: I'm going to ask you to tell us about your son

Michael and his treatment at the Birmingham Children's

11 we've never known haemophilia in our family. So, you

12

know, that's what -- he didn't suspect that. And he

13 used to give him vitamin C and stuff like that, and he

14 even asked me if I was knocking him about, and he said,

15 "I've got to ask you this", and I said, "Good lord, no".

16

Anyway, he retired and -- Michael would be about 2 -- we 17

had a new doctor, a young doctor, and we went through

18 it -- he had a swollen knee, I think it was, and I took

19 him to the doctors, and he said -- well, he just looked

20 back at the records and he asked me the questions and he

21 said, "I want to send you straight up to the hospital",

22 and he wrote a letter and he said, "I want you to take

23 this to the hospital in Wolverhampton".

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So that's what I did. And I was just amazed because they said, "We've got to keep him in", and he was just

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1 taken away and I had to go home. And it was like that 1 concentrate? 2 in those days. They didn't let you hang about, you 2 MS WOOLLISCROFT: Yes, that's right. 3 3 MS RICHARDS: But then, and your recollection was that it 4 So I went home and I did nothing but weep, you know. 4 was perhaps the early 1980s -- we can look at a document 5 I didn't know what was going on. Anyway, when I had to 5 in a moment, but it was switched to US commercial 6 go back they took me to one side and they said that he'd 6 concentrates? 7 got haemophilia. And I've got to be honest, I'd never 7 MS WOOLLISCROFT: Yes. 8 heard of it before. So I don't know whether it missed 8 MS RICHARDS: And it was the Armour concentrate, I think, 9 a generation, because they say it can, I don't know. 9 that you'd mainly remembered? 10 MS WOOLLISCROFT: Right, okay. I know it was the -- I can't 10 We've never, even to this day, found out. [... redacted remember the name -- now you've said it I recognise it, 11 ... and yet we'd never heard of it before. But anyway, 11 12 that's how we found out that he was haemophilia -- he'd 12 13 got haemophilia. 13 MS RICHARDS: Were you told anything, whether by Dr Hill or 14 Then I had him transferred from Wolverhampton to the 14 anyone else at the Children's Hospital, about the risks 15 Birmingham Children's, to the haemophilia department, 15 associated with the factor concentrates? MS WOOLLISCROFT: With the American? No. 16 and then we just had to keep going up. Every time he 16 17 hurt himself in some way we would have to go up the 17 Well. I went to the meeting that you mentioned 18 hospital. And when they're little they're always 18 earlier. To me, when they were on about this virus, 19 falling or doing something, aren't they? So it was 19 I hadn't really heard of that before. So it was like, 20 quite a journey every time, you know. But it had to be 20 you know, taking it all in and knowing what was going 21 21 done on, really. And I knew it was a worry. They were just 22 MS RICHARDS: Initially, Michael was treated with 22 talking as though they'd only just sort of found out, 23 cryoprecipitate? 23 that's the way I felt at the time. 24 MS WOOLLISCROFT: Yes. 24 MS RICHARDS: Before we get to that meeting, though, which 25 25 MS RICHARDS: Then I think a time when he had NHS was probably 1984, your son had been being treated 77 78 during the 1970s and the early 1980s, so before that 1 1 "Haemophilia A. Severe ... 2 2 meeting, did anyone ever tell you that the concentrates "Diagnosed at 3 years old. 3 might transmit hepatitis? 3 "Cryoprecipitate 1973-77." 4 MS WOOLLISCROFT: No. I was told by Sister Marion that they 4 MS WOOLLISCROFT: Yes. 5 5 would be stopping the British one because it -- it was MS RICHARDS: Then if we go to the next page and look at the 6 a lack of supply. So she said we're having it from 6 bottom of the page, the very bottom, we've got there: 7 7 America, and that's all she said. So you just accept "The date the client was first given Factor VIII or 8 that that's it, you see. So he was put on that 8 IX concentrate, 23.05.77." 9 9 treatment. And I can't remember how long it was from Then if we go over the page, we can see it says, 10 10 then to when we had the meeting. under the paragraph (b) at the top: 11 MS RICHARDS: We can look at a document which you've 11 "Armour 1977-83 and 1986 12 exhibited to your witness statement, and it was 12 "NHS 1978-86 (including Scottish 1984) 13 a document filled in, I think, at the time of the 13 "Alpha [which is a different commercial product] haemophilia litigation, and it's been filled in by 14 1986-87" 14 MS WOOLLISCROFT: Yes. 15 a doctor by reference to Michael's records. 15 MS RICHARDS: So it looks from this as though Michael was So if we look at WITN1616003. And if we go to the 16 16 17 next page, it's described as "Preliminary medico-legal 17 treated sometimes with NHS product, but certainly also 18 report on Michael Anthony Price", and then if we go 18 with the Armour product, and that's what you remember to -- or we can see it refers to documents, letter of from the conversation with Sister Marion: that they were 19 19 20 20 instruction, and then records from the hospitals, going to have to switch to that --21 uncertified copies of batch numbers from the Children's 21 MS WOOLLISCROFT: Yes. 22 Hospital. Then if we go down towards the bottom of the 22 MS RICHARDS: -- because they didn't have enough NHS?

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words:

page, we can see there that the doctor who has filled

this in had Michael's records, and then we can see the

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MS WOOLLISCROFT: And that's all I was told.

what treatment Michael would receive?

