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1 Thursday, 20 June 2019 2 (9.58 am) 3 **SIR BRIAN LANGSTAFF:** Good morning. 4 MS FRASER BUTLIN: Good morning, sir. 5 SIR BRIAN LANGSTAFF: Although it is just before 6 10 o'clock according to the clock on the wall, we will 7 start because I think you are all ready. 8 We have reached P in the alphabet for those of 9 you who have been watching proceedings and you will 10 know that that means that this witness, the first 11 witness, is going to be anonymous and be known as 12 Mr P. You'll know that that protects his anonymity 13 because it will be a contempt of court if anyone does 14 anything to reveal his name outside this room and 15 calls him anything other than Mr P. 16 But I have to make the order formally and I do 17 so in terms which will be familiar to those again who 18

have been here before and it is this, that the name and address of witness W0279 (that's Mr P to you and me) 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 W0279 must be referred to only as

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given a blood transfusion through the scars as well as a skin graft. I do believe I may have received plasma as well at the time because the scalds were so bad that they needed to give me some clotting agent to stop the bleeds.

- Q. Your understanding from your Mum is you received red blood and plasma?
- A. That's correct, yes.

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- **Q.** Do you have any medical records from that period when 10 you were in hospital with the burns?
 - A. I do. ves. but the medical records are missing a period from when I was scalded all the way up to when I was about nine years of age until I received my first letter from the NHS. There's little bits in there but even they have been cut out from the printout.

I've spoke to my GP and they've said that there's no more medical records that they have got. I have looked into trying to get them from the hospital as well from where I were, but the hospital itself is now shut down so I don't know where to turn to to try and get my medical records from that time.

Q. You've struggled to get them so all you've got is bits and pieces from the nine months to age nine and it's not entirely clear exactly what you received but your

"Mr P". The order remains in force for the duration of the Inquiry and at all times thereafter unless otherwise altered and I may vary or revoke the order by making a further order during the course of the Inquiry.

That's the order. That gives him protection. It will be observed by the press and, as I always do on these occasions, can I ask you to be very careful if you are taking photographs on your mobiles, however much you may wish to take a photograph, just check that you don't accidentally capture an image of him so that those who are listening outside this room can put two and two together and know who he is.

Mr P.

MR P, sworn Questioned by MS FRASER BUTLIN

- Q. Mr P, when you were nine months old in 1987 you were rushed into hospital. Can you tell us what had happened?
- A. I was in a baby walker at my Mum's friend's house and I managed to walk myself into the kitchen and the wire for the kettle was leaning over the side and I managed to pull the kettle over myself, scalded myself on my chest and on my right arm. The scalds were so bad, I was rushed into A&E for the burns. So then I was

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1 Mum is clear it was red blood and it was plasma?

- A. Yes, that's correct, yes.
- 3 Q. Was your Mum as far as you know given any advice or 4 information about the risks of receiving that 5 transfusion?
- 6 A. No.
- 7 Q. Then in 1997 you were aged about nine and you received 8 a letter. Before we talk about that letter, why are 9 you so clear that the letter was sent to you 10 personally rather than your parents?
- 11 A. On the day in question, the letter was received 12 through the door. It had my name, my name on it and 13 it had two love hearts on the right corner of the 14 envelope and at the time I actually thought it was 15 a love letter; so that's why it sticks with me and 16 I know it was written for me.
 - **Q.** What did that letter say?
- 18 A. I can't 100 per cent remember. I know it was an 19 appointment to go to hospital and it was in the state 20 of saying that they may have given me hepatitis C when 21 I received my treatment for my scald when I was nine 22 months old.
 - Q. How did you react when you read that letter?
 - A. I ignored it. I was eight/nine at the time. I didn't really understand it. I just handed it to my mother

1		because then I realised it wasn't actually for me.	1		for a fact. I was told when I was first told I was
2	Q.	You realised it wasn't a love letter?	2		told I couldn't play any contact sports. Football
3	A.	Yes, I did.	3		crazy, so to be told I couldn't do something I love
4	Q.	You gave it to your Mum?	4		was heart breaking. I couldn't physically go out and
5	A.	I did.	5		play with my friends, play football, I couldn't go
6	Q.	You went up to the hospital	6		climb walls. I had to look after myself like I was an
7	A.	l did.	7		adult from a young age because I weren't going to put
8	Q.	just after or just before your ninth birthday?	8		my friends at risk of catching what I had. I was told
9	A.	Yes.	9		it was I was able to pass it on but only in certain
10	Q.	That's when you were diagnosed with hepatitis C?	10		ways but at a young age it doesn't mean anything to
11	A.	Yes. I was went into the room and on the day the	11		you. You are just always cautious and you're always
12		nurse that actually took my bloods she said to me	12		wary of what you're doing.
13		I looked too fit and healthy to have hep C so I should	13	Q.	Once you got to high school I think you had a bit more
14		be all right, don't worry about it. Then I think it	14		realisation of what hepatitis C was really about?
15		was a few weeks later we received the news that I did	15	A.	Mm-hm.
16		have hep C.	16	Q.	What did you understand to be your life expectancy?
17	Q.	How were you told that you did?	17	A.	I was told I was going to live between 18 to 30 years
18		I think we went for a second appointment. I'm not	18		from a doctor. By this time, I was coming from age 11
19		100 per cent sure. I can't remember, sorry, but I do	19		and upwards. You are already counting down the years,
20		believe it was a second appointment and it was	20		even from a young age.
21		addressed to my mother this time and we were told	21		I knew it's hard knowing that you're going to
22		then.	22		die at some point and for someone to tell you that at
23	Q.	Can you tell us a little bit about how you think the	23		such a young age it was terrifying. You withdraw
24		hepatitis C affected you as you grew up?	24		within yourself. You can't do what you want to do.
25	Α.		25		You can't concentrate in school. You can't fulfil
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1		your potential because you don't think you've got	1		and understand what was going on, I can see why they
2		your potential because you don't think you've got potential to live long enough to fulfil that	2	0	and understand what was going on, I can see why they felt the way they did.
2		your potential because you don't think you've got potential to live long enough to fulfil that potential, so you don't want to I can't it's	2		and understand what was going on, I can see why they felt the way they did. How did it affect your relationship with your parents?
2 3 4	0	your potential because you don't think you've got potential to live long enough to fulfil that potential, so you don't want to I can't it's hard, it was really hard.	2 3 4		and understand what was going on, I can see why they felt the way they did. How did it affect your relationship with your parents? I wouldn't say it affected them. I think they did
2 3 4 5	Q.	your potential because you don't think you've got potential to live long enough to fulfil that potential, so you don't want to I can't it's hard, it was really hard. In those early years who knew that you had	2 3 4 5		and understand what was going on, I can see why they felt the way they did. How did it affect your relationship with your parents? I wouldn't say it affected them. I think they did look after me a lot more. They was a lot more
2 3 4		your potential because you don't think you've got potential to live long enough to fulfil that potential, so you don't want to I can't it's hard, it was really hard. In those early years who knew that you had hepatitis C?	2 3 4		and understand what was going on, I can see why they felt the way they did. How did it affect your relationship with your parents? I wouldn't say it affected them. I think they did look after me a lot more. They was a lot more cautious in what we did. I wouldn't talk to them
2 3 4 5 6 7	Q. A.	your potential because you don't think you've got potential to live long enough to fulfil that potential, so you don't want to I can't it's hard, it was really hard. In those early years who knew that you had hepatitis C? It was my mother and my father, and myself, and the	2 3 4 5 6 7		and understand what was going on, I can see why they felt the way they did. How did it affect your relationship with your parents? I wouldn't say it affected them. I think they did look after me a lot more. They was a lot more cautious in what we did. I wouldn't talk to them about anything. I've always kind of dealt with it on
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2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20	A.	your potential because you don't think you've got potential to live long enough to fulfil that potential, so you don't want to I can't it's hard, it was really hard. In those early years who knew that you had hepatitis C? It was my mother and my father, and myself, and the doctors. That was pretty much it at the time until I got a little bit older and then you start you need to tell your friends because you need someone to help you look after you when you're out. Some disappeared, some stayed and the ones that stayed have meant the world to me because they've stayed through thick and thin with me and that's pretty much it, that now. What about your brothers? Not from a young age. It wasn't until they got old enough to understand what was going on. From a young age I was well, people said I was treated as the golden boy, I was looked after better than well, it	2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20	A. Q. A.	and understand what was going on, I can see why they felt the way they did. How did it affect your relationship with your parents? I wouldn't say it affected them. I think they did look after me a lot more. They was a lot more cautious in what we did. I wouldn't talk to them about anything. I've always kind of dealt with it on my own. I never wanted to be an extra burden as what I was already. Why didn't you want to ask your Mum questions about hepatitis C? I didn't want to know. I didn't want to know. It was bad enough knowing that I had up to the age of 30 to live. I didn't want to know anymore. It was hard enough as a child to deal with what I was going through with that alone, let alone asking any more questions. You've said in your statement that the hepatitis C has made your family life now with your children difficult as you bring them up. Can you tell us a little bit

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thought that I was the special one and it was hard.

I knew why but until they was old enough to realise

they cut theirself I would get my wife to deal with it

just because I was always scared and I don't want them

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to grow up with what I had to grow up with.

It's hard as well because I'm not always a nice person. I have really severe mood swings. One minute I can be really extremely happy and the next minute I could be shouting at any of them for no reason. Psychologically it's hard on them as well because they don't understand what's going on. It's always daddy's got a poorly liver or daddy's got to go see the doctor again. It's just hard, it's really hard on the children.

- **Q.** When your wife was pregnant there was also a particularly difficult interaction that she had with a health visitor which I think you only found out afterwards?
- A. I did, yes.

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- 16 Q. What happened?
- 17 **A.** At the time she went for an appointment with the 18 health visitor and the hep C got brought up just so 19 she knew what was going on and told [redacted]. 20 (Pause)
- 21 **Q.** We will restart and I'll ask you the same question again, okay. When your wife was pregnant there was 22 23 also a particularly difficult interaction that she had 24 with a health visitor that you only found out about 25 later. Can you tell us what happened.

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- 1 A. I did, yes.
 - Q. What can you remember about those?
- 3 A. Treatment was terrible. You was always ill when you 4 had them. I've had so many it's hard to remember 5 which ones are which but you always ended up with the 6 same feelings. You didn't want to get out of bed. 7 You had constant headaches or constantly sore. One of 8 the first ones I had it was the local nurse had to 9 come in and inject me. I had to take urine samples 10 every time to make sure there was no blood in my 11 urine. It was time off school from a young age 12 because of the effects it was having on me. It was 13 time away from my friends. I wasn't that much out 14 because of these injections, I was ill, I was really 15 ill, because of them.
 - Q. Then in adulthood you have had three rounds of treatment to try and clear the virus.
 - A. That's correct, yes.
 - Q. What can you tell us about those?
- A. The first one was meant to last for 12 months. I did not get past three months. The interferon was dropped 22 in dosage because of the amount of weight I was losing and how ill I were because of the treatment.

The first one as well I was, if I remember right, I was over a million count on my hep C count

- 1 A. My wife had an appointment with the health visitor and 2 hep C were brought up because we wanted to make sure 3 everything was fine and my wife would be looked after 4 in the right way and have all the checks done and the 5 health visitor told my wife that she hopes I've 6 changed my life style and I've stopped taking drugs 7 and drinking alcohol. She automatically assumed that 8 I was a drug addict and I got my hep C from being 9 a drug addict, even though I got it from that blood 10 transfusion when I was younger. Every time we had an 11 appointment from thereon it was stated where I got my 12 hep C from and every doctor I spoke to because you 13 always felt like the impression was they thought I was 14 a drug addict, always.
 - Q. You felt the need in every appointment to explain how you contracted hep C?
 - A. I did, yes. I didn't want them to think I was a drug addict. I was nine month old, it was never even thought of, even growing up it was never even thought of, so I had to explain myself to someone because they were ignorant and automatically assumed where I may have got it from.
 - Q. In terms of treatment you've received, you believe that while you were a child you underwent some experimental treatments for the hep C?

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and it needed to get below a million and I never got close, so it was dropped and finished.

The second one --

- Q. In the first one you remember being the bed, in your statement you remember being in bed five months?
- **A.** Yes, even after the treatment finished I was in bed. I didn't feel myself, I didn't want to go face the world especially afterwards when you're told it's not worked as well that has a psychological effect on you. They build you up telling you that there's a good chance of it working and for it not to work you do go into a depression state. You know you're going to start again. It's not going to change.
- Q. The second time round was for about six months?
- 15 A. Yes, the second time, this time we did pass the marker 16 stage but then again it failed. Again, it was just 17 physically feeling ill. I couldn't, again, get out of 18 bed and this time round I had my first child. I was 19 stuck in bed and trying to explain to my child why I'm 20 in bed, why I can't go out and why I can't play with 21 him, why he can't come upstairs. It was hard.

I was physically had like, especially after the injection, I felt like I had a cold all the time, I was shivering I couldn't get warm. The aches and pains all over my body was terrible. It was really

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- 1 just really hard to deal with.
- 2 Q. You've talked about that second treatment of you 3 sitting down and arguing with the injection pen.
- 4 A. Yes.
- 5 Q. What was going through your mind at that point? What 6 were you saying to the injection pen?
- 7 A. I was arguing with it. I was telling myself and 8 telling the pen how fed up I were with the pen. It's 9 not nice to have to sit there on the edge of your bed 10 every week looking at it and injecting myself. It got 11 to the stage where I felt I couldn't do it anymore 12 unless I motivated myself by arguing with a pen and 13 that's the only way I got through it was arguing with 14 a pen. And then it got to the point where you argued 15 with it and then you just stabbed yourself because you 16 are still arguing and you're not thinking about what 17 you're doing. It was terrible.
- 18 Q. Then the third treatment was just for 12 weeks --
- 19 A. Yes.
- 20 Q. -- in 2015, and how was that?
- 21 A. Like the rest of them but this time they say it's 22 worked, they say it's gone, they say I'm clear, but it 23 was exactly the same as the rest. You still deal with 24 the side effects, you deal with your children and it's 25 a situation I should never have found myself in in the

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- 1 be disappointed --
 - A. That's correct.

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- **Q.** -- if it didn't work again. 3
 - A. Yes. It does kill you when it does come back. It knocks your life back. It puts you in a dark place. You're alone. Even though I've got family around me, you are alone. You deal with it all yourself.

I'm not a very -- I'm not the kind of person that speaks to people. I like to keep it inside. I like to deal with myself. It's going to sound wrong but I'm the man. I'm meant to be the person in the house that deals with everything and when that's taken away from you because you've been put in a situation where you should never have been put in and you can't be the man of the house anymore, it's destroying.

- Q. Because you've cleared the virus now but you still have liver cirrhosis?
- 18 A. Yes, that's correct, yes.
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- **Q.** Physically, what symptoms have you been left with? 20 A. I suffer from a lot of short-term memory loss. It's 21 got worse over the last few years to the point where 22 I could be told something, even for the Inquiry I've 23 been receiving emails, I read the emails, I look at 24 the emails, and then it will be four or five days

- 1 first place.
 - Q. Emotionally how did you find that third round?
 - A. I didn't really want to do it. The last two experiences of knowing it never worked. It was a sense of feeling it was never going to work. I was going to have to deal with this for the rest of my life.