MS RICHARDS: Do you feel you were ever given a choice about

1	MS WOOLLISCROFT: Not at that point, no, no. She just said	1	out what you say about it in your statement, Linda.
2	that's what was happening. So I just accepted it, you	2	So you say:
3	know.	3	"I believe in or around 1984, a special meeting
4	MS RICHARDS: And Michael, according to this document, was	4	was held at the BCH. I attended this meeting without
5	on home treatment from about 1977. Do you recall that?	5	Michael, taking my sister with me. I recall it was
6	MS WOOLLISCROFT: Yes, yeah.	6	Dr Hill who ran the meeting in a big hall that was full
7	MS RICHARDS: Prior to that when he'd received	7	of a mixture of doctors and parents of children who were
8	cryoprecipitate in the hospital, had he had any	8	being treated at the BCH. Dr Hill delivered
9	difficulties with the cryoprecipitate?	9	a presentation detailing information about HIV. He went
10	MS WOOLLISCROFT: No, none.	10	into depth saying that the outbreak was caused because
11	MS RICHARDS: We can take that down, thank you. Can you	11	the blood had been obtained from Americans who were on
12	then tell us what you remember about a meeting at the	12	drugs or were otherwise diseased. It was never
13	Birmingham Children's Hospital in 1984?	13	explained why this was allowed to happen. The meeting
14	MS WOOLLISCROFT: Yes. I can't remember too many details	14	was directed at letting the parents and patients know
15	because it was such a lot to take in, all evening, but	15	that some people may be at risk of infection. They said
16	they were just telling us about this virus, which I'd	16	if you want to know whether your child was infected, to
17	never heard of before, I've got to be honest. They were	17	ask. This was the first time I had ever heard of HIV or
18	showing you things on boards, you know, like diagrams	18	AIDS so it was very worrying. They told us to look out
19	and things of this virus and right, you know. And it	19	for certain symptoms."
20	was a lot to take in, but I knew it sounded bad but	20	So does that remain your memory of that meeting?
21	I didn't know exactly I mean, it wasn't in the news	21	MS WOOLLISCROFT: Mm, yes. Yeah.
22	either, then. It came on the news after about it. It	22	MS RICHARDS: Now you told us in your statement that you
23	built up on, you know, the AIDS and that, and then it	23	recognised some of the symptoms or thought you did.
24	sinks in how really bad it is, but	24	What can you tell us?
25	MS RICHARDS: If we look at your statement I'll just read	25	MS WOOLLISCROFT: Well, they did mention to watch out if 82
1	they came down with any illnesses. And Michael had	1	MS RICHARDS: And you understood it was about Michael
2	glandular fever and it worried me after because they	2	transferring to the adult haemophilia centre?
3	did mention that at the meeting, something about	3	MS WOOLLISCROFT: Mm, yes.
4	glandular fever. So on our next visit to the Children's	4	MS RICHARDS: And so you went to the meeting thinking that
5	Hospital, we had to go and see Sister Marion, and so	5	it was about that.
6	I asked her then if Michael was all right, because it	6	MS WOOLLISCROFT: Yeah.
7	was worrying me. And she said, "Don't worry about	7	MS RICHARDS: And at the end of the meeting, Dr Hill, as you
8	Michael, he's fine."	8	say in your statement, dropped the bombshell that
9	So after that we just took it he was fine. And if	9	Michael had HIV.
10	I can go on?	10	MS WOOLLISCROFT: Yes. And there was only me and Michael in
11	MS RICHARDS: Yes, please.	11	the room. My husband waited in the car because he
12	MS WOOLLISCROFT: A year and a half that's a rough guess,	12	thought it was just to do with moving hospitals, see.
13	I think he was about 15 or something then about	13	And well, it was we both went silent. I wish now
14	a year and a half later, probably when he was in his	14	I'd have said more, but I just lost it, really. I just
15	late 16, um, he was given the bombshell that he was	15	went we both went quiet. You know. And I had to go
16	infected. And yet I thought, seeing as he was all right	16	and tell my husband. And we drove from Birmingham to
17	then, going back, how come he was given it after that?	17	[redacted] and nobody spoke. We were just silent.
18	Why wasn't they careful? Because if they say he's all	18	MS RICHARDS: And I think it follows from your evidence that
19	right, then they should try and keep him all right. And	19	you hadn't been told that Michael was being tested
20	yet he wasn't. And for a year and a half, we just	20	for HIV?
20 21	thought it was fine, he was all right.	21	MS WOOLLISCROFT: No. Well, I hadn't been told, but
22	MS RICHARDS: You told us in your statement that this	22	I suppose I suppose they must check them but
23	occasion when you were told the bombshell came about	23	I don't know. It's complicated, really, because I just
23 24	you'd got a letter from Dr Hill.	24	thought he'd been obviously been tested for him to
25 25	MS WOOLLISCROFT: Yeah.	25	be told that he was all right, "Don't worry about him,
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1	he's fine". So you just carry on then thinking he's all	1	First of all, Linda, that reference there to
2	right. And for that whole year and a half, we just	2	October 1986, that's consistent with your recollection
3	thought everything was fine. And yet they'd	3	of it being a year and a half or more after that meeting
4	obviously were still giving him the treatment with	4	at which you were told?
5	the infected blood you know, the infected treatment.	5	MS WOOLLISCROFT: Right.
6	MS RICHARDS: If we go back to that medico-legal report we	6	MS RICHARDS: This document suggests that testing at some
7	looked at a few moments ago, so WITN1616003, and if we	7	point was carried out on a sample of Michael's blood
8	go to page 5, and I'm looking at this because we don't	8	from 1984, suggesting that he that the result was
9	have Michael's records but we have this report that	9	positive as at 1984. Was that something you were ever
10	you've exhibited to your statement that was based on	10	told at the time?
11	Michael's records.	11	MS WOOLLISCROFT: No. No, I wasn't told.
12	Then the question at the top of the page is about	12	MS RICHARDS: When you were given this bombshell news, and
13	on the date on which the first blood test carried out	13	in the weeks and months that followed, did you receive
14	that produced an HIV positive result. And the answer is	14	any support or advice from the hospital?
15	given:	15	MS WOOLLISCROFT: No. No, not concerning that, no. We
16	"First sample '1984' retrospectively tested but	16	moved to a different hospital, then.
17	report date not given.	17	MS RICHARDS: So you moved to the Queen
18	"First fully dated result, 21.2.86 sampled"	18	MS WOOLLISCROFT: When he dropped the bombshell I never saw
19	So I think that's the date the sample is taken and	19	him again. We went to the Queen Elizabeth and we was
20	then the report comes back 13 March '86.	20	under, um we was under Dr Wilde for quite a while.
21	"Sero-conversion occurred in or before 1984."	21	MS RICHARDS: You say in your statement, reflecting on the
22	Then question 10:	22	way in which you were told about Michael's diagnosis in
23	"On what date do the records show that the client	23	the way in which you've described, that you felt and
24	was notified of his HIV [positive] condition?"	24	still feel as though you'd been lied to.
25	"24.10.86."	25	MS WOOLLISCROFT: Well, I do, yeah.
	85		86
4	Mall for some fire of the county could be a	4	for the country that a country to the country that the form
1	Well, for some time I thought, well, I was told he	1	feeling all the while. And he gradually started to lose
2	was all right. Was that a fib? I don't know. If it	2	weight, you know, and wasn't eating as he used to. As
3	was, well, that was wrong, obviously. And then if it	3	it got nearer to when he was really, really poorly, he
4	was the truth, then why did they carry on giving it him?	4	used to keep being sick. Diarrhoea was bad. He just
5	And that's what was going in my mind all the while.	5	felt really ill all over. But he did have a lot of
6	MS RICHARDS: Michael was also infected with hepatitis C.	6	things before that. Certain things cropped up.
7	MS WOOLLISCROFT: Yes.	7	He had pancreatitis, which I just presumed it was to
8	MS RICHARDS: But you learnt about that rather later. How	8	do with the HIV. But thinking about it after, it could
9	did that come about?	9	have been connected to the hepatitis C. But I didn't
10	MS WOOLLISCROFT: Well, it was just by after Michael had	10	know he'd got it then, did I? So I just assumed it was
11	passed away, I had to go back to the Children's back	11	to do with the HIV.
12	to the QE for some reason, I can't remember now, but	12	And he had a bout of terrible headaches for, ooh,
13	I was on the car park, just walking across, and one of	13	well over a year. They were so bad he was on morphine,
14	the doctors that knew Michael, a lady doctor I don't	14	morphine tablets every day, quite high, to take these
15	know her name she saw me and come over to give her	15	pains away. And then the one day his head just swelled.
16	condolences and that, you know. And in the conversation	16	It was twice the size of what it should have been, and
17	she just said, "Well, of course he was hepatitis C	17	he had to stay in the hospital. And I didn't think
18	positive as well". Well, I never knew. If I hadn't	18	I think that they thought that he wasn't going to last
19	have met her on that car park, I wouldn't have known.	19	very long, but he did get over that, actually. I don't
20	MS RICHARDS: Can you tell us how Michael's health	20	know how, but he did. And that gradually went down.
21	deteriorated as he got older?	21	He had psoriasis in his scalp, you know, through
22	MS WOOLLISCROFT: Well, he used to have fatigue, lack of	22	stress and worry. So he had a lot of things, really.
23	energy. He used to get bouts of diarrhoea a lot, and	23	The headaches, and then he he did get meningitis at

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the end; passed with meningitis.

25 MS RICHARDS: What had been the effect on him, a teenage

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occasional sickness. And he always used to say he ached

as though he'd got the flu all the while. That sort of

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1 boy, 16 years old, learning that he had this diagnosis? 1 to be a sports photographer because he loved taking 2 2 How did that impact upon him mentally? photographs. And he couldn't play sport himself, but he 3 MS WOOLLISCROFT: Well, at first, you can tell it just 3 loved his football, and he said, "I'd loved to have been 4 knocked him for six, really. And he -- that's when he 4 a sports photographer". And he took some lovely photos. 5 had the psoriasis, not long after that. He went very 5 And, of course, in those days it was a proper camera 6 quiet. And he never really told me exactly how he felt. 6 with a film in, you see, and he did take nice, lovely 7 He sort of kept it in, you know. But he said he didn't 7 photos of animals and things. But that was what he 8 want anybody in the family to know, at first. And he 8 would have liked to have done. But I think in his mind, 9 said he definitely didn't want his nan know. They were 9 he thought: what's the point? You know. 10 very close. And she was -- she was nearly in her 80s, 10 MS RICHARDS: And did he receive any treatment for --MS WOOLLISCROFT: Sorry? 11 you know. 11 So anyway, we did tell the close family in the end, 12 12 MS RICHARDS: Did he receive treatment for HIV? 13 but he never told any friends, and that's the way he 13 MS WOOLLISCROFT: Yes, AZT. 14 wanted to keep it. But the family were very good, and 14 MS RICHARDS: And how was that? 15 they kept it in the family, you know. But as time went 15 MS WOOLLISCROFT: Well, I don't know, it was really well, 16 on, he did seem to cope in his own way, and I'm very 16 when they -- you see I didn't go in the room with him 17 proud of him in that way, of how he coped. 17 that day. He went to see Dr Hill, I think it was. 18 MS RICHARDS: Was he able to work? 18 Yeah. He went in on his own. And he looked really 19 MS WOOLLISCROFT: He did have one job. He didn't really 19 well. He'd been on holiday, and he looked really well, 20 want to do it. He couldn't see the point. But he did 20 and he hadn't lost any weight or nothing, and when he 21 21 go. He worked for the -- in the council offices at come out he said -- "Oh", he said, "A blood test has 22 Codsall. I think he only worked -- I can't remember how 22 showed that I need to go on treatment". There was some 23 long he was there. It could have been a year. I can't 23 alteration in his blood, "And I need to go on treatment. 24 remember now. But then he left. 24 I've got to start on this tablet". Well, it was AZT. 25 25 And he'd got no interest -- I mean, his ambition was And that's all Michael told me, he'd got to go on this 90 1 tablet. And he was on it for quite some time. But then 1 I looked after him. And that's when he went really 2 2 downhill, you know. And I -- I never saw her again, he seemed to go downhill, you know. except for Michael asked me to go and get some money 3 MS RICHARDS: You've described in your statement the last 3 4 few weeks of Michael's life. He'd come back to live 4 out -- I don't think this is in his statement -- in the 5 5 with you, I think, and you were looking after him. statement, but he said, "Mum will you go to the bank and 6 MS WOOLLISCROFT: Yes. 6 get me some money out?" And he gave me his card and 7 MS RICHARDS: Then he had to go into hospital. You've told 7 when I went, the account was empty. That was his -- the 8 us about that in your statement. Is there anything 8 ones he used to pay his bills on, not one that he kept 9 9 you'd like to tell us about it? It's entirely a matter his pay money in. And it was empty. And I come back 10 for you as to whether you want to talk about it. 10 and I said, "There's nothing there". And he had to 11 MS WOOLLISCROFT: Well, he -- he was living with his 11 phone the bank. 12 girlfriend. She knew all about everything. But, 12 Well, he was friends with the bank -- well, it was 13 I don't know, there was something that she -- she 13 Midshires Building Society, and he was good friends with just -- the one day, she just told the social worker, 14 the manageress, and anyway, she said that the money was 14 15 and the social worker spoke to me, and she said that she 15 drawn out. So that upset him. Anyway, we went back and 16 16 didn't want to stay with him anymore. And she just -got the card off her. 17 I was there but I didn't know until she said -- the 17 So he was with me then, and then he just come and 18 girlfriend said, "I've got to go to town", and she went 18 give me a hug and he said, "Mum, I'm glad to be back 19 out and left me alone with -- Michael was in bed and the 19 home with you". And I said, "Well, I'm glad to have you 20 20 social worker told me then that she didn't want to stay 21 with him anymore. And I never saw her again after that. 21 MS RICHARDS: Then in the last month of or so of Michael's 22 And we had to go and tell Michael. And he was really 22 life he was in the Heartlands Hospital and you remained 23 23 poorly in bed and he got upset and started to cry. there with him. Anyway, we got him home -- we had to get him home 24 24 MS WOOLLISCROFT: For a whole month, yeah. Yeah, I slept in 25 before she came back. So we got him home and then 25 a chair at the side of his bed. He'd got his own room

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1	and bathroom, you know and I looked after him, and	1	MS WOOLLISCROFT: He used to have a social worker that
2	washed his hair. He was mad on his hair being just	2	her name was Jill, and they were very, very close. And
3	right, you know. I looked after him, yeah.	3	she helped him a lot, but she used to help him with
4	MS RICHARDS: Michael died 1995, just before his	4	different things, but I didn't really get too involved
5	26th birthday.	5	with that. I think all that happened before he came
6	MS WOOLLISCROFT: Yeah.	6	back to me, see. So I wasn't there when she came. But
7	MS RICHARDS: You'd had to give up work, I think, yourself,	7	she kept in touch when she left, she went on a world
8	to look after him?	8	cruise, and she always send him postcards of where she
9	MS WOOLLISCROFT: Yeah, yeah.	9	was stopping, you know. And she kept in touch with him.
10	MS RICHARDS: And after Michael died, your husband had to	10	MS RICHARDS: And were you offered any kind of support by
11	take a year's unpaid leave to look after you?	11	anybody?
12	MS WOOLLISCROFT: Yeah, his boss suggested it. He said	12	MS WOOLLISCROFT: No. No.
13	because Paul was worried about leaving me on my own, you	13	MS RICHARDS: You've said in your statement that you still
14	know.	14	think about Michael every day.
15	MS RICHARDS: Michael was your only child.	15	MS WOOLLISCROFT: I do, yeah. Every single day, yeah.
16	MS WOOLLISCROFT: Yeah.	16	MS RICHARDS: And you describe it in your statement as
17	MS RICHARDS: And you've said in your statement you feel	17	a black cloud.
18	you've lost the chance to have grandchildren.	18	MS WOOLLISCROFT: Pardon?
19	MS WOOLLISCROFT: That's what he said to me, yeah. He said,	19	MS RICHARDS: You describe it in your statement as being
20	"You'll never be a grandmother". And I said well,	20	a black cloud that's lived over you since that time.
21	I just said, "Well, don't worry about it". I didn't	21	MS WOOLLISCROFT: Mm. Well, your life changes and nothing's
22	know what to say to him, you know.	22	the same anymore. And you can't just I don't know,
23	MS RICHARDS: At any point did you or your husband or	23	they're just there all the while. Well, not all the
24	Michael ever get offered counselling or psychological	24	while, obviously, there's times when you're doing things
25	support?	25	and they're not everywhere, but every day I do think of
	93		94
1	him, yeah.	1	weight still after this. You don't like looking at it
2	MS RICHARDS: We've got some photos, we'll just look at	2	but you think it's important that people see the
3	those. Is that all right?	3	reality?
4	MS WOOLLISCROFT: Yeah.	4	MS WOOLLISCROFT: That's all right. I brought that so
5	MS RICHARDS: If we could have Linda's photos, please,	5	people could see, yeah.
6	Lawrence. How old was he here, do you think?	6	MS RICHARDS: And there's just a couple of photos of Michael
7	MS WOOLLISCROFT: Err I'm not sure. I think he was	7	as a young adult, which you exhibited to your statement.
8	probably about 7 or something. I'm not sure. Because	8	So it's 1616002, please, Lawrence.
9	I never wrote it down. You don't think of these things	9	So we see a picture of him there and then there's
10	sometimes.	10	one other photo I think on the next page. And another
11	MS RICHARDS: Where was this?	11	there.
12	MS WOOLLISCROFT: That was on the beach at Borth, just	12	MS WOOLLISCROFT: Yeah, so you can see the difference with
13	outside Borth, and he loved the sunshine and he hated	13	there he'd lost weight.
14	the rain, and yet, just before he passed away it was	14	MS RICHARDS: Thank you, Linda.
15	raining and he said to me, he said, "Would you help	15	I'm just going to ask the three of you now just to
16	me" outside his room there was a corridor with glass	16	reflect on a couple of themes emerging from the evidence
17	windows you could see outside, and he said, "Would you	17	that you've all given to us today. The first is the
18	take me to see the rain?" oh, this is what upsets	18	issue of trust. Trusting in the doctors, and assuming
19	me because he knew he wasn't going to see it again.	19	that if treatment is being given, it's safe and it's the
20	Sorry.	20	right treatment. I think that emerged in particular in
21	MS RICHARDS: That's all right, don't worry.	21	your evidence, Linda, but from what all three of you
22	Lawrence are you okay	22	have said, is that right?
23	MS WOOLLISCROFT: Yes.	23	I'll start with you, Linda, you trusted the doctors?
24	MS RICHARDS: We've put up a picture that shows Michael when	24	MS WOOLLISCROFT: Well, you do, don't you? Your life is in
25	he's thinner and losing weight, and I think he lost more	25	their hands, sort of thing, and you believe what they