I didn't -- to be fair, I didn't really want to go on it no matter how much they promised me it was going to work because I've been there and I've done it. I didn't want to inject myself again. I knew I was going to get to the point of fighting and arguing with a pen again. I didn't want to have to take tablets twice a day. I didn't want to have to explain to my kids why I can't go out, why I can't play with them.

It makes you depressed. You didn't want to go to that place again. I'd been there so many times and it's a road that never seemed to end. Don't get me wrong, I'm fortunate that I am clear but I never felt I was going to get there. Even when she told me, I did not believe her. I expected to go back in a few months, oh, it's come back, because it always came back. That's how it was. It was always coming back.

Q. You said you didn't want to get your hopes up only to

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emails again, "Oh I didn't do this. I should have emailed them this". It's every day I'm losing bits of my memory and it's hard knowing that I'm getting told stuff and it could be important stuff and I still forget.

Being depressed -- I still believe I am in many respects a little bit depressed even though it's gone. I'm extremely tired all the time. I could have 12 to 16 hours sleep if I could get it and I'd still be physically drained all the time. I wake up tired. I'm tired in the day. I'm tired at night. It's just a constant cycle.

- 13 Q. You've also got pain in the right-hand side of your 14 stomach and the rib area?
- 15 A. Yes, that's constant.
- 16 Q. You've also spoken about the mood swings that you 17 still suffer from?
- 18 A. Yes, I still have real bad mood swings. It's all the 19 time. I could be really nice and then switch and it's 20 from nowhere and for nothing. I don't have to --21 there doesn't have to be a trigger to make me switch. 22 I just switch from being nice to being horrible and 23 it's not nice.
- 24 **Q.** Your wife works away from home two nights a week. 25 What effect do your symptoms have on family life

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later something will be brought up, I'll go through my

particularly when she's away?

A. She's got to ring me in the morning to wake me up.
I can set so many alarms. I don't hear them. My
daughter comes into the room, tries waking me up. I'm
so far gone, I'm so tired, I don't physically want to
get out of bed. It takes the wife ringing me and
shouting at me to get out of bed, for me to get out of

Don't get me wrong, my kids aren't in any danger and if anything were to happen like that I can deal with it. It's just -- it's hard. I shouldn't be like this. I'm fit, I'm kind of healthy, I'm working, I'm trying to get myself back into the right place I should be. I shouldn't be this tired all the time but everything I try it doesn't work. I'm still tired and it's hard.

- **Q.** It's then a struggle to get the kids to school in time and up and ready in the morning?
- A. It is, yeah. By the time my wife's rang me and woke me up, I've probably got 20 minutes to get both of my kids ready, fed and taken to school. It's a bit like Piccadilly Gardens in the morning, it's that hectic in my house, it's just ridiculous.
- Q. You have spoken a little bit about the emotional impact and ongoing depression that you feel you

I was told they'd have to refer it to the force's medical team and I'll have to wait to see if I'd be allowed to go in.

This was the biggest dream and the weeks and weeks went by and then all of a sudden I received a phone call telling me your dream's over. You're not allowed in.

Now, that took me back. I couldn't for a long while get over that. That's all I ever wanted to do, was join the army. I knew I wanted to go in the army. I had my career plan set out in the army from a young age. I knew exactly where I wanted to go, what I wanted to be and how far I wanted to take it, and for someone to tell you you can't do your dream because you were put in a situation from being given something from a young age, it was -- it did make me really depressed and, to be fair, I don't even think I've ever got over, it even to the day.

Even when I got the all clear, this is how much I wanted to do it, I got the all clear and the first thing I did was I rang the TA. I was too old to join the army but I could join the TA still. I rang them up and told them it's gone but I still do have liver cirrhosis can I get in? Within five minutes of being on the phone she rang somebody else and then came back

suffer. Have you been offered any counselling or psychological support during this time?

A. I have but again I feel like it's easy to deal with it myself. I don't want to keep talking to people about what's gone on, why I feel like this. I just feel like I keep going round in circles. It's easy enough to do with it myself. I do get myself out the depression zone. It just sometimes takes a little bit longer.

Yeah, I can't talk. I don't like talking about it. I don't want to talk about it. It will just keep coming back and keep coming back.

- Q. When you were growing up, how did your hepatitis Cdiagnosis affect your career aspirations?
 - A. When I was younger I had trials for a professional club. I was told I couldn't play because of it so that was knocked on the head straight away, so that was one of my dreams gone.

The biggest dream I had was to join the army. My father did it, my grandfather did it, and from a young age it was all about protect the Queen and country and then at the age of 16 I went to my local recruitment centre, did all the tests in the recruitment centre and then the question came up about medical history. It was spoke about having hep C and

to me and said, "No, you've still thought antibodies
in your system. You've still got liver cirrhosis.
You still can't join".

So, again, it's still taken me back and I still, like I say, I can't get over it.

Q. You said in your statement that:

"The hepatitis C just takes everything away from me. It brings on a burden and rips away all my aspirations."

- A. It has done. It still does and to this day I've told you my biggest dream that was taken away, football was taken away. I grew up with football. I couldn't do it. There isn't anything it lets you do. Police force, couldn't join that; couldn't be a paramedic; I just couldn't do anything to help anybody in a career path of going out to help people, I couldn't do. They limited you what you could do from a young age and it's just not fair.
- Q. You worked for a number of years as a train conductor
 and had difficulties managing that. You underwent
 performance management on a number of occasions. What
 happened in relation to the performance management?
 - A. Getting up late for work because I was tired. They're not the best of shifts in the world but it was something I enjoyed doing so I plodded on. I tried

1 but the last five years of being a train conductor it 1 2 2 got worse. I became ill. I had many times off 3 3 because of having treatment and every time I went back 4 I would be staged to the point where I was stage 4 at 4 5 least three times, which is normally instant 5 6 dismissal. Every time they wanted to do that they 6 7 7 said they couldn't do it because I were covered by the 8 8 Disability Act. Then all of a sudden they found a way 9 9 to dismiss me. 10 10 **Q.** You've moved on now and work as a warehouseman. 11 A. Mm-hm. 11 12 Q. How is that? 12 13 13 A. It's boring. It's not what I want to do. It feels 14 like it's the best I can do. 14 15 15 Q. Because it's 9 until 5? 16 A. Yes. It's a little bit easier on lifestyle but I'm 16 17 better than that and I just feel education-wise 17 18 because of the time and length I had off in school 18 first. 19 I never learnt what I could have. I'm not stupid. 19 20 I am actually quite clever but I've got nothing to 20 21 21 show for it. I've got -- my GCSEs weren't great 22 because of time off school, so I don't feel like 22 23 I could fill my potential in any role or whatever 23 24 I want to do. Now I'm stuck in a warehouse not being 24 25 25 able to do what I wanted to do. 21 1 physically fit but there are plenty out there that 1 2 have passed away, that are more ill than I am. 2 doing? 3 The whole situation should never have been 3 4 allowed in the first place. I believe they knew about 4 5 it and I believe that they've allowed people to suffer 5 6 6 for so long in a worse way than I have and it's wrong. 7 7 Q. Working on the farm? I just want to say I'm grateful, especially for 8 the campaigners for getting us into this situation 8 A. Yes. 9 where we are now and actually can give our stories 9 10 across, and that's pretty much it. 10 11 SIR BRIAN LANGSTAFF: Thank you very much indeed for 11 12 coming to tell us what happened to you from getting 12 13 13 hepatitis C at such a young age. Thank you very much. 14 14 A. Thank you. **SIR BRIAN LANGSTAFF:** We will take a break until 11.05. 15 15 MS FRASER BUTLIN: Thank you, sir. 16 16 17 17 (10.34 am) 18 (A short break) 18 19 19 (11.07 am) 20 20 **SIR BRIAN LANGSTAFF:** Our next witness is Courtenay, is 21 21 22 MS FRASER BUTLIN: That's correct, sir. 22 platelets? 23 COURTENAY HILDYARD, sworn 23 A. Yes. 24 Questioned by MS FRASER BUTLIN 24 25 25 **Q.** Courtenay, when you were a child you were very active

20 June 2019 Yeah, no, I don't want to work in a warehouse but I've got children. I don't have a choice. Q. In terms of your financial situation, you've received some payments from the Skipton Fund, from Caxton and from the EIBSS. What are your views of the process involved with those funds? A. Well, I've had -- they've been quick. They're not easy. I feel like I've got to explain and I've got to beg for any form of help. Early on I never asked for anything. I didn't want to go through the process. I know plenty of people that have gone through the process and it was a nightmare. So I didn't want to do it. I didn't want to have to beg for help but once you are on treatment you're out of work because of being on treatment. You've got next to no money because of it you need the help and it feels like they don't want to help, not without you having to beg them They want to know why you want it, how much you're earning and it's not right. I shouldn't need to beg for help when I've been put in this situation in the first place. Yes, it's just not right. Q. Those are the questions I have for you. Is there anything else you would like to say? **A.** See, I think I'm one of the lucky ones. I'm actually 22 and adventurous. What kinds of things did you enjoy **A.** A lived in the country so we had animals and I guess running around doing stuff and climbing trees and the usual things that youngsters do in the countryside,

working on farms and things.

Q. You were known as a bleeder but did you have very many problems with bleeding as a youngster?

A. I think I tended to sort of the dismiss it over the years but I think in hindsight it did affect me quite a lot and I think really given the time that I grew up I'm not guite sure how my parents coped.

I mean, I suffered a lot from nose bleeds. It was a time, you know, before kitchen roll was available, before tissues were available, when we still had shiny loo roll and really towels were the only -- if you were bleeding for days it must have been a nightmare for them.

Q. In 1963, you were diagnosed with low adhesion

Q. Then in 1970 you had a dental extraction and bled quite significantly after that.

A. Yes. 1 1 mild haemophilia A as opposed to von Willebrand's? 2 2 Q. What were you diagnosed with after that dental **A.** Yes. I think that was because they knew that a woman 3 extraction in 1970? 3 was not just a carrier and could be a haemophiliac. 4 A. In 1970 they decided that I had von Willebrand's. 4 **Q.** In the 1960s, you had moved to Newcastle to work in 5 I had a low factor 8. I think it was called 5 the Pathology Department at the Royal Victoria 6 anti-haemophiliac factor then. They decided I wasn't 6 Infirmary and then moved on to the General Hospital. 7 7 haemophiliac. I had von Willebrand's, largely because A. 8 8 Q. Where you stayed working until 1973. my mother had been a bleeder and it was thought at 9 9 that time that a woman could only be a carrier and not Α. Yes. 10 suffer from haemophilia but, basically, I was 10 Q. You said earlier to me that you had a close friend who 11 a haemophiliac. That's why I was given a card to say worked in the haematology labs then. 11 12 I was suffering from von Willebrand's. 12 A. Yes. 13 13 Q. In that early stage it was diagnosed as Q. What were you aware of about blood and blood products 14 von Willebrand's? 14 through that friend? Yes. 15 15 A. I think it was not just through him, I think the very A. 16 Q. Could we have document 2344124, Paul, please. 16 fact that the Regional Blood Transfusion Service was 17 17 We can see bits a letter from September 1977 and on the two floors below the building so that the whole 18 in the middle paragraph it says that you had been 18 regional transfusions took place from there, they went 19 retested and your Factor VIII clotting activity is 19 out to collect blood. So it was very much part and 20 28 per cent, Factor VIII-related antigen 93 per cent 20 parcel of the whole process, but I think we were quite 21 21 and platelet aggregation with ristocetin is normal: proud of the fact that it was a voluntary service and 22 "These results exclude classical 22 we were I think quite smug, in fact, I think, that we 23 von Willebrand's disease and show he has mild 23 were sort of like a world leader in the ethics of 24 24 haemophilia A." blood collection and donor. 25 25 So at this stage in 1977 you were diagnosed with Q. You said earlier that you were -- there was a sense in 25 26 1 the laboratory that you were smug about the British 1 discussions going on when you were in the labs in the 2 2 products. 1970s. 3 3 A. Yes, I think so. Things have changed so much now. A. I can just remember one specific -- well, no, yes, 4 4 I think there was a feeling of belonging for I think it was part and parcel of that sort of feeling 5 communities and the very fact that collection teams 5 of, you know, at least we have a decent whatever the 6 6 went out to village halls and to factories and to States do and however good they are and however, you 7 7 Women's Institutes and people felt as though they were know, fiddly we are in the UK, at least our sort of 8 giving something back to it, I think it was quite a, 8 transfusion service is quite good and we're proud of 9 you know, a pride within the community, that there was 9 10 a contribution to. It was advertised as a gift of 10 Q. After you finished working in the hospital labs, you 11 life, all the transfusion vehicles were labelled with 11 worked in film and advertising. 12 that logo, so it was ... 12 A. Yes. 13 13 **Q.** And built up something of a property portfolio? **Q.** Did you ever have any conversations about American 14 14 A. Yes. products? 15 A. I can't remember specific conversations but I think it 15 Q. Then on 26 October 1981 you had an operation to remove

A. I can't remember specific conversations but I think it was generally known that it was because donors were paid I think that was the crucial thing and there was little control over the people who were donating blood, whereas in this country if you had had jaundice you couldn't give blood and I don't think that really applied in practice in the States. I think there was a sort of skid row clinics, that was a term that was used. It was as though it was a low quality product, you know, that it ...

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Q. You said earlier you remember those sorts of

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A. Yes.Q. Were you aware that you were given Factor VIII at this time?

If we can have document 2344011, please, Paul.

We can see in the middle of this letter dealing

with the operation, this was treated surgically under

the cover of infusions of Factor VIII, yes? Do you

25 A. Not at all. I mean, the first I knew of that was when

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a spermatocele.

remember that?

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- 1 I got my -- I obtained my hospital records, I think, 2 a year or so ago, a year and a half ago. 3
- **Q.** By this time you were married?
- 4 A. Yes.
- 5 Q. You had a photographic studio and contemporary art 6 gallery in Newcastle and you had bought your dream 7 house on the North York Moors?
- 8 A. Yes.
- 9 **Q.** You planned to settle there with your wife and have 10 a family?
- 11 A. Yes.
- 12 Q. In June 1983, you had an accident when you were roller 13 skating. Can you tell us about that?
- 14 A. I was asked by Newcastle Council, because of my 15 supposed skill at skating, to check out Jesmond Dene 16 as a proposed venue for a roller skating spectacular 17 and it's a very steep-sided slope and I managed to 18 find some excavation on one of the paths and had a bit 19 of an accident damaged my knee.
- 20 Q. You are very softly spoken. Can you speak up a little 21 bit more so everyone can hear you.
- 22 A. I do mumble. Sorry.
- 23 Q. So you had the roller skating accident, you injured 24 your knee and you went into the RVI in Newcastle?
- 25 A. Yes.