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1 say and you've got to trust in them. You've got no MS RICHARDS: And then the second theme I wanted to just 2 choice. Then it makes you think, after, you know, 2 briefly ask you about, then, is the issue of choice. 3 3 should you trust doctors. You know, it's ... yeah. From the evidence all three of you have given, it 4 MS BUGGINS: I, like Linda, took my eldest, Richard, from 4 doesn't appear as though any of you were really given 5 Wolverhampton, where he was referred back to from 5 a choice of treatment for your children. You would take 6 Liverpool to Birmingham, because it was the regional 6 your child to the hospital, and the treatment would be 7 centre, and I thought it was the place where he would 7 aiven. 8 receive the most expert care. And in those days, you 8 MS HADDOCK: Yes. 9 didn't expect to be asked consent for everything, 9 MS RICHARDS: You didn't get told what the different risk 10 because that wasn't the custom and practice at the time. 10 factors were, and you weren't given a choice. MS WOOLLISCROFT: No. No. 11 So it felt like it was auto consenting. But it was 11 12 a relationship of trust, and they had to trust us to do 12 MS HADDOCK: No. No. there was no choice. 13 the right thing with the product, particularly on home 13 MS WOOLLISCROFT: Nothing like that at all. 14 treatment. But absolute trust was given with the most 14 MS HADDOCK: I remember, with the Factor VIII, you went up, 15 precious things we had in the world. 15 and it was what was available in the fridge on that day. 16 MS RICHARDS: Brenda? 16 That's what it seemed to be. 17 MS HADDOCK: Yes, yes, we did trust the doctors. I think --17 MS BUGGINS: Yes, and I think sometimes the professionals 18 we'd got a child with an ongoing condition -- we put our 18 didn't have as much choice as they wanted either because 19 faith in the doctors to do the best for our children and 19 there was a constraint about the supply. I can remember 20 we believed what they said and we followed what they 20 some conversations -- I think it was probably around 21 21 1984 -- where NHS Factor VIII was so much in demand advised. Without question. And looking back, maybe we 22 should have questioned more. But you didn't in those 22 everywhere that there wasn't enough for the children who 23 days. I think maybe people do more now. But in those 23 might have been at the top of Dr Hill's list to be only 24 days I don't think people did question as much as they 24 given Factor VIII rather than commercial concentrates. 25 25 now -- as they do. But he didn't have enough to do that, so it was a sort 97 98 1 of diagram which involved the professionals as well as 1 given any tools to help him cope -- cope with it. 2 2 us, but clearly the consequences were much more Which, you know, was really difficult. 3 significant for us. 3 I think we had our suspicions that he infected, but 4 MS RICHARDS: And then the last theme I, again, wanted to 4 taking that decision to actually physically go and ask 5 5 bring out of your evidence is the issue of how the was a difficult thing to do. So maybe I did shy away 6 information was given to you that your sons had been 6 from doing that until I saw it written down in his 7 infected with HIV. And we've heard from Elisabeth, 7 notes. But I think it could have been handled a lot 8 seeing the names on the refrigerator in the treatment 8 differently. Yeah. 9 MS RICHARDS: Linda? 9 room. We've heard from you, Brenda, that your son was 10 told at a relatively young age, and you were not. And 10 MS WOOLLISCROFT: Well, I think when I was told, it was done 11 then we've heard from you, Linda, that you and Michael 11 in a cold way, you know? No emotion or -- it was just 12 were told, but told much later on, and not even knowing 12 like it was just reading it off a page, you know what 13 that that was what the meeting was about. 13 I mean? No feelings about it. That's the way he was, 14 The way in which you were told this news -- and it 14 I'm afraid, that doctor, you know. But I was just 15 can never be good news; it can never be anything other 15 annoved that with that gap that I spoke of. 16 than a terrible thing to hear -- do you have any 16 MS HADDOCK: Yes, when you thought everything was all right? 17 reflections on the way in which you found out? 17 MS WOOLLISCROFT: Yeah, for a year and a half we just kept 18 MS HADDOCK: I think maybe the parents -- in the case of 18 thinking, oh, he's all right, because they'd found out 19 children, the parents should have been told before the 19 about it, you know, that this virus was about, in some 20 20 child, so that we could be prepared to help our child of the -- some of the treatments. But we just presumed 21 accept and take on board that information. Whereas we 21 we were all right for all that time. 22 didn't even know he'd been told and we couldn't 22 MS HADDOCK: I just find it unbelievable the way they sent 23 23 understand why he changed so much, and lost interest in a letter out telling someone of their hepatitis

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REDACTED VERSION

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everything that he loved before, because he thought that

he'd got no future. So, you know, I think we weren't

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infection to a teenager, for a letter just to drop

through the letterbox, with no warning whatsoever.

1	I think that was pretty disgusting, to be quite honest.	1	could have passed it to friends you know, he did have
2	MS BUGGINS: I think the difficulty was that the emotional	2	a girlfriend then, he was just sort of leaving school.
3	and psychological impact of that information wasn't	3	But fortunately they didn't do anything that but,
4	accounted for. And the thing that I find very difficult	4	I mean, he could have passed it on, because he wasn't
5	is that everybody who was working within the hospital	5	told.
6	would have known information about my son that I didn't	6	SIR BRIAN LANGSTAFF: He was I think you said he
7	know. And then that undermined trust because you don't	7	was 16 he was actually 17 when he was told. And he
8	know what people are thinking, to whom you're talking.	8	knew
9	And we used to have to interact with a lot of different	9	MS WOOLLISCROFT: Yeah.
10	health professionals, depending who was on duty at the	10	SIR BRIAN LANGSTAFF: or they knew when he was 15
11	time we were taking the children in. And so it was	11	MS WOOLLISCROFT: Yeah, he didn't know until he was just 17.
12	it undermined trust generally I think, which had	12	SIR BRIAN LANGSTAFF: During those years did he have
13	knock-on consequences then when we're dealing with	13	a girlfriend? He had one at 16, plainly. You just
14	a much more difficult scenario.	14	mentioned that.
15	MS HADDOCK: We used to take them to the dentist at the	15	MS WOOLLISCROFT: He had a girlfriend when he was at school,
16	Children's Hospital, didn't we? It was quite possible	16	finishing school. He had two girlfriends, the second
17	that the dentist the dental department knew more	17	one we were talking about before. But the first one
18	about our sons than we did, you know. And other	18	I mean, everything was fine, but it might not have been.
19	agencies that you come up against as well.	19	That's what I'm trying to say.
20	MS WOOLLISCROFT: I think another annoying thing is that	20	MS RICHARDS: And the hospital wouldn't have known that
21	because Michael was a teenager, and not knowing for	21	everything was fine.
22	a year and a half, he could have passed it on.	22	MS WOOLLISCROFT: You know, it's like he should have been
23	MS RICHARDS: He could have passed it on to you or to	23	told whenever he infected. But we don't know when he
24	friends or girlfriends	24	infected.
25	MS WOOLLISCROFT: He could have passed it on to me, even, he	25	MS RICHARDS: I'm just going to check behind me to see
	101		102
1	whether the legal representatives for the witnesses have	1	made could have been corrected at the time and therefore
1 2	whether the legal representatives for the witnesses have anything further.	1 2	made could have been corrected at the time and therefore had less of a consequence. And I would like when
2	anything further.	2	had less of a consequence. And I would like, when
2 3	anything further. Before I ask each of the witnesses if they've	2 3	had less of a consequence. And I would like, when institutions decide that they wish to destroy records,
2 3 4	anything further. Before I ask each of the witnesses if they've anything to add, sir, do you have any questions?	2 3 4	had less of a consequence. And I would like, when institutions decide that they wish to destroy records, that the family or the patient has the opportunity to be
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a greater understanding as well of what happened, because she was eight years younger than Andrew and we did try to shield her from a lot of what was happening because I didn't want it to blight two lives. I wanted her to have her life, and, you know, be successful, and have a happy life.

So, you know, finally she's becoming -- you know, knows a lot more about it, and I'm hoping it helps me to put things to bed maybe a little bit, and maybe I can --I can talk about it a bit more.

But, I mean, my mother was -- Andrew was her only grandchild for eight years, and he was the light of her life. And she really suffered. And she died six months after Andrew died. I think, you know, it did have a big effect on her as well. So, it's ...

You know, we can't change the past but I'm hoping that some good will come out of all of this now and. like Elisabeth says, people in the future won't have the same mistakes made, and people can handle things differently.

MS RICHARDS: Linda, is there anything you would like to 21 22

23 MS WOOLLISCROFT: I just hope that we get some answers at 24 the end of the day, after all this time. Because it's 25 took too long in the first place, you know. We just 105

really know now what the answer is going to be, do we? 3 Who is at fault or why did it happen, you know? I just 4 feel very proud of my son, the way he handled it, you 5 know? And I just miss him that much. I don't know what 6 else to say. It's just ruined your life. It ruins your 7 8 MS HADDOCK: It does ruin your life. You never ever get 9 over it. It is like a black cloud. It's always there 10 in your mind. Always. It never ever goes away. MS RICHARDS: Thank you. 11

Sir?

SIR BRIAN LANGSTAFF: Well, I would just like to say a few words

need some answers, and just -- we don't know -- we don't

It is -- you should know, it's been deeply impressive to me to sit here and to listen to you and the way you have, first of all, been here, despite -- and you've said as much, Brenda -- despite your misgivings. You've, as it were, brought yourself to do it. And no one who has watched could fail, I think, to see that you have struggled with your own emotions, each of you, in your own way. And I'm glad that the Inquiry has been a place where you could feel that you could express your emotions, if you wanted to. And you have each attempted to be as constructive as you can be, 106

despite everything that has happened. And in many ways your testimony has been the best testament to your children. So thank you, each of you.

[Applause]

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MS RICHARDS: Sir, we have two more witnesses of fact, our anonymous witnesses.

SIR BRIAN LANGSTAFF: Well, we will take a break first. MS RICHARDS: If we could take a break. And just as a reminder to those listening, there will be no live stream, Zoom, YouTube access to this afternoon's remaining evidence.

SIR BRIAN LANGSTAFF: Yes, I shall make an order -- I have 12 made the order but I shall read it out and describe it to you as I always do when we come back at 3.00 pm to hear our next two witnesses. But in the meantime. please just remember not to take photographs around this hearing room to, just in case you happen to catch someone you shouldn't.

19 (2.36 pm)

(A short break)

21 (3.00 pm)

> SIR BRIAN LANGSTAFF: Anyone who looked at the timetable may have seen "Anonymous Witness" in the singular. Both are anonymous witnesses. They gave statements some time ago and decided, having seen how things worked this

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morning -- something of a testament, perhaps, to our last witnesses -- they decided that they would both wish to give their evidence this afternoon.

In the case of both, however -- or each, I should say -- I have to make a restriction order. I will do it for each separately, starting with witness W4013, who is to be known as Mr BE, Bravo Echo, if you don't catch the BE.

The order is this: the name and address of witness W4013 and any other identifying information, such as the witness's image or a description of their appearance, cannot be disclosed or published in any form unless express permission is given by me or by the Secretary to the Inquiry acting on my behalf. Witness W4013 must be referred to only as Mr BE.

This order remains in force for the duration of the Inquiry and at all times hereafter unless otherwise ordered, and I may vary or revoke the order by making a further order during the course of the Inquiry.

So far as witness W4014 is concerned, she will be referred to only as Mrs BE, Bravo Echo. I order that the name and address of witness W4014 and any other identifying information, such as the witness's image or a description of their appearance, cannot be disclosed or published in any form unless express permission is

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1 given by me or by the Secretary to the Inquiry acting on 1 So don't worry if you do. It will not be on any 2 my behalf. Witness W4014 must be referred to only as 2 transcript, and everybody here is bound by the order 3 3 Mrs BE. The order remains in force for the duration of that the Chair has made. 4 the Inquiry and at all times thereafter unless otherwise 4 So he was diagnosed with haemophilia A when he was 5 ordered, and I may vary or revoke the order by making 5 about six months old. How did that come about? 6 a further order during the course of the Inquiry. 6 MR BE: Well, as he was a little boy, he woke up crying. He 7 Now, the first step is to have Mr and Mrs BE 7 got up in the middle of the night and wanted either 8 8 feeding or changing his nappy, and he didn't want that. separately sworn. 9 MRS BE (sworn) 9 He was still screaming. So I sat him on my lap and 10 10 MR BE (sworn) rubbed his back and found this almighty great big lump MS RICHARDS: You're here, both of you, to tell us about the on his back. Shouted [redacted]. So we both jumped in 11 11 the car and took him to [redacted] hospital. 12 treatment of your son at the Birmingham Children's 12 13 Hospital. Your son is still alive. 13 They then brought in a doctor, a locum. He looked 14 MR BE: Correct. 14 at him and he went, "Nah", shook his head, and said, 15 MS RICHARDS: And it's in his interests that you're giving 15 "Take him home and give him some paracetamol. See you 16 evidence to us, but giving evidence anonymously. You're 16 in the morning". We'd just moved to [redacted] from 17 giving evidence and telling us about him and what 17 [redacted]. And then we went back to our own doctor in 18 happened to him with his full knowledge and agreement. 18 [redacted], and he looked. He says, "Right. What I'm 19 MRS BE: Yes. 19 going to do now is I'm going to call for an ambulance. 20 MS RICHARDS: So he was born in 1980; is that right? 20 I want you to go to Good Hope." 21 21 MR BE: Correct "Don't worry about that. We're in the car." 22 MS RICHARDS: And if you use his name in the course of your 22 Within 20 minutes, we were at Good Hope. We went 23 evidence, it's absolutely fine because it's going to be 23 into Good Hope. Went into their intensive care in 24 hard for you to talk about him or talk about each other 24 a room, basically. Doctors come in, looked at it, shook 25 25 without mentioning his name possibly from time to time. their head, prodded him, went back out. That went on 109 110 for about an hour, hour and a half. "What is it? Is it 1 1 MS RICHARDS: Don't worry. Don't worry. a growth or is it an abscess?" That's what we were 2 2 MR BE: That's okay. And we'd never heard of haemophilia. 3 told. 3 It's not in [redacted] s family. It's not in my family. 4 It was a very hot day, and [redacted] hadn't -- my 4 It's out of the blue. We don't know nothing about it. 5 5 son hadn't had anything to drink or eat, and by about And I can remember just thinking, the doctor, he 6 five o'clock, he then got moved to a ward. They tried 6 appeared, and he just explained, "[redacted] s 7 to take blood from him and they couldn't, so what they 7 a haemophiliac, and he's got to have treatment for his 8 did, they wrapped him up in a blanket where I actually 8 blood -- to clot his blood." I think he was in there 9 held him, and they took blood from his neck, and then he 9 for about three or four days. And we were then sent 10 went to -- he went up to the ward. 10 home, with referrals backwards and forwards to the 11 He was able to get something to eat, and then they 11 hospital, with things like that. That's what happened 12 came to us and said, "I'm ever so sorry. We're 12 with [redacted], and that's how we found out that 13 transferring you to the Children's Hospital." 13 [redacted] was a haemophiliac. 14 So, again, back in the car. Straight to the 14 MS RICHARDS: And as part of that process, there was 15 15 a period of time in which the hospital or doctor thought

So, again, back in the car. Straight to the Children's Hospital. In intensive care again. Seen a doctor. She decided to take more blood, and I said -- questioned, "Why more blood? You've already taken the blood. Can't you take -- can't you use the blood from ..."

"No, we can't. We've got to take ..."

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So that went on. And shortly after that, they then admitted [redacted] into hospital then into a ward where we then stayed with him all night. It was only the following morning that we found out what the problem was with [redacted], with my son. Sorry.

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sort of questioned [redacted]. There was no allegations or anything like that. And then they sort of -- they apologised, saying, "We're ever so sorry but we don't know". But a couple of days later I went back to see the GP and had a right go at him. I wanted a public

MR BE: Yes, yeah. They -- when we was at the Good Hope,

the police were brought into it and questioned me and

the GP and had a right go at him. I wanted a public apology because he should have -- but as he said to us, "I don't come across this all the time". But he should

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that it might be child abuse?