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- A. The consultant asked the sister who was there to 1 2 confirm that I hadn't been treated before, which 3 I don't know why, I mean, I had no knowledge of that 4 reason but it does stick in my mind.
- 5 Q. The nursing sister said you hadn't, which actually we 6 know is not right.
- 7 A. Yes.
- 8 Q. But your recollection of the conversation is the 9 nursing sister said, no, you hadn't received any 10 treatment.
- 11 A. Yes, she confirmed what he thought, that I had not 12 been treated before.
- 13 SIR BRIAN LANGSTAFF: By treated you mean what? Treated 14 with what?
- 15 A. With I assume blood products or, as I say, that 16 I wasn't really -- I mean, you're in pain and stuff. 17 You don't take conversation but they just stick in my 18 mind. They were her words, that she assured him that 19 I had not been treated before.
- 20 SIR BRIAN LANGSTAFF: So in the context that had to relate 21 to blood products.
- 22 A. I assume, yes.
- 23 MS FRASER BUTLIN: Please can we have document 2344004, 24 please.

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25 If we can turn it round we can see you were

- **Q.** And what happened?
- 2 A. Well, I wanted -- all I said I needed was sort of bed 3 rest and, you know, a bag of -- not a bag of peas but 4 frozen compress because I was in a lot of pain, my leg 5 was totally stiff. I had guite a large swelling and 6 they kept me in and treated me. 7

Initially they thought, perhaps, I had an infection, even though I was convinced it was a bleed. a joint bleed and they took me to theatre to do an investigation and it turned out that it wasn't an infection. It was a bleed.

- Q. At one point you had a conversation with a consultant?
- 13 A. Yes, I didn't want any blood products. I was quite 14 adamant about that because I think that that was part 15 of my philosophy. I think blood is quite a precious 16 thing and there's always an element of risk with blood 17 transfusions and I felt it had no application and 18 I refused any blood products.

The consultant assured me that it was perfectly safe and on that basis I think I thought that it was -- I knew there was a new chemical on the market that had coagulant properties which I now know as DDAVP and I assumed that's what I was getting.

Q. Can you tell us anything else about that conversation just before you were given the product.

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- 1 given cryoprecipitate at 1500 hours?
- 2 A. Yes.
- 3 Q. You think you might also have received Factor VIII but 4 it's not entirely clear whether that was the position 5 or whether you only received cryoprecipitate at that 6 time.
- 7 A. Yes.
- Q. Although you've gone through your records and we've 8 9 gone through your records we can't track exactly what 10 you received at that time.
- 11 A. Yes.
- 12 Q. You underwent the surgery to the knee to exclude 13 infection and you were then discharged and went on 14 holiday to Portugal with your leg in a split, in 15 a cast.
- 16 A. Yes.

- **Q.** What happened while you were out there?
- 18 A. Well, I think basically I spoilt everybody's holiday 19 I was such a misery and I was not well. I was sick 20 and I turned yellow fairly early on. It was obviously 21 something amiss. We were there for three weeks. 22 By the time we came back to the UK, largely my colour 23 had started to return to normal, so really they didn't
- 24 see that much evidence of my jaundice.
- 25 **Q.** But you are clear that while you were in Portugal you

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- 1 had been very unwell and had gone yellow.
- 2 A. Yes, absolutely.
- 3 Q. When you got home you went to the hospital.
- 4 A. Yes.

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- 5 Q. What did they say?
- 6 A. They assumed that it was because of my treatment and 7 I assumed that it was because of cryoprecipitate, that 8 I'd received that.
- 9 Q. In terms of what they said to you, they confirmed it 10 was non-A non-B hepatitis?
- 11 **A.** Yes, that's what they called it then, yes.
- 12 **Q.** What were you told about the long-term prognosis.
- 13 A. I was really concerned because I had a pretty active 14 job and I was very much committed to it and I was told 15 I would make a complete recovery. In fact, I couldn't 16 work for a year. I was not good.

Within that year, the -- my bank actually considered trying to make me bankrupt, having described me as a rising star the year before. So that was a bit of a problem. But I assumed from what they told me that I would make a complete recovery and I think, you know, the jaundice and the hepatitis was considered to be relatively minor or I assumed, that's the impression I was given, that wouldn't have a long-term effect.

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1 and it was in a way incidental. It didn't have 2 a great deal of meaning. I was supposed to sign in 3 with Professor Savage at St Thomas' but never did 4 because, as I say, I had no need to so I never really 5 moved on from the RVI in Newcastle to the London 6 hospital, so I think to a large extent they lost touch 7 with me.

- 8 Q. Had you been told you were being tested for HTLV3?
- 9 A. No, no, no, not at all, no.
- 10 Q. By about 1985, it had become more clear to you and 11 your wife that the hepatitis was more serious than you 12 had understood.
 - A. I don't think -- I was just not well. I mean, we knew that there was something amiss and I was not -- I just didn't feel good at all. I think that continued and there was nobody who said yes, this is what it is and that's, you know, to be expected. We had no communication. It was only much later in '93 or so when I collapsed that my GP started to look at things with some enthusiasm.
- 21 Q. Sadly, while you were in London, your wife was 22 pregnant?
- 23 A. Yes.
- 24 Q. And she lost the baby when she was knocked over in 25 a tube station?

- Q. You've said in your statement that the consultant assured you that you would make a complete recovery and would have no further problems.
- 4 A. Yes.
- 5 Q. But, as you say, you were unwell for about a year and 6 things with your business were going horribly wrong.
- 7 A. Yes, largely -- well, in fact, everything fell apart 8 basically, the gallery, the studio, because 9 I obviously was the driving force behind it and from 10 day 1 it was just impossible to work at all.
- 11 Q. You and your wife decided to return to London --
- 12 A. Mmm.
- 13 **Q.** -- in about 1985?
- 14 A. Before that probably, '84/'83, the end of '83, '84.
- 15 Then in about 1985 you received a letter to say you 16 were negative for HTLV3?
- 17 A. Yes.

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- **Q.** What did you understand that to be about?
- 19 A. Well, at first we didn't really know. I think we 20 assumed it was HIV but that was -- it was all sort of 21 new, a new area that we new nothing at all about. We 22 just assumed that's what it meant.
 - I was out of touch with the haemophilia department. I was working seven days, seven nights a week, whatever, trying to get back to where we were

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- 1 A. Yes.
- 2 Q. We have a statement from your wife and we have her 3 permission to discuss it with you. She said in her 4 statement that once you both realised the dreadful 5 implications of hepatitis C you felt it was 6 irresponsible to try and have another baby, so she 7 says she's been robbed of any chance of a family life. 8

Was that something you discussed together?

9 A. I don't think so. I think we just really just sort 10 of, you know, bashed on together, worked together. We 11 closed our minds to options really. I think we had no 12 choice financially and I think it was felt that -- we 13 didn't know what the problem was. We knew that 14 I wasn't well, and because there was no guidance or 15 information, we really had nowhere else to go so we 16 just, I guess, just ploughed on with what we were 17 doing.

> I don't feel as though we had an option really to discuss that, financially. We were both working very hard to try and get back to where we'd been, some sort of stability.

Q. As you say, you were in London and you had managed to work again at Pinewood Studios. Your wife was working but you continued to feel unwell. Can you tell us a little bit more about exactly how you were feeling?

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- **A.** Working in filming you start work very early, you work late, and it was an immense struggle. As I say, without any guidance we just knew something was amiss and it was a permanent problem and eventually I did collapse. Well, I got out of the business because I realised it was too much for me and it was just quite unrealistic to continue doing what I was doing.
- 8 **Q.** As you say you collapsed in 1993.
- A. Yes, that was after I set up as a photographers' agent and it was just beginning to make sense when I did eventually collapse in '93 and went to see my GP in 12 London.
- 13 **Q.** What happened then?
- 14 A. She looked at my records and decided there was still 15 a question mark about the hepatitis and instigated 16 some further investigations at the Royal Free.
- 17 **Q.** Your GP had gone back through your records and seen 18 that you had had periodic tests is the '80s for liver 19 function?
- 20 A. Yes.

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- 21 **Q.** And they had been slowly increasing over time?
- 22 A. Yeah, I didn't know that. I think in a way that was 23 a bit remiss of the people who treated me because 24 I think that was an indication that something was 25 changing, was not quite in keeping with what they had

1 hindsight really silly.

- 2 Q. Because you were trying to sort out the financial mess 3 that had arisen from the Newcastle gallery and studio 4 from your --
 - A. We'd sold our property in Newcastle with a view to moving to London anyway where property was for some reason still very cheap where it started to move in Newcastle and the money we had we could have probably bought maybe two or three houses in Highbury Islington which were selling then for probably less than 20,000 each. I think we sold up for somewhere close to 100,000 in the end and that was the plan and then we delayed things because Ann finished her college and then of course illness changed all that.
 - Q. So you're in London trying to recoup --
- 16 A. Yes.

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- 17 Q. -- what's gone wrong and 1993 you have collapsed. 18 You were referred to the hepatology department 19 in London and in 1994 started on interferon treatment 20 for six months.
- 21 A. Yes.
- 22 Q. What was that like for you?
 - A. We'd been burgled at the house so I decided to go there whilst I was on treatment in order at least to sort of man the barricades, as it were, but initially

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- 1 told us. I think initially if we had been given any 2 words of warning as -- even if they didn't know what 3 the future held, if they had said, "Actually, we don't 4 know what the prognosis is. Perhaps you should be 5 a little bit more careful as to what you are doing to 6 do", I think we would have just stayed put in 7 Newcastle, which I think would have been a totally 8 different story.
 - Q. You said you feel that if you had had any inkling that there was a major issue or a possible major issue you simply wouldn't have uprooted down to London?
 - A. Not at all, no. I mean, we were perhaps a bit cavalier I think but not stupid. You know, we were perfectly capable of making things work there. We had property and Ann had a perfectly good job. It was not a problem. I think it was just trying to go back to therefore we were. I knew I could earn more money doing what we did do, in theory, than treading water.

I think there's a degree of, I don't know if any illness, but there's a degree of lunacy takes over when you're still driven to get back to where you were without having all the same abilities that you had before and certainly without the mental -- not strength but understanding and I think it makes it difficult. I'm pretty sure I did things that were in

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1 stayed in London and interferon had such a -- well, 2 I think it just changes your whole personality. 3 I became almost a threat to man and beast really. 4 I was very difficult to live with and we separated on 5 that basis, that I would be in the north and Ann was 6 in London. But that seemed to justify my being there, 7 that at least I felt I was doing something whilst

I was on treatment.

But it's an unbelievable, for me anyway, it was an unbelievable treatment. I was totally deranged I suspect and had quite a bad accident while I was there. I think your reasoning powers disappear almost completely I think, really.

- Q. So at that stage during the treatment your wife and you separated.
- 16 A. Yes.
- 17 **Q.** You were back up in the north in a house up there 18 while she was in London.
- A. Yes. 19
- 20 **Q.** You have described the interferon treatment, as 21 a friend had said, that he wouldn't give interferon to 22 a dog.
 - A. Yes, he was a vet. But it did do one thing. It actually stopped me working, which probably --I probably don't think I would have had the sense to

(10) Pages 37 - 40

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- 1 do that. I think I'd have just tried to keep on
 2 working and eventually dropped and, I don't know,
 3 failed, so it did do one good thing but, as I say, it
 4 had quite serious consequences.
 - Q. You have said in your statement that it had a huge impact on your mental and physical faculties and you had to stop work. Financially, things became quite difficult?
- 9 **A.** Yes.

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- Q. You tried to activate various insurance policies you
 had in relation to your mortgage and bank loans. What
 happened with that?
- 13 A. Well, they decided that I think in benefit of 14 hindsight that the jaundice and hepatitis were 15 sufficiently serious that -- I'd assumed they weren't 16 and we hadn't mentioned them when we took out 17 insurance policies on mortgages and loans so they 18 refused to pay and that really was the start of 19 suddenly we had a fairly monstrous debt which we had 20 difficulty addressing.
- Q. Because when you signed those insurance policies you
 and your wife understood the situation to be that
 there would be no long-term effects of hepatitis?
- A. I think the whole status of hepatitis was played down.
 The fact that it was well known that there would be

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knowledge and attention, we were just left to our own devices and couldn't quite understand that and wrote to, as I say, every health minister I think since the early '80s. But of course we were assured they were being treated correctly.

You couldn't actually just access your medical notes then at all. It came in later, I think in the '90s, that you could through a solicitor, you could apply to see them in, say, in the GP's surgery, so it was difficult to find out what had happened.

- Q. Did you manage to obtain many records?
- 12 A. Only a year and a half ago when I obtained my records13 from Newcastle, yes.
- 14 **Q.** Your treatment in 1994 didn't clear the virus.

Can we have document 2344013, please, Paul. If we look at the main part of the letter, it's a letter from 2008. There's reference there to you drinking very little alcohol. When you got your records elsewhere in your notes there were references to significant alcohol intake. What is your view of how much alcohol you were actually drinking?

A. I'm not quite sure why they said I was drinking very little because I don't think I was drinking any, and certainly in terms of any excess that just wasn't true. I'm not quite sure where that came from.

- long-term effects I think which had been known for
 years and years and the effects were unknown but there
 would be some sort of consequence.
- Q. At the time you signed those insurance policies, you
 had also been told that your Factor VIII levels were
 normal?
- 7 **A.** Yes.
- Q. And you had been taken off the haemophilia register in about 1986?
- 10 A. Yes.
- Q. So when you signed those insurance policies you hadalso not had to declare anything about haemophilia?
- 13 A. Yes.
- 14 Q. Yet they were refused?
- 15 A. Yes.
- Q. Around this time, you tried to get hold of yourmedical records.
- 18 **A.** Yes.

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- 19 Q. Why was that?
- A. I think we really didn't know what had happened. We
 assumed it was an accident but I think had doubts
 about it and there was sort of -- I don't quite know
 what instigated those doubts but I think we felt we
 needed some sort of explanation.

We were very much on our own in terms of

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I did once ask my GP to say not to drink any
alcohol in the very early days because I felt it
didn't agree with me and stopped anyway but I was just
drinking wine in the evenings with a meal or whatever.
I've never been a boozer person, as it were.

- Q. But despite having stopped alcohol very early on, through your medical notes you found references to having been drinking more substantially.
- A. Yes, quite strangely. We never quite understood it until relatively recently when we heard it has been used by the doctors to -- as an add-on to their records for perhaps no reason.
- **Q.** If we see the main paragraph, it says:

"He has considered his options carefully. He is now adamant he doesn't want re-treatment with interferon under any circumstances."

Why was that?

A. Well, (1) it didn't work and it really -- I don't think I was the same after that ever, really. You know, six months' treatment and then probably two or three years to recover, it's time out of your life with no effect whatsoever. I think my viral count dropped six months after I had finished treatment a little bit but that was it, so I felt it wasn't worthwhile.

1 And in terms of the biopsy, I mean, I did have 2 a bleeding problem so it's a risky business. 3 I suspected it just wanted to be done for academic 4 purposes really. They had no treatment to offer even 5 if my cirrhosis had progressed, so I couldn't see the 6 point in it. 7 Q. So at that stage you were also declining a liver

- biopsy?
- 9 A. Yes.

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- 10 Q. And it says you were aware of the risks and decided 11 not to.
- 12 A. Yes.
- 13 Q. 2015 you did undergo treatment with Harvoni and 14 ribavirin?
- A. Yes. 15
- 16 Q. What was that like?
- 17 A. Relatively easy in comparison to interferon but still 18 had the same sort of flavour to it. That was --19 treatment was delayed because for -- I mean, I had an 20 accident. I had had an artery cut in my head and was 21 taken into hospital and I was treated for a pseudo 22 aneurysm and whilst doing that they found out that 23 I had a raised alpha-fetoprotein which is an 24 indication of cancerous growth.

So that was a bit of a problem, but they decided

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1 2015/early 2016?

2 A. Yes.

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- 3 Q. Until June last year?
- 4 A. Yes.
 - **Q.** Then what has happened since June last year?
 - A. I used to, when I see my consultant I would get a blood form and so I'd go in two weeks before my appointment so I had something to talk about rather than wait for the next time. So that was the end of June and I had a raised alfa theta protein again and my consultant asked for another CT scan to find out what was going on.

But for that and then the joint disciplinary meeting which took place, I think that happens every two weeks, and then to arrange to see the surgeon took something like four months, which was a little bit foolish, and then I couldn't be fitted in for an operation for another two months so it was six months from that.

I went to theatre in the end of December and I was anaesthetised and then they found out the tumour had moved from the body of the liver into the portal vein so they couldn't do anything, which was a bit disappointing.

Q. Then you said you had an excellent surgeon who

1 not to do anything until I had had treatment with 2 Harvoni, but treatment with Harvoni was delayed, I was 3 told by my consultant, because the NHS had asked NICE 4 not to release it because they didn't have the money 5 for it, so that put back everything for quite a long 6

- 7 Q. But when you did have the Harvoni it cleared the 8 virus?
- 9 A. Yes.
- 10 Q. But as you say, in 2015 you had also discovered that there were concerns, more serious concerns about your 11 12 liver?
- 13 A. Yes.

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- Q. Can you tell us what treatments you have undergone for
- 16 A. Initially, they did I think it was called TACE, where 17 they put a catheter into your liver and surround it 18 with chemicals, which is like a chemotherapy to try 19 and seal off the tumour and destroy it and then later 20 I had what they call an ablation, which is like they 21 insert a microwave rod really and burn it out and then -- that was relatively stable and I had a low 22 23 alpha-fetoprotein, the growth enzyme, and then that 24 started to rise again last year, last June.
 - Q. You were relatively stable from about the end of

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1 scrambled over Christmas.

- 2 A. Yes, people have been amazing. Yes, they managed to 3 get hold of some yttrium, radioactive yttrium beads, 4 which they installed in my liver in the January which 5 again the idea was that would destroy or hopefully to 6 destroy the tumour.
 - **Q.** What has happened since January?
 - A. I don't think it worked quite. It's still there, still active, and we're not quite sure what the next step is. I was booked in to see the oncologist but that took a month to even -- I phoned up after a month and there was -- my application was still there but they were reluctant to see me and they don't know what to do basically because I think the chemotherapy that's available is limited success, and I think within the framework of the NHS they've got such a narrow field of choice because of the regulations and availability of products, you know, where there's so much going on in the outside world.

It's supposedly being a very exciting time for cancer treatment so they say worldwide and nationwide but within the NHS of course they are so trapped within the system there's very little they can offer at the moment, so I really don't know what the next step is. I'm due to see the professor next week and

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- Q. You think that in terms of conventional medicinethere's not much more they can offer you?
 - A. Within the Health Service, from what I can gather where I am, yes. I think other places may be, there are other things on offer and certainly within probably what they call now integrative medicine there are lots of options which aren't part and parcel of the NHS regime.
- Q. For those who aren't so familiar with integrative
 medicine, it used to be called something like
 complementary medicine?
 - A. I think it's now accepted there's more to healing than what is offered within traditional medicine but I think they are looking at drugs that are out of licence, which are used for specific things. So basically they are very cheap to use and cocktails of these things rather than a specific drug which has been processed and there's lots of money to be made within the pharmaceutical industry.
 - Q. Emotionally, you've said in your statement that this has all taken a huge toll on you, but you find it very difficult to talk about.

Is there anything you want to say in relation to that? You are welcome not to?

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years of hepatitis.

I have a very dear friend who is a doctor who works in the field of integrative medicine and his philosophy was we keep my liver sufficiently healthy until such times as there was a cure, which we did by nutrition and diet and supplements I guess and that worked to a large extent and I think that that's, you know, we're back in that process.

- Q. In terms of the support that your wife's been providing for you over the years, she's also been supporting you financially but that's now got to a crunch point for both of you?
- A. Yes. I mean, she was supporting in terms of things like supplements and stuff like that. So I mean, very much separate in other fields but, no, she's an age and stage where she can't work and I'm supporting her. We still have property or she has property which at the moment is unable to get any benefit because she has two properties, one, the house we bought the year I was given hepatitis, we've never lived in, so that's been what was meant to be a dream has been something of a nightmare really.
- 23 **Q.** You are now trying to sell or you have tried over the years to sell all that?
 - **A.** Sell everything really, sell everything. I mean,

1 A. I think that I do feel actually guilty that I've 2 dragged, you know, the people around me who have loved 3 me into, you know, me doing almost like a headless 4 chicken, pursuing what I did do without any guidance 5 or advice as to -- nobody to say, well, hang on, 6 perhaps you should think about this, with 7 justification, perhaps, because we were always hoping 8 for some compensation and also for some truth, which 9 might have affected my decision.

So in a way I've just ploughed on over the years and dragged the people around me with me and I suspect that, you know, hindsight that's been fairly selfish -- not deliberate -- by the way it's been and I have some regrets on that.

- **Q.** Although you have been separated for 20 years your wife continues to support you.
- A. Yes. I mean, we decided to work together until something was resolved and, you know, as I say, other people in my life have been the same. I've been very lucky that I'm well loved and supported in terms of what I've been trying to do.

We have I suspect from now on yet another battle which will be part and parcel of my own research and, you know, into what there is to offer to try and survive really, which is what we did for 30 or so

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- I have come to my senses at last and realised that,
 you know, I can no longer do what I have been trying
 to do for years and, you know ...
 - Q. You are in the process of instigating insolvency proceedings?
- A. Yes.
 - Q. In terms of financial assistance from the funds, you have received stage 1 and stage 2 payments but relatively recently you also applied for some items, about six items.
- 11 **A.** Yes.
 - **Q.** What happened when you made that application?
- 13 A. To the NHS -- the EIBSS, yes. They just sent it back 14 saying I had to apply for each thing individually, 15 which is quite a long rigmarole and, you know, you 16 need three estimates for counselling or two elements, 17 and to show a copy of the certificate of the 18 qualification and even for things like car repairs you 19 have to show two estimates and so I'm not sure anybody 20 will apply for these because it's again another 21 hurdle, another -- which irritates me because in a way 22 the NHS is where we all started. There's a degree of 23 responsibility and I think it should be rather easier 24 than it has being made at the moment.
- 25 **Q.** You had applied for six things in one go.

A. Yes. I had to. 1 1 them 2 Q. And you were sent back six separate forms that you had 2 I think that, it's not a question -- the 3 to apply -- you were told you had to apply for 3 Government always says there's never been a scientific 4 individually one item per form. 4 consensus about the dangers of blood products but 5 A. Yes. I think -- well, not form, I think there was 5 I think they've asked the wrong scientists or 6 three double-sided forms for each application, so it's 6 scientists with vested interests primarily and I think 7 7 quite a process. that it was more a question of common sense. 8 Q. For you that's just been too overwhelming to try and 8 You know, if I was -- if somebody gave me blood, 9 9 it's a body fluid, you are exchanging blood, which 10 A. Yes. 10 carries all the diseases that any individual has, so 11 Q. Those are the questions I have for you. Is there 11 it's a dangerous process anyway and a risky business. 12 anything else you would like to say? 12 Once you start multiplying that in the case of 13 13 A. I'm sure there is. I'm really not very coherent. cryoprecipitate one or two donors but Factor VIII 14 I think that there are a couple of things about the 14 which can be countless thousands, it's something that 15 15 whole situation with blood and blood products and the average ten year old can work out quite happily. 16 I think it always concerned me that from my own it was 16 You don't need any scientific evidence at all and 17 17 I think that's something I find quite difficult how almost like a sort of worm's eye view of medicine and 18 18 state, that it was known that American products were people can -- how they could have even considered 19 19 inferior to the UK and I think the business of the UK importing it, but I guess it was about finance. There 20 products being considered to be a gift of life. 20 was -- somebody was going to make a lot of money when 21 21 Our community felt involved in that and I think they considered blood products as a commodity. 22 that they -- I find it -- I think if somebody had told 22 As I say, in my notes I wrote to the present 23 me when I was treated in 1983 that there was a chance 23 Secretary of Health recently having seen her on 24 24 that I'd been given or anybody had been given products television, who seemed to put blood products and 25 25 from the States, I don't think I would have believed medicines together which is exactly what must have 53 54 1 happened in the '70s, when you think suddenly they 1 that. So different notes say, yes, I was at risk and 2 both come under the same banner, that they've both 2 I gather my GP in London was informed in 2006 and 3 been tested to the same extent and it's just not true. 3 I was never informed of that. 4 4 I think that's, you know, things I find difficult to Q. But in July 1983 the bio-hazard marking is put on your 5 5 understand. Sorry. I'm probably rambling. blood test results and you weren't aware of that? 6 6 Q. I am just going to turn and see if Mr Williams who, as A. No. no idea what it means until I received those 7 you know, is representing you, has any points he 7 records. 8 wishes for me to raise. (Pause) 8 MS FRASER BUTLIN: Sir? 9 There's just one point that Mr Williams would 9 SIR BRIAN LANGSTAFF: I think we all have been 10 like me to raise. We can't put the documents on the 10 appreciative of your quietly reflective account which 11 screen but although you were told that there was no 11 I think rather understates what you have suffered over 12 12 long-term implications of the hepatitis C, in your the years. So can I thank you for myself for doing so 13 13 medical records in about 1983, July 1983, the blood and say that what you have said has been noted. 14 14 results, I think you were aware because you've seen A. Thank you very much. 15 them, have been stamped with the symbol and the note 15 SIR BRIAN LANGSTAFF: We will take a break there. I think "bio-hazard". 16 16 the way we will proceed is we will have time, 17 17 Were you aware of that at the time? I suspect, for a third witness before a slightly later 18 A. No, I have absolutely no idea. That logo which I've 18 lunch but it does depend upon the view which 19 19 Ms Richards has as to the time that the next witness never seen before and have no idea what it means. 20 20 There was always a problem, whether it was CJD risk will take.

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I don't know, there has always been a problem as to

whether I was at risk of CJD infection, I think

largely because whether I'd been treated with

Factor VIII or not was read by different people at

different times and there was a bit of confusion about

55 (14) Pages 53 - 56

MS RICHARDS: Sir, there are a significant number of

evidence will be short.

relevant documents that I will want to show during the

evidence of the third witness and so I don't think his

SIR BRIAN LANGSTAFF: Let's stick with the original plan

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1 then and have lunch now, a slightly early lunch. It 1 2 2 gives us all the more time and nobody should feel 3 3 pressed for time. I want to hear everything that your early years? 4 4 anyone would wish to say to me. 5 MS RICHARDS: Thank you, sir. 5 6 6 SIR BRIAN LANGSTAFF: So we will take lunch now and come 7 7 back at 1.10 and then we hear from? 8 MS RICHARDS: We will hear from Richard Warwick and then 8 9 9 after Richard's evidence we will hear from Mrs Q. 10 SIR BRIAN LANGSTAFF: Thank you. 10 11 11 (11.55 pm) 12 (Luncheon Adjournment) 12 13 13 (1.19 pm) 14 SIR BRIAN LANGSTAFF: First of all, let me say sorry for 14 15 15 having kept you waiting. It shouldn't have happened, out of hospital? 16 it did, I'm sorry. But we're now ready for our next 16 A. Mm-hm. 17 17 witness who wishes to be known as? 18 MS RICHARDS: Richard, sir. 18 ice packs? 19 **SIR BRIAN LANGSTAFF:** Richard, please. 19 A. Yes, that's right. 20 RICHARD WARWICK, sworn 20 21 Questioned by MS RICHARDS 21 22 **Q.** Richard, you have severe haemophilia A? 22 23 A. Yes. 23 24 Q. That was diagnosed at Hull Royal Infirmary when you 24 25 were about three years old? 25 57 1 there. They were extremely annoyed with Scarborough 1 2 hospital because they hadn't recognised the problem 2 3 and that was the first time I had cryo, yes, in hull. 3 to the cryo? 4 4 Q. You recalled in one of your statements a particular A. That's correct. 5 day where you had a very swollen leg? 5 6 6 A. Mm-hm. 7 Q. Your leg was effectively locked and you couldn't bend 7 8 it? 8 9 A. Yes. 9 10 Q. And a burly nurse sat on it? 10 11 A. This was -- I'd probably be six or seven. It was 11 12 a side room, actually, to the children's ward. They 12 13 laid me on a black leather covered table, two nurses 13 14 young nurses restrained my feet and one on my 14 shoulders. I know the nurse's name and she -- my leg 15 15 16 was locked at about, I don't know, 25/30 degrees and 16 17 17 she just slowly sat down on it and pushed down on it 18 18 and I'll never forget that day as long as I live. It 19 19 was just horrific. 20 20 Q. Now, in being treated with cryoprecipitate. You had A. Yes. 21 21 a severe reaction to it. 22 22 A. I used to mix and and administer it myself, yes. A. Yes. Normally, I would be treating -- I'd always get 23 reactions to cryo but I would be treated with Piriton 23 Q. If we just have a document up on screen please, Paul, 24 and other antihistamines to prevent reactions. At 24 a document from September 1975. It is 1592002.

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a later stage they actually gave me Piriton to start

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20 June 2019 **A.** Yes, two years and nine months. Q. How did your haemophilia affect your childhood and A. Before I was diagnosed I spent a great deal of time going up to my local hospital in Scarborough. They did not know what was wrong with me. The lumps and swellings I was getting all over my body were put down to infections. They tried all sorts of different methods to try and control them with drugs and the like but it was mainly splints and other medication that they tried but they had no idea that there was anything to do with haemophilia. **Q.** Then you described in your statement how you spent really the first eight years or so of your life in and **Q.** You spent periods of time in traction, in casts, with Q. You also received cryoprecipitate? **A.** In 1970 that was the first time, I think actually travelled to hull, my parents were extremely concerned and wanted a second opinion. I had a very large swelling on my right hand, got a golf ball sized and I was taken through to Hull and they gave me cryo 58 with before the Factor VIII -- before the cryo. Q. That was because of effectively an allergic reaction Q. At the age of about nine in the middle of 1975 you were referred to St James's University Hospital under the care of Dr Swinburne? A. Dr Elaine Swinburne, yes. **Q**. That is the point you were put on a home treatment program receiving Factor VIII products? A. Yes. It was Kryobulin. They decided it might be a good idea to start at home. My Dad used to go up to the path lab at Scarborough Pathology Department, pick it up from there and bring it back home and I started on Kryobulin home treatment in I think it was September '75 I first started having Kryobulin. **Q.** You are very softly spoken, Richard, so if you speak a little closer to the microphone there's a lot of people keen to hear your evidence. Q. You yourself learned how to administer it as well.