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1	have been more aware.	1	MS RICHARDS: And were you ever told about the possibility
2	MS RICHARDS: Now, in 1981, so when [redacted] was a year or	2	of NHS concentrate rather than the American Armour
3	so old, if that, he started to be treated with	3	product? Was that ever discussed with you, as far as
4	Factor VIII concentrates, and the product that he was	4	MR BE: I don't think it were.
5	treated with was the Armour product, Factorate.	5	MS RICHARDS: Do you remember that ever being discussed?
6	Were you ever given any information at that point in	6	MRS BE: No, no.
7	time about any risks of hepatitis associated with that	7	MR BE: No.
8	product?	8	MS RICHARDS: Now we've got UKHCDO records which just sho
9	MR BE: Nothing at all. It wasn't mentioned anything at all	9	the treatments given, on an annual basis.
10	about anything. We were just glad there was this	10	So if we have on screen, please, WITN4013012, and we
11	treatment there for [redacted].	11	go to page 6.
12	MS RICHARDS: Was there any reference, as it went into	12	We can see if we look at the bottom of this table
	•		
13	'82 or '83, to any risks associated with AIDS?	13	the treatment for each year. 1981, at the bottom of the
14	MR BE: No. Not at this point.	14	table, Birmingham Children's, Factorate, and that's the
15	MS RICHARDS: And I think the two of you shared	15	Armour US product. 1982, again, Factorate. 1983,
16	responsibility for the hospital appointments, and	16	Factorate. 1984, Factorate. 1985, Factorate.
17	sometimes it would be you and sometimes it would be you?	17	So it would appear from this that this was the only
18	MR BE: Yeah, yeah.	18	product in those five years of your son's young life
19	MS RICHARDS: Was cryoprecipitate, as a treatment, ever	19	that he received; is that your memory?
20	offered to you for him?	20	MR BE: Yes.
21	MR BE: Not in that phrase, no. It was just that, "We're	21	MS RICHARDS: How did you learn that your son had been
22	giving [redacted] this other treatment", and that's how	22	infected from these treatments with HIV?
23	it was done. We didn't know what treatments there were.	23	MR BE: Um, [redacted] started being ill. He got yellow
24	It was just that, "This one is a new one come on the	24	jaundice. We then took him to the hospital, and we
25	market", and to carry on like that.	25	found out then they basically said, "[redacted] has
	113		114
1	got yellow jaundice, which he's got um hepatitis."	1	weren't told at the time that he was HIV positive?
2	"Okay? What's that? What do you mean by that?"	2	MR BE: No, no.
3	"He's just got hepatitis, and we've just got to	3	MS RICHARDS: We've heard from other witnesses this morning
4	watch what we're doing."	4	of a meeting of parents, a general meeting, that took
5	"What implications was that?"	5	place possibly two meetings, but certainly at least
6	"Make sure that everything is washed, cleaned,	6	one meeting, in around October 1984, at which there
7	sterile. Make him drink out off his own beaker."	7	was a Dr Hill held a meeting, lots of parents, and
8	Everything else like that was	8	gave some information about HIV and factor concentrates
9	"Okay, that's fine."	9	with which boys at the hospital had been treated.
10	Which we did.	10	Did you attend any such meeting?
11	That's how we found out that [redacted] had got	11	MR BE: No, we didn't. No, we didn't.
12	hepatitis and that's all we do. And every time they	12	MRS BE: No.
13	actually spoken to us about it, it was always said	13	MS RICHARDS: Just in terms of the hepatitis B, that led to
14	hepatitis. It was never said behind the scenes, "Oh,	14	issues in relation to your son's schooling.
15	he's got HIV" [whispering]. It was never said that, it	15	MRS BE: Yes.
16	was just "hepatitis", until [redacted] was about 11. So	16	MS RICHARDS: What was the problem? What happened?
17	we weren't aware of that at that particular time.	17	MR BE: Because hepatitis is a notifiable disease, the
18	MS RICHARDS: So you there's reference I think in the	18	school had to be informed. Now, as soon as they knew
19	documents to [redacted] having jaundice, being yellow.	19	that, they kicked him out of school and would not let
20	You remember that?	20	him in. So we had a case in our hands to get him back
21	MRS BE: Yes.	21	into school. And we tried to got the hospital to back
22	MR BE: Yes.	22	us up, and also the council. They refused to have him
23	MS RICHARDS: I think it's January 1985 from the records	23	back. So we went to the papers. And eventually he was
24	that he was diagnosed as having hepatitis B, as you've	24	allowed back into school. And there were a few things
25	described. Is this right: you didn't realise or you	25	that was said to us, "Oh, he can have private teaching

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1	at home".	1	MR BE: Well, I would probably personally, I would
2	We said, "No, he's not because we want him to have	2	probably say he was about 11 or 12 when we actually
3	a fair life. We want him to mix with people and	3	found out. Nobody at the hospital had actually told us
4	everything else like that."	4	when we was going there.
5	Well, we can send him to another school, basically.	5	Would you agree with that?
6	I said, "No, he's not going to another school.	6	MRS BE: [Redacted] was told by himself.
7	So we wanted him in that school."	7	MR BE: Yes.
8	We'd just moved our house from where we were to	8	MRS BE: He went to see it was an outpatient appointment
9	[redacted], to be right next to the school. And that's	9	with Dr Hill, and [redacted] went in on his own. He
10	what we bought. And you could where you are now,	10	came out. But [redacted] didn't speak to us about it
11	that's as far as the school was. So we could be there	11	because he assumed that we knew. And it wasn't until
12	with him, and anything like that. Don't pick up the	12	a few years later [redacted] had spoken to us and said,
13	phone, just walk over.	13	you know, what the doctor had said to him. He said,
14	And to be near our family, if [redacted] because	14	"But I thought you knew, Mum and Dad. I thought you
15	at that particular time we'd just got [redacted], and so	15	both knew". We said, "No, we wasn't told."
16	it was difficult for [redacted] to do everything. So	16	MS RICHARDS: So you had, without knowing, a son who was HI
17	Nan and Grandad sort of come and helped and wherever	17	positive?
18	they could. Even if [redacted] had to go to the	18	MRS BE: Mm, mm.
19	hospital and I had to go to the hospital and everything	19	MS RICHARDS: And a haemophiliac, so someone who would be
20	else like that. And that's how we knew when we took	20	prone to bleeding, potentially
21	him eventually we had a big fight on our hands, we	21	MRS BE: Mm.
22	got him back at school, because [redacted] is a very	22	MS RICHARDS: at home. You had two other children, young
23	bright lad and I'm not letting him go to another school.	23	children, and you didn't know that your son at that
24	MS RICHARDS: Now, how and when did you find out that he	24	point was
25	infected with HIV?	25	MR BE: Not at that point, no.
	117	20	118
1	MS RICHARDS: HIV	1	"Date
1	MR BE: Even though we basically said the Children's	2	"Last negative date
3	•		"First positive"
	Hospital was our second home, the amount of times per	3	•
4	week we would spend there going back for treatments and	4	Which would be testing on stored samples. And that
5	everything else, because [redacted] was put on	5	gives a date for his last negative test as July 1983,
6	prophylactic treatment because his joint bleeds, he'd	6	first positive April 1984, which would suggest
7	got two really bad elbows, and they were always back and	7	seroconversion between those two dates.
8	forth, back and forth, here we go again. Oh, he'd done	8	You say, I think, in your statement, that blood
9	something, he'd knocked his head. So it was our second	9	samples will be taken for testing routinely.
10	home. And lots of times he stayed there.	10	MRS BE: Yes, yeah.
11	MS RICHARDS: Then if we just have up on screen WITN4013006,	11	MS RICHARDS: Did you understand usually what those tests
12	please. We can see, these are some treatment records,	12	were for? Were you told that there was HIV testing
13	and if we look towards the bottom of the page, we can	13	being undertaken?
14	see a date, 17 December 1984. Then it says, "Heat	14	MRS BE: No, just keeping a regular check on his bloods.
15	treated commenced".	15	MR BE: And also on the hepatitis, because they might have
16	Do you recall any discussion with you about the	16	thought it was going to affect his liver and things like
17	switch to a heat-treated product or what the	17	that, so they wanted to make sure that was being tested.
18	significance of that might be?	18	MS RICHARDS: When you learnt that he was HIV positive, what
19	MR BE: No.	19	can you recall of the impact of that on the two of you
20	MS RICHARDS: Then if we could have back on screen the	20	and on your son?
21	UKHCDO records, so WITN4013012, please. We go to page 8	21	MR BE: A very big impact, because [redacted] and I sort
22	this time.	22	of did I blame you or did you blame me? You know, it
23	We've got dates there. There's reference to	23	was arguments. It's our son and we was very upset and,
24	a sample date in November 1987, and an HIV positive	24	you know, what's going to happen? Where are we going to
25	result. Then we've not the entries:	25	go down this line? Recause there was so much stigma

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1
         about things. You've got HIV, you've got this. Are you
                                                                                   1
                                                                                           friends, sort of, like -- [redacted] s married now, but
2
                                                                                  2
         going to have a gun at your head thinking all of
                                                                                           when he was courting, he -- basically he'd been courting
3
                                                                                  3
         a sudden he's gone? You know, like -- today, I think we
                                                                                           this girl for a while now, and he got involved with her
4
         were very, very lucky. We are very lucky to still have
                                                                                  4
                                                                                           quite badly and fell in love, as you do. And then he
5
         [redacted] and things like that. But it was a big shock
                                                                                   5
                                                                                           came home crying one night and I said, "What's the
6
         to both of us when we found out, and -- yeah, wasn't it?
                                                                                  6
                                                                                           matter?"
7
    MRS BE: And just not having anybody to talk to. We
                                                                                  7
                                                                                                And he said, "I've finished."
8
         couldn't talk to anybody. We'd only got each other.
                                                                                  8
                                                                                                "What do you mean 'finished'?"
9
    MR BE: No, we didn't understand nothing about it. No, we
                                                                                  9
                                                                                                "Dad, I can't do it, I can't do it."
         wasn't given any counselling. Nobody talked to us about
                                                                                  10
10
                                                                                               I said, "What do you mean you can't do nothing?"
                                                                                                He said, "I can't tell [redacted] about the
11
         it. You know, it was just carry on -- just carry on
                                                                                  11
12
         with what you're doing.
                                                                                  12
                                                                                           haemophilia and this that and the other and what I've
13
    MS RICHARDS: And I think it's right to say that members of
                                                                                  13
                                                                                           got."
14
         your wider family did not know.
                                                                                  14
                                                                                               I said, "What do you mean? Why?"
15
    MR BE: They still don't know.
                                                                                  15
                                                                                                And he was like that for over a week, so I says,
    MRS BE: Still don't.
                                                                                  16
                                                                                           "Come on", so we rang up -- and [redacted] was ringing
16
17
    MR BE: This the first time we've actually spoke about this
                                                                                  17
                                                                                           every day to speak to [redacted] and [redacted] was so
18
         in the 40 years that we've -- with [redacted]. We've
                                                                                  18
                                                                                           depressed and everything, and so we went round and sat
19
         been a very quiet family with -- in letting people know.
                                                                                  19
                                                                                           down with [redacted] and -- and explained to everybody
20
    MRS BE: Three --
                                                                                  20
                                                                                           else like that and they were fine with it. And then
                                                                                  21
21
    MR BE: Even my mum, whose 90, she doesn't know about
                                                                                           they started courting again, which was great, and they
22
         [redacted], because she's -- she would sort of push him
                                                                                  22
23
         away and don't want to love him and kiss him and this
                                                                                  23
                                                                                       MS RICHARDS: And you've said in your statements that you
24
         that and the other, even today. So -- she's a very
                                                                                  24
                                                                                           thought you were going to lose your son. You thought
25
                                                                                  25
         funny woman, my mum is. And it's only been very local
                                                                                           your son would die.
                                     121
                                                                                                                        122
    MR BE: Yeah, you know, with everything else.
1
                                                                                  1
                                                                                           know you're going to get it. And, yeah, he sort of --
                                                                                  2
    MRS BE: Yeah.
                                                                                       MS RICHARDS: I'm just going to read a little of what
    MR BE: As soon as you hear that HIV, next comes AIDS, then
                                                                                  3
         there's no treatment for it at the moment. There isn't
                                                                                  4
                                                                                           [redacted] has said in his statement to the Inquiry --
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REDACTED VERSION

2 3 4 5 anything that's there. It's just watch your son 6 deteriorate MS RICHARDS: And did he began to be very poorly? He 7 8 developed severe migraines. 9 MR BE: Yeah, he had --MRS BE: Yes. Yes. 10 11 MR BE: He was having headaches all the time. When he --12 the first job he used to have, he used to go sorting out 13 computers for people in industry, because as I said, he was very -- but it was driving. And I had to say to 14 15 fredacted]. "You're not doing that." because he would ring me up sometimes and say, "Dad, I've had to pull 16 17 over. I've got a severe headache, migraine. I can't 18 even see the road. I can't even -- basically, I've 19 blacked out." And I said, "No, you can't do that." 20 So he then came to work for me, which I created 21 a job for him. But he used to love that job. But he

had terrific headaches. He'd have to go into a room and

lie down. He was prescribed some tablets to take before

colours. One's when you've got one, and one's when you

his treatment and throughout. There was two different

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I think it will resonate with those who heard the evidence earlier today in particular -- in terms of the experience of a teenage boy hearing this news. So he said this in his statement:

"In the mid-'90s when Dr Hill told me of my infections. I thought my life was over. I felt that it shattered all my plans of a normal life, such as finding a wife and having children of my own and even growing old. I felt that my world was crumbling. All I wanted to know was when I was going to die. It definitely had a big psychological impact on me as I didn't see the point in doing anything, and I constantly questioned everything. I hated the thoughts that used to go through my head. My behaviour soon spiralled out of control. I wasn't a nice person to be around, and I was always snappy and didn't want to know or be told anything. I was just angry at the world."

Then he talks about feeling there was a ticking clock, and that he'd already been issued with his death sentence.

MRS BE: Mm.

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1	MR BE: Yes.	1	upset, crying a lot of times, you know, because she's			
2	MS RICHARDS: And you, as his parents, were having to do the	2	very upset, sort of "What's going on?" And as you would			
3	best you could to help him through that?	3	do. As you would do. And it's, you know we've seen			
4	MR BE: That's right.	4	yeah. Yeah.			
5	MS RICHARDS: [redacted] also tested positive for	5	MS RICHARDS: And from your point of view? MR BE: What do you think?			
6	hepatitis C. Do you recall when you were told about the	6				
7	hepatitis C, or when he was told about the hepatitis C?	7	MRS BE: Everything just changed for me. I just went sort			
8	MR BE: No.	8	of bad tempered, nasty. Like, aggressive towards			
9	MS RICHARDS: And he went through interferon treatment over	9	people. Didn't trust people, because we'd been told			
10	the years.	10	lies about him anyway, you know, and that sort of thing.			
11	MRS BE: Yes.	11	I just feel that it changed us, and we'd only got			
12	MS RICHARDS: Or interferon or ribavirin treatment on three	12	we'd only just got it was just the five of us, wasn't			
13	occasions, each of them unsuccessfully?	13	it?			
14	MR BE: Yeah.	14	MR BE: Yeah.			
15	MS RICHARDS: And it was only more recently, with one of the	15	MRS BE: It was like the five of us against everybody else.			
16	newest treatments, that he was able to take that and	16	MR BE: Yeah, I think that's why we sort of kept it quiet.			
17	clear the hepatitis C.	17	We'd deal with it in our own way.			
18	What's been the impact on the two of you, as	18	MRS BE: The [siblings] were very good, though, weren't			
19	parents, of your son's diagnosis and, over the years,	19	they? They didn't ask a lot of questions. They grew up			
20	the impact that's had on him physically, and how has	20	saying [redacted] was special. That was all they ever			
21	that been for you, as his mum and dad?		said: [redacted] was special. But as they got older			
22	2 MR BE: It's been fear, thinking, you know, what's going to		they asked questions, which we've you know, we've			
23	happen? You know, how long have we got [redacted]?	23	answered their questions. So has [redacted]. They know			
24			all about him but they don't talk about it.			
25	everything else. Very upsetting. And, you know, mum's	25	MR BE: No, their friends don't know either.			
	125		126			
1	MS RICHARDS: Again, I'm just going to briefly read	1	Now that resonates, I think, very much with what you			
2	something from his statement about the stigma, and then	2	have told us about how the two of you felt?			
3	ask for any additional reflections you have.	3	MR BE: Yes, very much so, and we yeah, very much so.			
4 He said this:		4	MS RICHARDS: In the evidence we have already heard today			
5			about how things were done at the Birmingham Children's			
6	anyone about my infections, they knew of my haemophilia.	6	Hospital, there are a handful of themes that emerged,			
7	Neither my parents nor I were able to talk to anyone	7	and I just wanted to ask for your reflections on them.			
8	about our situation and with the stigma. Having people	8	First was the question of trust. The witnesses we've			
9	constantly accusing me of having HIV and telling me	9	heard from this morning talked about how they trusted			
10	I was going to die was very difficult to deal with.	10	the doctors. They trusted that the doctors would be			