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We can see it's not a terribly clear document

but it's a letter dated 17 September 1975. It's from Dr Swinburne and it refers in the second line to your severe reactions to cryoprecipitate in spite of Piriton and her recommendation was that you would use freeze-dried preparation and she was enclosing a note to authorise the purchase of that since it could only be done by directors of the haemophilia unit and Kryobulin was the specific product that was there named.

You have said in your witness statement that about a year later when you were about to start at Treloars, which you started I think in September '76?

A. September '76, yes.

- Q. The then haematologist, Dr Peter Kirk, at Treloars wrote to Dr Swinburne saying that you should be restricted to Kryobulin?
- A. That's correct, yes.
 - **Q.** You remained at Treloars from September '76 to July 1982.

If we just have another document on screen 1592004, please.

We can see, Richard, perhaps most clearly from the bottom document a date stamp, 10 September 1976. So very soon after you would have been starting at Treloars and we can see there, writ large, the words

know what was going on.

They served us food separately and I think the serving — the stainless steel serving dishes, as I remember, oval serving dishes, they had red stickers on them and it just seemed extremely strange to us that they actually physically separate haemophiliac boys, it was all boys, it was a boys' school at the time, from all the other disabled children and it sort of shocked us.

- Q. You've also recalled in your statement an occasion where you and a number of others were taken ill.
- A. Mm-hm. That would be -- I think that was '81 glandular fever outbreak.
- Q. Before that, Richard. We will come on to what was thought to be a glandular fever outbreak, but you identified in your statement, it is either 1977, '78, '79, I don't think you were clear in your statement, just a period of time when a number of boys were ill and then not long after that are tests in your records for hepatitis B?
 - A. That's correct, yes.
- **Q.** Can you recall anything about the nature of the illness?
 - A. I think a few of us were taken into sick bay but I think it was just -- I think at the time was just

1 "hepatitis risk".

- 2 A. Yes.
 - **Q.** Was the existence of a risk of hepatitis something you or your parents were aware of at the time?
 - A. Not at all.

Q. You have described in one of your statements, Richard, an episode you remember from a relatively early stage at Treloars where boys with haemophilia and other children were separated in the dining hall.

What can you recall about that?

A. This would be, I would say, around 1977. I was actually in Burnham House. I remember that very distinctly. Our house master was Mr Green -- Cabbage. I remember that particular period at the lower school.

We were -- I can't exactly be totally specific whether it was the spring or the autumn of '78 but I know it was cold. We were queueing for dinner towards the dining hall as normal and as we were going in, turning into the door, there was someone that actually segregated the haemophiliacs from the other disabled children and there were two long tables, refectory tables, and we were seated, you know, around these two tables and all the place settings were laid out and the blue plates all had red stickers on them and we looked at each other very confused. We didn't

what we thought was some sort of weird infection, you know, that just happened with the haemophiliac boys.

Q. If we have up on screen 1592009, please, Paul.

We can see here a document from your Treloars medical records and column is headed "Serum hepatitis", and we can see if we look four lines down 18 January '79, positive; 30 April 1979, positive. That's in the antibody column.

Were you ever told that tests for what was being described then as serum hepatitis were being undertaken and what the results of those tests were?

- **A.** No. no.
 - Q. You have recorded in your statements that whilst you were at Treloars blood samples would be taken, perhaps every four weeks, sometimes as often as every two weeks?
 - A. Yes, there was one episode where in my notes there was two lots of samples were taken in one month but it was like clockwork I would say from September '76 through to '78 and '79 and it was basically every month and at the end of every term, it was usually Dr Aronstam he would send copies of all the test results and all my bleeds back to Dr Swinburne in Leeds and there were several covering letters to that effect.
 - **Q**. We will have a look at a couple of records one is, in

1 fact, a letter to your father 1592010 from 1 when you were at Treloars. 2 2 Dr Swinburne. This is 14 November '78. We can see We can see written on the top "no cryo", 3 3 presumably for the obvious reasons that you had reference in the second paragraph to discussing the 4 liver problem at some length. That is discussion that 4 a severe allergic reaction to cryoprecipitate and then has taken place between Dr Swinburne and Dr Aronstam 5 5 these words: 6 and then if we have on the next page -- sorry, 1592012 6 "Not to be included in any trial." 7 7 please, Paul, a letter dated 12 December '79. Do you know what that refers to or what, if any, 8 8 This is from Dr Wassef at Treloars to trials were being undertaken at Treloars? 9 9 Dr Swinburne and if we look in the last paragraph we A. No. 10 10 can see there reference to the SGOT being **Q.** You have observed in your statements, Richard, that 11 intermittently raised since January 1979. 11 you understood that the intention was that the 12 You have identified in your statement that there 12 Factor VIII products you had received would be 13 13 are liver enzyme tests, liver function tests, liver restricted to Kryobulin? 14 problems being identified. 14 A. Yes. There was specifically a letter that was sent, 15 15 A. Yes. I think -- yes, Dr Swinburne had conveyed with Altem, 16 Q. Do you know what was discussed with you or with your 16 Treloars and asking I think it was Dr Peter Kirk at 17 17 parents at the time about that? the time whether he would make sure that I stayed on 18 A. Nothing that I remember relates to those tests at all. 18 Kryobulin, and he wrote back to her and confirmed that 19 As far as I know SGOTs. I think that was the old name 19 that would be the case. And I think I was on 20 for ASTs, but all of my blood test results are 20 Kryobulin for -- I think it was virtually a whole year 21 21 actually headed SGOT along with other enzymes and, no, they kept me on Kryobulin and then they suddenly 22 I had no knowledge of that at all. 22 started treating me with Hemofil and then it was Koate 23 Q. If we just look at one further document, 1592005 and 23 and Factor VIII of course. Armour Factor VIII. 24 24 we look at the top of the document it is an Q. If we have up on screen please, Paul, 1592011. 25 25 orthopaedic chart for you during part of your time This is a letter from Dr Aronstam to 66 1 Dr Swinburne 23 April 1979 and we can see by this time 1 it would just be every morning, you know. 2 you receiving a range of different products as you 2 Q. There are again a number of time periods in your time 3 just described. Second paragraph: 3 at Treloars where we can see that and we'll just look 4 4 "Since Richard has been with us he has received at one merely by way of example. It's 1592023. These 5 a total of 208 transfusions. The material he has 5 are some treatment records for 1982. We can see the 6 6 received is broken down as follows: Kryobulin 80, product that you are receiving there is Factorate and 7 7 the treatment in every line is prophylaxis? Lister 73, Factorate 24, Hemofil 16, Koate 15." 8 Then there is reference in the last paragraph 8 A. Yes. 9 9 to: **Q.** Do you recall any discussion with you about why you 10 "... difficulties that we experience in 10 received so much treatment prophylactically? 11 supplying replacement material for 55 severe 11 A. No, I had two real target joints and that was my left 12 haemophiliacs", and Dr Aronstam's preference not to 12 knee and my right elbow, but I can't understand why 13 13 they would give me consecutive doses day after day, confine you to a single concentrate. 14 14 literally at 24-hour intervals for a whole month in It's right, isn't it, you spent some time going 15 through your records. They show you receiving a range 15 that case. I just don't understand it. 16 16 of different Factor VIII products? **Q.** Then if we look at one further document it's 1592013, 17 17 **A.** Huge range of commercial products, yes. please, Paul, this is a letter from Dr Swinburne to 18 Q. What your records also show is that you received 18 Dr Aronstam16 April 1980 and there's a reference in 19 19 significant quantities of Factor VIII on the second paragraph to you having mild symptoms with 20 20 a prophylactic basis. lister Factor VIII and then in the last paragraph 21 A. They were crazy about prophylactics at Treloars. It 21 suggesting it might be safer to treat you with one of 22 was like every day. In many cases it would be come in 22 the proprietary brands, by which one assumes she meant 23 after breakfast and go in to the sick bay out and 23 commercial brands of Factor VIII rather than the 24 either something would be laid out for us or we'd mix 24 Lister concentrate of Factor VIII? 25 25 our own but generally it would all be pre-prepared and A. Lister, that's the 8Y Elstree product, isn't it?

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1 Q. It is. 2 A. I always found that quite interesting because I read 3 a few entries like that: 4 "Has been having reactions to British-produced 5 Lister 8Y." 6 But, yes, I did have reactions to it. As I say 7 I just think it's ironic they changed, swapped me from 8 that to an American commercial product. 9 Q. You mentioned glandular fever and you have described 10 in your witness statement how in about July 1981 there 11 was what was suspected to be an outbreak of glandular 12 fever amongst some of the haemophiliac boys at 13 Treloars. 14 What do you recall? 15 A. It was summer '81 and I think there were probably 16 about 10 or 12 boys that I remember. We all sort of 17 had the same sort of high temperatures and swollen 18 lymph glands and all the rest of it, and they ran 19 tests on the boys. I think they did two 20 consecutive -- did one one month and then followed it 21 up I think it was July/August looking for the Epstein 22 Barr virus. I think in the notes and the comments the 23 doctors or doctor had written "looks like glandular 24 fever to me", and then second one just suspects 25 glandular fever, and it was about ten of us and it all 69 1 the reports received from haemophilia centres on the 2 patients who received the same batches of blood 3 products as the Cardiff and Bristol AIDS cases." 4 If we look at the next page please, Paul, 5 there's a histogram. It's the top histogram we need, 6 please, Paul, histogram 1, showing number of patients 7 having received commercial Factor VIII related to AIDS 8 case A/1 and the bottom right-hand corner of that 9 table, Richard, you have identified a batch number 10 there R6511. 11 A. Yes, that's Armour Factor VIII batch R651 -- yes, 12 13 Q. Then if we have up on screen please, Paul, document 14 1592051 we can see an entry from your Treloar notes 15 again, Richard, if we look at the third date down, 16 29 June 1978, and then we read across we see there 17 Factorate 817 and then the batch number R6511. 18 You received that again on a date in July. The 19 precise date is unclear but it is obviously early July 20 and then again on 4 July 1978, R6511, and then if we 21 look down at the Christmas term, the same page, the 22 second entry, 28 September 1978 and here you are 23 receiving it prophylactically Factorate from R6511.

1 happened just like that. 2 Q. We can look at the document you are referring to. 3 It's 1592017. 4 Turn it round please, Paul. 5 So there's reference to Paul Bunnel negative, so 6 that's the test, as you say, for the Epstein Barr 7 8 "Looks very like glandular fever", and then in 9 the other test says: 10 "Looks like early glandular fever to me." 11 This is 1981 and you've identified in your 12 witness statement that there is medical literature 13 that links glandular fever-type symptoms to early HIV 14 infection. 15 A. To early HIV infection, yes -- progression, yes. 16 Q. One of the other pieces of research work you have

Q. One of the other pieces of research work you have undertaken has been to identify a link in terms of the batch of Factor VIII that you received under a Public Health Laboratory report.

We will just look at those, please. 1592026. We can see here this is a document from The Public Health Laboratory. It is dated 10 September 1984 and it is headed:

"Current situation regarding AIDS.

"The attached table and histograms are based on

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find, you know, a comprehensive list of batch numbers right from 1976 up to I think it was late 1980. I did not have the full six years.

I went on to the Tainted Blood timeline and just did a key word search for batch numbers and I think half a dozen popped up. I thought let's have a game of bingo. Let's just sit down with them and just go through the pages and I did a double take. When I saw the match as I went through each column and I got to the end column, nothing, and Hemofil references and I got to the end column and I saw R6511, and it was like this between the notes, and I actually rang Tina at work and said, "When you come home I've got something to show you", but the thing that's always puzzled me is the date. This is 1978.

In that report that mentions the Cardiff and Bristol cases, it clearly suggests these batch numbers were related to AIDS cases and I still don't understand how it can be right but the date, the batch numbers are there, there's a letter prefix followed by a four-digit number and that is definitely Armour product.

Q. You know from some of the other records that you have shared with the Inquiry, amongst the many different types of product you were given during these years at

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A. I was absolutely fascinated by this. We got a copy of

my Treloar notes via Basingstoke. I was delighted to

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- Treloars the Armour product Factor VIII featuredlarge?
- 3 A. Yes, very large, yes.
- 4 Q. You started to have seizures in the summer of 1981,5 which was diagnosed as grand mal epilepsy?
- 6 **A.** Yes
 - **Q.** Is there a family history of epilepsy?
- 8 **A.** No.

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- Q. Again, you have identified in your witness statement
 from literature and research you have looked at an
 association between HIV infection and the onset of
 seizures.
 - A. Aggressive -- seizures can basically be an indication of aggressive -- early aggressive HIV infection, if it's not being treated and the virus level is getting incredibly high, with the HIV virus being able to cross the blood brain barrier I think it is in about 6 or 7 per cent of cases that people have developed HIV HTLV III go on to develop grand mal epilepsy or some different types of epilepsy and it can happen very quickly and -- yeah, I believe that's what happened to me. The year's right, you know. If those previous batch numbers are correct, you know, the time-frame just matches perfectly.
- 25 Q. You left Treloars in July 1982.

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He has had Factorate without problems in the past. Because of previous anaphylaxis reaction Richard should not receive Elstree Factor VIII."

First of all, Richard, what, if anything, do you recall about seeing that television programme and having a discussion with Dr Swinburne?

- A. As I remember, it revolved specifically around Hyland Laboratories, Travenol Labs, and their product, yes, their product Hemofil and I was just shocked. I was just shocked by it and I contacted -- I can't remember whether I telephoned her or wrote by letter. I was just very anxious about that, yes, asking for her advice really.
- Q. It would seem to follow from this letter but please correct if I'm wrong that you weren't given any warnings or any reason to be concerned about the Armour product?
- A. That's correct, yes.
- 19 Q. If we look next at 1592025, this is about a week
 20 later, 4 May 1983, it is a letter from Dr Swinburne to
 21 you saying this:

"We are carrying out blood tests on haemophiliacs to see if their immune reactions are normal. I know you are concerned about AIDS. If you would like to have a test please ring my department."

- A. Mm-hm.
- Q. And you returned to the full-time care at that pointof Dr Swinburne, in terms of your haemophilia care?
 - A. In Leeds, yes.
 - Q. If we have up on screen please 1592024, we can see a letter there dated 28 April 1983 from Dr Swinburne to Dr Balfour at Scarborough General Hospital and it says this:

"Dear Dr Balfour, this young man, like many other haemophiliacs, was severely upset by the recent Panorama programme on AIDS. After discussions with myself and his parents, he would like to treat himself with Armour Factor VIII instead of Hemofil. Both companies collect their plasma by plasmapheresis from known panels of donors. All are busily engaged in screening out homosexuals, et cetera. In addition Armour have a policy of collecting only from low hepatitis risk areas, which would correspond to low AIDS area. I have not made any recommendations to the Warwicks and, in fact, said that I was not aware of any significant differences between the products. No UK cases in haemophiliacs have been reported in spite of millions of units of millions of units of Factor VIII imported. Nevertheless in view of their concern I feel it would be wise to accede to their request.

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Do you recall either receiving the letter or what your response to the letter was?

- A. I probably -- well, obviously, I did receive the letter. I can't remember if I rang back, though. I don't know whether I followed it up. Yes, I think I did -- yes, I don't actually remember receiving the letter.
- Q. Have you as someone who is, obviously, very familiar with such records as you have, have you ever seen any documents that suggest that after this letter in May 1983 that some kind of blood test was done?
- 12 A. No, no.
 - Q. What we do have at 1592027 is a letter from the end of the following year 14 December 1984. I know again you are familiar with this, Richard. It is from Dr Swinburne, at the bottom of the letter it hasn't been copied, but Dr Swinburne to Dr Balfour and picking it up in the second paragraph:

"We've had discussions with Dr Tovey and Dr Hutchinson about heat treated Factor VIII and other meetings to be held next week. There is general agreement we should switch to heat treated Factor VIII as soon as possible. Heat treated Elstree material should be available from April. In the meantime we shall continue to use up stocks of Elstree and expect

deliveries to be uninterrupted. We also agreed not to purchase any more untreated commercial material. Patients who have already had part of a batch can continue to use it until new material is available."

Then there's a request to return any stocks of new batches, and then it says this in the last paragraph:

"We are taking samples of blood from patients prior to giving them their first dose of heat-treated material. At the moment there are no general facilities for testing HTLV3 so I am freezing the samples until they can be tested and compared with later samples. By that time, I hope we shall know how to interpret the results."

A. Yes.

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- 16 **Q.** What comment do you have on that, Richard?
 - A. Okay. She wrote to me regarding my concerns in I think it was May '83 --
- 19 Q. Yes.
 - A. -- the previous year. If I had indeed got back to her and went in for a test, based on this letter I wouldn't have been -- she wouldn't have been able to do the test. This was a year previously.

The end of this letter basically states "I've taken a sample", which you haven't got here, "I've

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1592028. It's a January '85 radioimmunoassay test for anti-HTLV III recorded as positive.

If we go on to 1592029, please, Paul, we have antibodies to HTLV III identified as present and that's dated 20 December 1985.

Then if we look at 1592030, please, if you look at the left-hand column, Richard, halfway down, HTLV III and then we have positive 23 January 1986.

- Q. So a number of reference and there are plenty of others that you have drawn to the Inquiry's attention in your records in 1985, 1986, 1987.

Were any of these test results drawn to your attention at the time?

- A. No, they were not.
- **Q.** Did you even know that tests were being undertaken other than that letter from Dr Swinburne and the sample that was going to be frozen?
- 19 A. Other than the one from 1984, I wasn't aware that 20 tests were being done.
- 21 Q. If we have up on screen 1592032, this is a letter from 22 1 December 1986 from Dr Balfour, consultant 23 haematologist at the Scarborough Hospital to a 24 consultant ophthalmic surgeon. First sentence: 25

1 taken a sample from Richard", but this was, you know, 2 a year later. Even at this point she couldn't do the 3

4 Q. You've got your UKHCDO records or some of them and they show, if we have up on screen please, Paul, 6 1592 -- I don't have the reference. It's probably 050 7 I suspect, Paul.

8 **SIR BRIAN LANGSTAFF:** Can I just raise one question. 9 There is a difference I think between the testing 10 proposed in 1983 which according to the letter was to 11 test your immune reactions, to see if your immune 12 reactions were normal. As I read the letter in 13 14 December 1984 it was to test for the presence of 14 HTLV3. There may be a difference.

15 MS RICHARDS: We now have your UKHCDO records. If you go 16 to ninth page please, Paul. We have here your HIV 17 data and the date that's given as the first positive 18 is 27 December 1984, although the sample date slightly 19 curiously appears to be three years later than that 20 but, in any event, that is what you have taken from 21 your records as being the first positive HTLV3 HIV 22 test.

- 23 A. That's correct.
- 24 Q. We've got elsewhere in your medical records, Richard, 25 a number of HTLV3 tests. We can look at them briefly.

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1 So doctors providing you with treatment in late 2 1986 knew that you were HTLV III positive?

3 A. Mm-hm.

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Q. If we have up on screen 1592033, we have an accident and Emergency Department record from December 1986 and someone has handwritten in capital letters across that "Positive to HTLV III", halfway down the page.

> So that's again 1986 and then last document for these purposes, 1592034. Here we have the date is halfway down the page, 29 January 1987, and again we have antibodies for HIV present down the bottom of the

So these various references now '86/87 were any of these passed on to you?

- 15 A. No.
- 16 Q. When did you find out and how did you find out that 17 you were HIV positive, Richard?
 - A. It was an appointment I had with my GP in Scarborough. It was sort of half routine and, as I remember, he wanted to chase up the quite recent number of severe epileptic attacks that I'd been having, going down in the street and just fitting in general, and he actually told me in -- it would be 1988 at that routine appointment, and I remember walking home and

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"This patient is a haemophiliac HTLV3 positive."

the journey seemed to take forever.

1 It was actually your Mum and Dad's house and we, 1 **Q.** We've got a couple of letters from about three years 2 2 you know, we talked about it there, didn't we. after that, 1991, 1592040, 047 please. Paul. 3 3 **Q.** You remember walking home to tell Tina, your fiancée, This is a letter to Dr McVerry from another 4 now your wife who sits beside you, of your diagnosis. 4 doctor and we can see in the second sentence: 5 One of the reasons you can pinpoint that to 1988 5 "I understand he has been known to be HIV 6 is that you and Tina started going out in late 1987? 6 positive for about five years but was only told the 7 7 A. That's correct, yes. diagnosis a year or 18 months ago." 8 Q. So you were told you were HIV positive in 1988 by your 8 The precise time-frames may be slightly out but 9 9 GP in a semi routine appointment? the delay there being recorded. 10 10 A. Yes. A. Yes. 11 Q. Having been told by your GP in those circumstances, do 11 Q. If we have 1592041 we have got a letter of the same 12 you think you were given adequate information about 12 date from Mr Brown, consultant physician, to the GP 13 the diagnosis? 13 and this was the same GP who had given you the 14 A. No, no. It was -- to be guite honest with you, 14 information and it says this: 15 15 I think -- I don't know whether he was my "He obviously feels very angry that Dr McVerry 16 haematologist or haematologists were scared or whether 16 withheld from him the information that he's HIV 17 17 they were just unsure, whether they felt guilty even positive and this anger continues", and that's how you 18 18 about divulging such information, especially as I was felt at the time? 19 seeing them for so long, you know, ten years and more. 19 A. Yeah, it not only put myself at risk but the people 20 I do not know, I don't know the mindset. 20 that I was around, including any potential girlfriends 21 There were all the obvious TV, you know, ad runs 21 and partners, you know. It's just -- you couldn't 22 at the time. It was very scary for me and for my 22 make it up, you really couldn't. 23 family but I don't understand why I wasn't actually --23 Q. I should say, Richard, we received your second 24 no-one actually sat me down and explained what it 24 statement yesterday morning so these matters have not 25 meant. 25 yet been explored with Dr McVerry but they have been 81 82 1 put to Dr McVerry and in the event a response is 1 Please let me know if you require any further 2 received that will be published. 2 information and I would then of course have to obtain 3 A. Okay. 3 Richard's permission for this." 4 Q. Just a couple of further documents 1592036, please. 4 So Dr McVerry didn't give very much if to 5 Again, these are part or the materials you have 5 Dr Aronstam. 6 6 supplied to the Inquiry, Richard, so I know you are A. Gave none. 7 7 Q. Had you been aware of this exchange of letters before familiar with this. This is a letter from Dr Aronstam 8 to Dr Swinburne June 1989: 8 you looked at your medical record? 9 "We're attempting to follow up the fortunes of 9 A. No, none whatsoever. 10 ex Treloar College boys who have been treated in our 10 Q. So it was not brought to your attention at the time? 11 haemophilia centre in the past. I would be grateful 11 A. 12 if you could provide me with some very simple 12 Q. In 1989, Tina became pregnant. information about these patients such as whether they 13 Yes. 13 Α. are well or not. Please feel free to use any code you 14 Q. What happened? 14 like in your reply and I can assure you of total 15 A. It was an unplanned accident, shall we say, and 15 16 confidentiality." 16 I think -- well, we both knew that something was amiss 17 Then we see Dr Swinburne's reaction at 17 and my wife knew pretty soon after. She did a home 18 18 testing kit and tested positive, of course, and she 1592037 -- sorry, Dr McVerry's reaction. So 19 19 Dr McVerry writes back to Dr Aronstam, 26 June 1989: went to see her doctor and we went up, you know, 20 20 "Dr Swinburne forwarded your letter to me things were discussed and we went up to I think it 21 regarding this man who was an ex Treloar college boy. 21 was -- was it your doctor at Scarborough or my doctor? 22 I am not really sure what information you would like." 22 TINA: I don't remember exactly. 23 Then it refers to your personal circumstances 23 A. It was decided in the situation, the current 24 and your general health. Then in the last paragraph: 24 situation, it was decided it would be -- well, we were 25 25 "I think that is all I should say at this time. advised in no uncertain terms not to go, for Tina not

1 to go ahead. 2 It was a very bad time. I was fitting a lot and 3 the prognosis, shall we say, wasn't very good at all. 4 I was living on borrowed time. I felt I was living on 5 borrowed time at that particular time of our lives. 6 So she had to have the termination, which was 7 incredibly tough. 8 **MS RICHARDS:** You put it in this way in your statement. 9 Richard, and I know you and Tina are willing for this 10 information to be shared: 11 "It was explained to us in very strong terms 12 that it would be best for Tina to abort her unborn 13 child as there was a high probability that the child 14 could be born HIV positive. The mortality rate of HIV 15 positive adults was very high and I had been lucky to 16 date but was living on borrowed time. I was expected 17 to live for up to two years following infection. 18 There was absolutely no treatment available for HIV at 19 the time. We were both heart broken." 20 Can I just ask you about the circumstances in 21 which you became aware that you had also been infected 22 with hepatitis C. We can look at a letter on screen 23 again, Richard. It is 1592038. 24 A. I hadn't been told at any point that -- certainly 25 not -- at no point I had been told -- I knew nothing 85 1 your GP that you had hepatitis C. 2 A. Yes. 3 **Q.** How physically did your hepatitis C and your HIV 4 infection affect you in the '80s and '90s? 5 A. Tiredness, lethargy, I've got some notes here which --6 this is a list. I'm sorry. Rashes, itching skin all 7 over, yeah, fatigue, lethargy, nausea, diarrhoea, that 8 sort of thing. You have probably heard it before but 9 it was not nice. 10 Q. You said in one of your statements the years '81 to 11 '87 were the worst. 12 A. That's mainly because of my epileptic attacks I was 13 having. They were just constant and they sort of form 14 a dominant part of that particular part of my life, 15 more than anything else, I think. Yes, it was very 16 difficult. Q. You were started in March 1991 on AZT for the HIV 17 18 infection. 19 A. Yes. 20 **Q.** What can you tell us about the side effects of that? 21 A. Horrific, awful. It was an anti -- I think it was an 22 anti-cancer drug, wasn't it. Yes, pretty bad. 23 Q. You have described in your statement dizziness, 24 nausea, diarrhoea, that it was dreadful is the way you 25 put it in probably a very understated way?

1 about non-A non-B, yeah. 2 **Q.** This is a letter, although we haven't got the bottom 3 of it copied, it is from Dr McVerry to Dr Balfour 4 28 February 1991 and the second paragraph refers to: 5 "Persistently abnormal liver function tests, 6 almost certainly means he has chronic non-A non-B 7 hepatitis." 8 Then it refers to interferon and says this: 9 "I rechecked Richard's liver function test today 10 and if these once again are abnormal then I may 11 suggest to him when I next see him that he has a liver 12 biopsy performed to see whether he is a suitable 13 candidate for interferon therapy or not. I did not 14 discuss this particular point with him when I saw him 15 today." 16 **A.** No, never offered a liver biopsy at that time. 17 Perhaps I dodged a bullet there in all fairness 18 because I think the standard interferon, it was three 19 injections a week, so yeah. 20 Q. You weren't told --21 A. No. 22 Q. -- in February 1991 that you almost certainly had 23

chronic non-A non-B hepatitis.

What you said in your witness statement was that you were told in perhaps April or May 1993 again by

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A. Yeah.

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And you continued on AZT from 1991 to January 1997.

A. Six years. I was also taking, shortly after I started AZT because I think I started on, I think it was, initially, I think it was five twice a day, which I think is 1,000, I think that was referenced in a previous thing that was up on screen, and then they reduced it down, I think, to 600 but they also I started having I think it's called cotrimoxazole sepsin. They introduced that.

> So I was getting -- before I started treatment I was getting like carpets of thrush inside my mouth. It was very difficult to eat and then didanosine, DDI. I had I think it was about six weeks after starting that, I had these incredibly swollen feet, all my feet were swollen up and up my calves. You couldn't actually see the gaps between my toes. They were that bad. That was very interesting, a very interesting reaction but they stopped me very quickly after that.

Then obviously various different -- over the years, various different types of HIV anti-retrovirals. I developed quite a lot of mutations to the virus over the years.