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10 I was going to die was very difficult to deal with. 11 I always used to tell people who asked me that I was 12 fortunate and did not get any infections, I was so 13 worried about the stigma. I was forced to live in silence with HIV and hepatitis, which is still always 14 15 a big cloud over me. I had to pre-plan everything 16 through my life, from relationships to where I was 17 working, to where I was going on holiday. This made me 18 have a really negative outlook in life." 19 And then, in turn, talks about his ability then to 20 talk to his wife about it, says this: 21 "This whole ordeal has in turn put a strain on my 22 wife and her parents, as they all have no one other than 23 who is already in our tightknit circle to confide in. 24 This has left all of us very isolated and, at times,

25

secluded."

their children. And then a sense of, in differing degrees, how that trust had been betrayed. Do you have any reflections on that issue? 15 MR BE: Yeah, we trusted them. We trusted them, partly because that was their profession. They knew. They knew what was going on. But it's only been today that we've heard a few things, that's just, you know, opened our eyes, basically. Dr Hill knew about it way before [redacted] was born. So what was going on there? Why was he given this treatment? Is it all to do with money? Buy it off the Government at, you know, a cheaper price of this, that and the other, to do -you don't know. I don't know either. But that's what you do. You trust the profession. And that's what they 128

doing the right thing, giving the right treatment to

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(32) Pages 125 - 128

7	knew about, where Dr Hill, you know, he was dealing with	1	National Health. The only one that we were given is the
2	children for a long, long time. And we're a minority,	2	one that [redacted] had got, so what choice had we got?
3			MS RICHARDS: And then the other theme or one of the other
4	dealing with. So, yeah, we put our trust in him to help	4	themes that's emerged is the question of communication;
5	us or help [redacted], and the team that were there.	5	how information was given about diagnosis and what
6	MS RICHARDS: Do you have any reflections on that, that	6	information or advice or support was provided. You've
7	question of trusting in the doctors?	7	told us how you learnt about your son's diagnosis.
8	MRS BE: No.	8	MR BE: But there was no support.
9	MR BE: Would you trust them again?	9	MS RICHARDS: That was going to be my next question. Did
10	MRS BE: I don't think I can.	10	you get advice, information, support from the hospital?
11	MR BE: No.	11	MR BE: No. Nobody came to see us. Nobody said, "We need
12	MS RICHARDS: Another issue that has emerged from the	12	to sit you down." Nobody said this. Nobody told us how
13	evidence that we've heard today is the lack of choice,	13	to treat or anything like that. There was no support
14	so not being given a choice of treatments that	14	there whatsoever, as far as I was concerned.
15	essentially	15	We went to the hospital, seen the hospital. They'd
	•		
16	MR BE: Well, was there a choice?	16	come and examine him, whether it was a local doctor, one
17	MS RICHARDS: being given just the one treatment and not	17	of the doctors, Sister Marion. "Yes, he needs
18	being told of alternatives. That was your experience.	18	treatment. Give him his treatment." That was it. No,
19	MR BE: Yeah, we wasn't given a choice. What choice would	19	there was no support. And there was no "Sit down.
20	there have been? You know, you could have had the	20	I need to tell you what's going on."
21	British one, or you could have had but that wasn't	21	When [redacted] had the meetings with Dr Hill, he'd
22	available.	22	go in and just look at his arms, and this that and the
23	MRS BE: No, it wasn't.	23	other. "How are you feeling, [redacted]?" "Yeah, I'm
24	MR BE: That wasn't there. Again, I've just heard today	24	okay." "Okay." Write a few things on his notes.
25	about the National Health one. It was never spoke about	25	Today, we've seen more notes that we've ever seen. That
	129		130
1	was never given to us. And that was it. An appointment	1	That's how it was.
2	next month.	2	MS RICHARDS: Sir, do you have any questions for our
3	So there was no there was nothing there to tell	3	witnesses?
4	us or to guide us in the way to go. I don't think there	4	SIR BRIAN LANGSTAFF: Yes, I do. And I want to ask this in
5	is well, what would you have done? I don't know.	5	turn, but first of all, to you, Mrs BE, if I may.
6	MS RICHARDS: I'm just going to turn and see whether your	6	The question is: what do you think has been the
7	legal representatives have any further matters.	7	single worst or biggest consequence for you personally
8	Just give me a moment.	8	out of what has happened?
9	Yes, it's just I'm just, I think, very helpfully	9	MRS BE: Just all what's happened to my son, that's all.
10	invited to just flag up one additional paragraph in your	10	MR BE: (overspeaking) the treatment.
11	son's statement, when he gives his perspective on your	11	MRS BE: The treatment.
12	position. He says this:	12	SIR BRIAN LANGSTAFF: One at a time on this occasion,
13	"My parents suffered a great deal from back when	13	please.
14	they were both told of the heartbreaking reality that	14	MRS BE: Just not telling us. Not informing us. You know,
15	their only child had been given multiple	15	sometimes all you need is to be told. You just want
16	life-threatening viruses caught from a contaminated	16	somebody to tell you something, to give you some
17	batch by the very people they entrusted their son's	17	information, you know. That's probably all I can say.
18	wellbeing to. They had no information about the viruses	18	It's just somebody to talk to us.
	and felt their son's future had been taken away. They		
19		19 20	SIR BRIAN LANGSTAFF: And what about you? MR BE: He should never have been given the treatment. They
20	were forced to suffer in silence as they had no one to	20	•
21	turn to with the stigma around, and they could only talk	21	knew it was infected, and he should never have been
22	to the hospital staff who were the same people who had	22	given the treatment. If he hadn't been given that
23	contaminated their son."	23	treatment, he'd still have been a haemophiliac, but he
24	That's his take. Is that one your recognise? MR BE: Yeah. Yeah. I couldn't add anything to that.	24 25	wouldn't be where he is today. He wouldn't have so yeah, he should not they knew about it, which they
25			

REDACTED VERSION

(33) Pages 129 - 132

did clearly know about it, but they still carried on giving the treatment. SIR BRIAN LANGSTAFF: What I'm hearing you saying is that the worst aspect, so far as you personally are concerned, is the sense of injustice? MR BE: Yes. Well, you know, even, like I said earlier, it's having a loaded gun. We don't know when it's going to go off. Even now, with the treatment he's got, we still don't know. I mean, we're one of the lucky ones, and we put it down to being one of the lucky ones. I've heard of people, the children dying. Parents don't die before their children, you know. So, yeah so that's 12 my that would be me. They shouldn't have give the 13 treatment if they knew it was infected, which they did, years before this happened. 15 SIR BRIAN LANGSTAFF: Thank you. 16 MR BE: Thank you. 17 MS RICHARDS: I'm just going to ask each of you in turn if there's anything else that you'd like to add. I start 19 with you. Is there anything else you'd like to say? 20 You don't have to say anything. It's all right. 21 It's only if you want to. 22 MRS BE: No. No. 23 MS RICHARDS: And you? 24 MR BE: Yeah, I'd just like to say thanks to the Inquiry 25 MR BE: Yeah, I'd just like to say thanks to the Inquiry 25 MS RICHARDS: Sir, that's our evidence for today. Tomorrow we have four witnesses, the last two of whom will be giving evidence anonymously. And the issue or particular theme that we're going to be hearing about tomorrow is the position of those recently diagnosed with hepatitis C. SIR BRIAN LANGSTAFF: So those recently diagnosed with hepatitis C. SIR BRIAN LANGSTAFF: So those recently diagnosed with hepatitis C, evidence panel tomorrow, starting at 10.00. Thank you very much.	Without your help, these would still be brushed under the carpet, and none of us would be aware of what's happened and everything else, and yeah. MS RICHARDS: Thank you. MR BE: You're welcome. MS RICHARDS: Sir Brian? SIR BRIAN LANGSTAFF: Well, can I thank you both. I think no one listening to you, Mr BE, would realise that it is the first time that you've been able to bring yourself to talk openly, albeit anonymous within the Inquiry, you're still talking openly about	г
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11 MS RICHARDS: Thank you, sir.		
12 (3.40 pm)		
13 (The hearing adjourned until 10.00 am the following day)		
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