I've probably had about everything, but I'm now on a four combination drug therapy and touch wood it's

1 kept everything at bay. 1 And, of course, it is just bleed after bleed 2 2 Q. Even with that, you experience loss of appetite and after bleed after bleed and it's frightening because 3 3 sickness? you have no control over your muscles and it's 4 4 terrifying. You actually think your bones are going A. Oh, yes, yeah. 5 Q. That's after many, many years of having to go through 5 to break when they go past full extension and then snap back together. 6 different treatment regimes for HIV to which you 6 7 7 developed a multitude of side effects. **Q.** This is a permanent feature of your days and nights. 8 8 A. Yes. I mean, I think it's been getting worse, hasn't A. Yes. 9 9 Q. And resistance. 10 A. Yes. 10 TINA: Yes. 11 **Q.** You have also developed peripheral neuropathy? MS RICHARDS: In terms of hepatitis C treatment, you 11 12 A. That's -- I can only describe peripheral neuropathy, 12 embarked upon a course with pegylated interferon 13 13 at least the effects that I have from it, if you ribavirin November 2003 through to February 2004. 14 imagine strapping a couple of sparklers to your lower 14 A. Yes. 15 15 calves and just setting them off and it's that sharp Q. That was stopped because it was not having any effect. 16 fiery like pain in your feet and your lower legs and 16 A. I think it was stopped after the three or four months 17 17 your lower limbs, and over the last decade I would say I think they stopped it. There was absolutely no 18 I've been having another issue which I think is 18 impact whatsoever on the virus, on the viral load, and 19 related is to it, is that my legs will go into spasms 19 they decided rather than risk reducing the chances of 20 and my left leg is particularly bad. 20 a second round of treatment in the future they would 21 21 This happens every night and I can't straighten stop it then to give me the best chances at a later 22 my left leg but the contractions are so severe that my 22 date. 23 23 Q. What were the side effects of that course of leg goes from that (indicated) to past extension and 24 the ends of the bones snap together and that happens 24 treatment? 25 three times second. That is incredibly painful. 25 A. I became a different person. I was only on it for 12 89 1 weeks but I was awful to be with, wasn't I? 1 "Assessment for treatment of ribavirin and/or 2 2 interferon for patients with hepatitis C relative and I wanted to tear my skin off it was so bad, the 3 rashes, constant itching. I had a real problem with 3 absolute contraindications to treatment." 4 4 my scalp. It felt like my head was on fire, a burning Then about halfway down the list of bullet 5 5 sensation all the time on my scalp and it was -points is epilepsy? 6 6 I think it's psychologically as much as anything else. A. Yes. 7 7 **Q.** Then if we look at 1592047, these are some handwritten You couldn't lie down because it was so painful to lie 8 down if you were tired, but you were tired all the 8 notes in your medical records: 9 time. You had these flu symptoms all the time. 9 "Epilepsy interferon is CI [contraindicated] in 10 So even when you wanted to lie down you couldn't 10 epilepsy, i.e. manufacturers recommend it should not 11 because it was so painful. You covered vourself in 11 be used." 12 cream every -- twice a day bottles of Aveeno cream, 12 Then there's a discussion about it and then: 13 13 oatmeal cream. I put it all over myself or Tina would "HIV and medication. Patient's co-infected with 14 help putting it on me and it was awful. I feel so 14 HIV and HCV have a lower response rate than HCV 15 lucky I think for the first course I was only on it 15 infected patients." 16 16 for 12 weeks. Can you recall whether these issues about 17 17 **Q.** You said in your statement that those side effects in epilepsy or the co-infection of HIV were discussed 18 18 with you? that first course were severe and frightening. 19 19 A. They were frightening, yes. A. I think they were actually discussed at quite great 20 20 Q. You became a different person and you got very length. I think they were keen to get me on the 21 21 frustrated and angry and irritable. treatment and I think the risks at the time outweighed 22 22 the potential benefits of clearing the hep C. So A. Very irritable, yes. 23 Q. Again in the documents you have supplied to the 23 I think we mutually decided to go ahead and just keep 24 Inquiry, if we look first of all at 1592048. This 24 an eye on things. 25 25 Q. In October 2004 you received a letter in a form which says:

		The infecto
1		I think we've seen a number of times now warning of
2		the possible risk of vCJD.
3	A.	Yes.
4	Q.	Then you received letters, subsequently, in February
5		and July 2009. What can you recall about those letter
6		and what your reaction was?
7	A.	Do you know, at the time I thought here we go again.
8		There's only so much shall we say mud you can have
9		thrown at you, to be polite, before it stops sticking
10		and, yes, it was very worrying especially at the time
11		with all the news about vCJD but, you know, it was
12		just another thing, wasn't it. Just just waiting
13		for the next thing to drop through the letter box, you
14		know. What have they got for me this time, that sort
15	_	of thing.
16	Q.	You had a second course of treatment for hepatitis C
17	_	in June 2013?
18	Α.	Telaprevir, yeah.
19	Q.	Along with the pegylated interferon and ribavirin.
20		Again, that didn't reduce the viral load?
21	Α.	No.
22	Q.	And was terminated prematurely?
23 24	A. Q.	Yes, it was. You had similar side effects?
25	Q. Α.	Probably a bit worse. I think they were introducing
20	Λ.	93
		93
1		in comparison to the earlier treatments?
2	A.	No, there were the side effects to the ribavirin you
3	Λ.	may think but compared to the PEG interferon, which
4		made you feel like crap, you know, nothing like,
5		nothing like.
6	Q.	You had a follow-up test after six months and after
7		one year following the conclusion of that course of
8		treatment.
9		Have you had any follow up or monitoring of your
10		liver since then?
11	A.	Not since the first full year I've been clear, nothing
12		at all, which has puzzled me because you would have
13		thought they would have at least wanted to keep an eye
14		on you.
15	Q.	So no further fibroscans or ultrasounds?
16	Α.	No, nothing whatsoever.
17	Q.	Can I ask you about the psychological effects of the
18		infection, the co-infection with HIV and hepatitis C
19		and the treatment you received for it.
20	Α.	Specifically hepatitis C.
21	Q.	Or the HIV. Whichever you wish to answer.
22	A.	I think generally speaking, it's living with the
23		viruses and the drugs, you know, to fight them.
24 25		Obviously, there was the rashes, the feet and legs
25		swelling up. I'm sorry. Anxiety and something that

the drug as well called G-CSF, they added to that particular treatment as well, something to do with your white blood cells to try and boost those. Yes G-CSF I think it was, they tried that and it still didn't make any difference. **Q.** So having had that course of treatment unsuccessful and having to be terminated, you then had a fibroscan in late 2014? A. Yes. That showed advanced cirrhosis? Yeah. It was 24.8 I think it was, something like Α. Q. Exactly right. Your third and final course of treatment for the hepatitis C was August to November 2015? A. Yes. **Q.** What drug combination? A. That was Harvoni and ribavirin, I think, yes. That was a 12-week course. I think -- I found that pretty much plain sailing compared to the previous treatments, of course, the ribavirin interferon-based treatments, and although I think I'd, well, cleared the virus it wasn't detectable at eight weeks, they decided to carry on for the full twelve. Q. You didn't have appreciable side effects, at least not

hasn't been talked about is that when you are -- when you have HIV you're very wary about being out in public.

I basically -- I've been housebound for 20 years. I haven't been able to drive or get out of the house. So I haven't mixed with the general public at large but it's -- one thing that frightens me is if is have a seizure or fall down or trip and I cut myself and bleed out at the side of the street or whatever, that puts other people at risk and, of course, I have to divulge my status to them.

So I do have, you know, almost anxiety attacks, fear about mixing with people and also you probably noticed today I have real trouble sort of putting sentences together in either — in an unfamiliar environment or with people I haven seen or recognised, I'll just freeze like that. I don't think of it as a brain fog. As far as memories are concerned I think of it more as a wall with random bricks missing and through those gaps I can see memories.

But, yeah, I'll be speaking to someone fluidly and then it will just stop, just like shutters coming down, but there's dozens and dozens of side effects.

Q. Just picking up on the issues in relation to memory you've got problems with both long-term and short-term

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- 1 memory?
- 2 A. Yes.

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- 3 Q. You can't recall important dates and events such as 4 your honeymoon.
- 5 A. Yes, just no recollection of it. I know it was in '91 6 but I have no recollection of it at all. Nothing. 7 It's just gone, just gone.
- 8 **Q.** You talked in your statements about one of the worst 9 things being the feeling of stigma, the feeling of 10 being dirty?
 - A. Yes, with relation to the HIV/AIDS in the early days, good Christian people don't get AIDS, all that sort of thing, and it was just awful. You felt like you were the lowest of the low. They were grouping people in different parts of society, gay plague and all that, and it was just awful.

Again, I feel lucky that I wasn't, that we kept our heads down, you know, the whole family just didn't talk about it, didn't talk about it, even though there was the connection there with being haemophiliac but there was obviously that risk but it wasn't talked out about at all, not even close family, parents, used to talk about it.

- **Q.** You mentioned anxiety you also experienced depression?
- 25 A. Yes.

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where he lived and I think I'd spoken to him on the phone once and we joked and I asked him have you got the lurgy, meaning HIV, and we sort of laughed and joked about it, and that was the last time I spoke to him and it wasn't until quite a few years after we'd read -- we heard that he'd died and the reason he died was because his wife had had a heart condition and she died and he just stopped taking his HIV meds and consequently he died shortly afterwards.

I'll never forgive myself at not actually going to see him even though it was such a short distance away and just speaking to him because I feel as though I could have made the difference by visiting him in that time of need.

- Q. Richard, one of the observations you have made in your witness statement in terms of the psychological impact of the HIV medication, and you made this comment by reference to AZT, is that one of the dreadful things about having to take it was that it's a constant reminder that you have HIV.
- A. Yes. As all anti-retroviral drugs are, you know, you have to take them in my case twice a day but in the early days, we had a horrible instance when we went to collect drugs, didn't we, from the hospital, we had to go into a basement to collect the AZT retrovir. It

- Q. You have experienced guilt at being a survivor from Treloars?
- 3 A. Yes. I often ... I just think why me? Why am I still 4 here? What have I done differently? I just don't 5 understand why I'm still here. Was it different 6 Factor VIII? Was it different concentrates? Was it 7 different lifestyle? We're all in the same place, you 8 know. Okay, I was there a couple of years earlier 9 than others but, yeah, it's just guilt of losing all 10 those friends. I can name ten that I knew that are 11 iust gone. It's horrific. 12
 - **Q.** There's one Treloars boy, Andrew, who lived not far from you and you wanted to specifically mention him.
 - A. Yes. In 1976, my parents knew a lad that wasn't too far away, let's say 15 miles away from us, who had haemophilia and my Dad, my father and his father used to take it in terms to shuttle our respective sons to the train station for the long train journey down to King's Cross at the beginning of each term and it was alternate.

I think he was a couple of years ahead of me and when I left Treloars in '82, I think he would have already been back home and unbeknown to us when we shortly, about a year after we got married, we got a bungalow and it happened to be within a mile of

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1 2 just felt like dirt having to go down there together 3 and to specifically collect AZT. 4 They ran out of it I think on two occasions and 5

they had to get it restocked, didn't have it at the hospital, and this was when I was supposed to be taking it on a regular basis, but that was so demoralising. I felt awful, yes.

- Q. Let me ask you a little about the impact on your 10 family and your private and family life. You said in 11 12
- 13 **A.** Yes and then some. They supported me -- they saw what 14 I went through as a toddler, as a child, and not being 15 diagnosed for so long, and then after that it's just 16 been constant for them every step of the way. They 17 have been so supportive but it's been awful for my 18 extended family as well. They have had to go through 19 it all ... and you.
- 20 Q. You said you have an extremely loving and supportive 21 wife.
- 22 A. Yes and she's everything to me.
 - Q. A source of great sadness to you both has been that you haven't had children?
 - A. Yes.

was stored separately from normal medication and we

your statement that your parents had gone through

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Q. You've said in your statement that sperm washing and IVF became available too late for you.

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- **A.** Yes. There was a guy, I think a guy in Italy, they call him the mad doctor. He developed this technique for sperm washing and other medical professionals didn't like it at all, you know. He's putting people's lives at risk but he was giving people hope in Italy. I forget the guy's name but he was doing sperm washing, and it was a fair few years later when it became available in the UK, but it was just too late for us.
- Q. For the reasons you have explained, you and Tina decided to buy a small bungalow in a quiet area so that you could lead the very quiet very private life you described.
- A. We were terrified that, you know, if something had got into the community, if it had got spread about it would have been -- it would have made our lives hell so we just moved somewhere quite a way out of town, little two-bed bungalow, just one neighbour a fair distance away.

It's probably -- in hindsight it was probably a bad move because with me not being able to drive and Tina being, well, she works part-time because she has to look after me but I'm stuck in that one place most

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perhaps burbling on a bit and not stringing sentences together, I have constant pain in all my joints and I have to take some degree of analgesics to keep that bearable, and the side effects of all the other drugs as well for the epilepsy, which tends to slow you down, sodium valproate, the original epilepsy drugs I was taking -- I think I mentioned it -- Epanutin, they caused my gums to overgrow, I lost loads of teeth. It wasn't working. They tried me on gabapentin and all sorts of different things, but all these different combinations -- the combination of all these different cocktail of drugs, and the pain and the arthritis and not being able to walk properly, it just drags you so far down. And people say, "Oh, you're looking well today, Richard. How are you?" And you think okay, yeah, thanks for that compliment.

- Q. The financial impact of everything you have described has been immense --
- 19 A. Yes.
- 20 **Q.** -- because you have not been able to work.
 - A. Yes. Obviously, if you can't go out and work, that's bound to have a financial effect. It's not being able to provide on a personal level for my family, for my wife, and it really does play on your mind, you know. You're not able to provide what we need, and it's not

1 of the time and it might have been better that we did 2 try and get a bit nearer.

> Yes, it's just guiet. That's the main thing. It's quiet.

- Q. You had wanted to become an electronics or software engineer but the combination of HIV infection. epilepsy, severe haemophilia and the treatments you've undergone for both your infections have prevented
- A. The thing is what's really prevented me I can't entirely blame my career problems solely on the HIV hep C co-infection but combined with the epileptic attacks, which are quite frightening even to myself, I was a danger not only to myself but to others. In a workplace environment that would have been unacceptable, so it's been very difficult.

And these viruses have had such a profound effect on my life in general. They've defined -- my life's been defined by these viruses. The thing is I haven't known anything different. This is what people short of say to you how have these viruses affected your life? Well, if it's all you've known, you know, you haven't really known anything different, I mean, most of the time I'm in constant pain.

One of the reasons today I've sort of been

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1 all about the money either. It's the dignity. It's 2 the dignity of being able to have a productive -- lead 3 a productive life, be a productive member of society, 4 if you like, that you can contribute to society. 5

But it's, yeah, just being denied that really.

- **Q.** You have been unable to obtain life insurance and that distresses you because you can't provide for Tina in the event of your death.
- A. Yes. That applies I think across the board with anybody that's ...
- 11 Q. You have had limited forms of counselling offered to 12 you from time to time but nothing that you've wanted 13 to take up or thought would be helpful?
- 14 A. No. It's just not my thing, talking. I tend to have 15 a very regressive attitude. I keep everything in. 16 I sort of put a shell around myself, if you like, when 17 I'm talking to other people and I try and deal with my 18 own problems by doing things online for other people. 19 I mean, many in this room will know me for the work 20 that I do for the campaign. It's not for the campaign 21 per se, it's for actually giving people the 22 opportunity to see what they've done. If they've been 23 on radio or the TV or whatever or if there's some news 24 out, it's just for them, you know. It forms part of 25 the big jigsaw puzzle of people's voices and people's

- feelings and for it to be a part of history, if you like.
- **Q.** That, in addition to your family, is where you found your support, through that community?
- **A.** 100 per cent, yes. They are my extended family.
- **Q.** There's one specific treatment that you say would 7 alleviate some of your pain and that's hydrotherapy?
- **A.** Hydrotherapy for my joints.
- **Q.** Do you get that?

A. None of the Trusts seem to be interested in providing it. We will come on to those later.

But, no, it was so beneficial to me. I used to have it at Treloars College and it made such a difference. You know, it was more than a hot bath. You could -- you know, you could really -- it really eased your joints up, you do exercises, because I can't do much in the way of physical exercises because it just sets bleeds off. But that was really beneficial. We thought about sort of investing in a hot tub but it's not the same, it's not the same. But hydro is something that -- I think our nearest hydrotherapy pool is 30 miles away and I think there was one private BUPA hospital that could provide it. But that's something that I really miss, yes.

Q. You participated in the 1991 HIV litigation.

to find, chip in, quite a lot of money towards it because, of the three quotes that they require, they give you the -- they go along with the lowest quote always and, as it happens, when the guys had finished, shall we say, "fitting" the double glazing, it was rubbish. We had to get somebody else in to put the job right and then they went into liquidation just to add insult to injury. So that was our experience with Skipton Fund.

What else have we had from them? Not much, no. The MFT was brilliant when it first started up. They had these weekends -- I think they were once every two years -- something for the weekend, which is where partners could go as well, and men-only weekends. And they were -- it's respite care, nice hotels and the like, and that was -- I miss that because they stopped that within a few years. But that's where we could all get together and sort of share our experiences.

The process of getting help through the Trusts was, and I believe as is today, is just awful. So many hoops. They're so demeaning. It's just an awful, awful process. It makes you feel like a beggar.

Q. You have described it as intrusive, demoralising and monotonous in your statement.

- 1 A. Yes.
- 2 Q. You signed some form of waiver.
- 3 A. I think that was in Sheffield.
- **Q.** At that time in 1991, you were in fact hepatitis C positive but didn't know it?
 - A. I didn't know it, no.
 - Q. What's been your experience of the process of approaching the Trusts and schemes for financial assistance?
- **A.** Okay. Well, to start with, I think we only ever made one claim to the MFT and that was for money towards a car, a replacement car. We had an old Datsun Bluebird, a coupe with a dashing blue vinyl top and we went all over the place in it. But there was a problem that it had holes in the floor, particularly on the passenger side, and it was just getting dangerous. All we wanted was some money towards a replacement vehicle, not a new vehicle, and we were flatly refused on that. I think we ended up saving from buying a Nissan Bluebird as opposed to a Datsun Bluebird.

As far as The Skipton Fund goes, yes, I think we've had a couple of -- we had some, the usual cliche, double glazing, help with double glazing. We did get that. We had to chip in quite -- yes, we had

- A. Yes.
- Q. Richard, those are the questions I have for you. Is there anything you would like to add?
- A. Yes. Just a little summary.

Listening to the stories and testimonies of those infected and affected is both heart-breaking and humbling. I respect and honour the courage, dignity and bravery shown by our small and rapidly diminishing community. I have made a great many friends and acquaintances over the last 20 years whose circumstances vary widely and we all love and support each other.

But the one emotion that has been building and growing for over 30 years is that of anger. The rage I feel at being lied to, dismissed and pushed aside, when all we asked for is recognition of our plight and meaningful recompense for the lives we have had so cruelly stolen from us. Instead, we have been treated with disrespect, distain, and as if we are irrelevant, a group of people who shouldn't have expected any better because, by some, haemophiliacs are already disadvantaged and deemed lesser members of society, we should go away, not question our betters and die quietly.

The truth is having haemophilia does not prevent

1	a person having a successful career, a family life or	1	times.
2	prevent them from being a full and contributing member	2	I would also like to recognise and thank the
3	of society. There are extra challenges, especially	3	campaign groups and, in particular, the Tainted Blood
4	for severe haemophiliacs, but many disabilities and	4	community for their unending support and friendship.
5	conditions, whether genetic in nature or not, require	5	We have campaigned together, grieved together and
6	making adjustments without compromising a successful	6	shared stories together. You have all played a huge
7	life.	7	part in my life and helped me get through this.
8	However, being multiply infected absolutely	8	Finally, thank you to Sir Brian and the Inquiry
9	prevents a normal life being possible. Sufferers are	9	team for allowing me to tell my story.
10	consigned to the fringes of society, forever fearful	10	MS RICHARDS: I am going to ask Mr Snowden if there's
11	of public reaction, without support from life or	11	anything else if you just give me a moment. (Pause)
12	mortgage insurance and all the usual ways that people	12	There's nothing further, Richard.
13	can protect themselves and their families from	13	A. Think you.
14	hardship through being unable to work. Desperately	14	SIR BRIAN LANGSTAFF: There is one question which I would
15	sick, exhausted and terrified about the future, this	15	like to ask you, if I may. I'm sorry for asking
16	is the result of decisions made by those who were paid	16	a question after what you have just been saying but
17	to do better. In the comfort of their offices, they	17	it's this. I wonder if we can have 048 back, Paul.
18	pushed papers across desks, set aside the warnings and	18	If you go overleaf to the handwritten part, there
19	decided to gamble with people's lives for the goal of	19	should be a handwritten page.
20	saving money. It is hard to avoid the conclusion that	20	MS RICHARDS: That's 047, sir.
21	we were deemed expendable, collateral damage.	21	SIR BRIAN LANGSTAFF: 047, thank you. This is when you
22	I want to thank my loving supportive parents, my	22	remember there being discussions between yourself and
23	family and, above all, my wonderful wife who has been	23	the hospital. Under the heading "Epilepsy", the
24	my rock throughout this living nightmare. She has	24	second sentence:
25	steadfastly stood by me in the most difficult of	25	"The hospital takes responsibility for
	109		110
1	prescribing it."	1	SIR BRIAN LANGSTAFF: Our next witness will be known as
2	So here is the hospital about to give you	2	Ms Q. She is anonymous. Most of you I think probably
3	interferon which is counter-indicated and they are	3	all you were here this morning when I described what
4	saying or noting that they take responsibility for	4	anonymity meant so I don't need to go through that
5	prescribing it.	5	again, do I. Let me just however read the order.
6	Did they tell you what they meant by taking	6	The order is the name and address of witness
7	responsibility?	7	W1234, that's memorable (Ms Q to you and me) the
8	A. No.	8	surname of her husband who died and any other
9	SIR BRIAN LANGSTAFF: Do you remember them saying so?	9	identifying information such as the witness's image or
10	A. No.	10	a description of their appearance cannot be disclosed
11	SIR BRIAN LANGSTAFF: That's all that I have to ask.	11	or published in any form unless express permission is
12	Can I say that it has been deeply impressive to	12	given by me or by the solicitor to the Inquiry acting
13	me that someone who has spent a lot of his life	13	on my behalf.
14	wishing to be private, who knows that in public he may	14	Witness 1234 must be referred to only as "Ms Q".
15	struggle from time to time with bits of memory, is	15	The order remains in force for the duration of the
16	nonetheless prepared to come and share what is deeply	16	Inquiry and at all times thereafter, unless otherwise
17	personal, not only with those people who are here but	17	ordered. I may vary or revoke the order by making
18	with the world out there. It matters to me that you	18	a further order during the course of the Inquiry.
19	have done so. Thank you.	19	That's what I order.
	A. Yes, thank you.	20	Ms Q.
20 21	SIR BRIAN LANGSTAFF: 3.15.	20 21	ivis ପ. MS Q, sworn
22	MS RICHARDS: Thank you, sir.	21	Questioned by MS RICHARDS
23	(2.46 pm)	23	Q. Ms Q, you are here to give evidence about your late
23 24	(A short break)	23 24	husband.
	(A SHOLLDIEGK)	44	naobana.
25	(3.20 pm)	25	A. Yes.

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- 1 **Q.** And you are going to refer to him by his first name, 2 which was David?
- 3 A. Yes.
- 4 Q. That information will be public but the remainder of
- 5 information about your identity and his will not be.
- 6 A. Thank you.
- 7 **Q.** You have provided us with a photograph of David which
- 8 for obvious reasons won't go on the screen but you
- 9 provided it so that Sir Brian and I can see who he was
- 10 and that he was a real person, in your words.
- A. Yes. 11
- 12 **SIR BRIAN LANGSTAFF:** I have seen it. Thank you.
- 13 MS RICHARDS: You and David met at school at the age of
- 14 about 15 or 16.
- A. Yes, we did. 15
- 16 Q. You married in 1981.
- A. We did. 17
- 18 Q. He had haemophilia A but it was very mild.
- 19 A. Yes. He wasn't diagnosed properly until he was 16.
- 20 Q. When he was four years old, he had an accident and
- 21 fractured his skull and had surgery of some form of
- 22 another?
- 23 A. Yes, he had two craniotomies, one at the front of his
- 24 head and one at the back.
- 25 **Q.** He didn't require any treatment for his haemophilia.

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- David what the injection was? 1
- 2 A. No, not a clue.
- 3 Q. That was the first time he received Factor VIII and no
- 4 information was given?
- 5 A. None.
- 6 Q. And certainly no advice or warnings about any risk of
- 7
- 8 A. No.
- 9 Q. Was there any discussion with David about any
- 10 alternatives to Factor VIII?
- 11 A. None at all. no.
- 12 Q. He didn't see a haematologist again until 1981 --
- 13 A. That's right.
- Q. -- when he was seen because he was going to undergo 14 15 some form of eye surgery?
- 16 A. Yes.
- 17 **Q.** What happened then?
- 18 A. He wasn't seen by the haemophilia doctors at all. He
- 19 was admitted to Manchester Eye Hospital and I was at
- 20 work. When I went to visit him in the evening, he had
- 21 a drip up which, to be honest, put the fear of the
- 22 heavens in me. They'd given him some Factor VIII
- 23 which we found out later and he was infused again
- 24 whilst I was there and then he had to go every day for
- 25 two weeks afterwards to have more Factor VIII, which

- A. No, none at all.
- Q. He used to play rugby.
- 3 A. Yes, he was prop forward.
- 4 Q. So, as you say, he lived his childhood without
- 5 experiencing any difficulties in relation to his very
- 6 mild haemophilia.
 - A. None at all.
- 8 Q. In August of 1978, he was referred by a dentist to 9
- Manchester Royal Infirmary for a tooth extraction.
- 10 A. That's right. In 1976, he'd a rugby injury and he'd
 - had a very bad bruise to his thigh and the GP at the
- 12 time sent him to Manchester Royal to find out why he'd
- 13 bruised so badly and they had decided then that he was
- 14 haemophiliac. So by 1978 they weren't going to risk
- 15 a tooth extraction and they sent him to Manchester 16 Royal.
- 17 Q. You said in your statement at that stage of his life
- 18 he'd never even spoken to a haemophilia doctor?
- 19 A. No, never seen one or anything.
- 20 **Q.** Then what happened in terms of his treatment?
- 21 A. He went in, he had Factor VIII, nothing was discussed
- 22 or no information at all, had his tooth extraction,
- 23 was astonished that he hadn't bled and carried on as 24
- 25 Q. You have said in your statement no-one told you and

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- 1 seemed an awful lot because his factor level was
- 2 15 per cent.
- 3 **Q.** You have said in your statement he was given
- 4 Factor VIII on that occasion before and after the
- 5 surgery.
- 6 A. Yes.
- 7 Q. He was given it for a week in hospital afterwards.
- 8 A.
- 9 Q. And then he was given it -- he to go back --
- 10 Every day. Α.
- 11 **Q.** -- to the hospital for a further week, so the two
- 12 weeks afterwards.
- 13 A. Yes.

- 14 Q. Again, on that occasion was any advice, information or 15 warnings given about the risks of infection?
- 16 A. No, none.
 - **Q.** Or any discussion about alternatives?
- 18 A. No, no, I don't even think he even saw a haemophilia
- 19 doctor before he actually went down for surgery and
- 20 I think it was the house officer who was covering the
- 21 wards that gave him the Factor VIII.
- 22 **Q.** He had an immediate reaction on that occasionally on 23 returning home. What was the reaction?
- 24 A. Yes, he was really, really poorly. He was raging
- 25 fevers, passing -- they had thought he had a urine

- 1 infection because he had so much pain in his back and 2 his kidneys and he lost loads of weight. He lost at 3 least 2 stone in just a few weeks and, like I say, the 4 GP said it was a urine infection. His Mum, actually, 5 ironically said it's that damn stuff they gave him to 6 which I said no, no, no, it can't possibly have been.
- 8 Q. You observed that although David was a very mild 9 haemophiliac, there are references in his notes and 10 records to him being a moderate or moderately severe or severe haemophiliac. 11

How wrong was I?

12 A. Yes.

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- 13 **Q.** You have a fear that perhaps they'd mixed him up?
- 14 A. Yes.
- 15 **Q.** And he was simply given the treatment unnecessarily?
- 16 A. Yes, I do. I still to this day believe that it always 17 seemed a bit odd to me that he had so much treatment 18 post op and that they'd muddled him up with somebody 19 else and that's why he was given, you know, such 20 a long course of treatment.
- 21 Q. He wasn't seen again for his haemophilia between that 22 time and 1985.
- 23 A. No.
- 24 Then in August 1985 he received a letter saying he 25 might have been infected with HTLV III and to come and

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- 1 a hairbrush and don't have any children".
- 2 Q. What was your family situation at the time?
- 3 A. I had a four month old and a 20-month old.
- 4 Q. You were told that you and the children would have to 5 be tested.
- 6 A. Yes.
- Q. What was David told about prognosis? 7
- 8 A. Two years.
- 9 Q. What was he told in terms of coming back for 10 a follow-up appointment?
- 11 A. Turn up again in six months.
- 12 **Q.** What about telling other people?
- A. Oh, absolutely, do not tell anyone. They would count 13 14 the number of people that we told. You mustn't tell 15 a soul.
- 16 Q. I should say the concerns you have expressed about 17 those matters have been put to Dr Wensley and 18 a response is awaited and will be published in due 19 course if received, sir.

You were tested there and then?

21 A. Yes.

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- 22 Q. Was any counselling or discussion --
- 23 A. No.
- 24 -- taken place about it?
- 25 A. No. It was just like it was normal routine blood test

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- 1 be tested.
- 2 A. Yes.

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- 3 What can you recall about that?
- 4 **A.** I remember we were -- we'd not long since had a baby 5 and he showed me the letter and he said, you know,
- 6 what's HTLV III for a start, so I said I think it's.
 - you know, the AIDS virus, and he said, "Well, that
- 8 can't be. I've only had it, you know, once -- twice.
- 9 How can it be?" So I said, "Well, you'll have to go",
- 10 but I was I had the little ones so I couldn't go with
- 11 him, so he went to the hospital on his own and had the 12
 - blood test and came home.
- 13 **Q.** Then you got a letter?
- 14 A. Then we got a letter to say, "Come back, we've got the 15 results now".
- 16 **Q.** You went with him to that appointment?
- 17 A. Absolutely, yes.
- 18 Q. You saw Dr Wensley?
- 19 A. Yes.
- 20 Q. 30 August 1985?
- 21 A. Yes.
- 22 **Q.** What can you remember about that appointment?
- 23 A. We walked in, we sat down, he said it, "It looks like 24 we've given you the AIDS virus. Don't share your
- 25 toothbrushes, don't share a comb, don't share

- 1 that they did on everybody and that was it.
- 2 Q. Then an appointment was made for you to take the 3 children to Pendlebury Children's Hospital?
- 4 A. Yes.
- 5 Q. How that was that?
- 6 A. That was horrendous, having to hold down two small
- 7 children while they took blood from them, wondering
- 8 whether or not they had a life-threatening disease.
- 9 It was just awful.
- 10 Q. David phoned the hospital for the test results in 11 relation to the children and was told fortunately that
- 12 they were negative.
- 13 Α.
- 14 **Q.** He was also told your results over the phone.
- A. Yes, he was. 15
- 16 Q. Also negative?
- 17 A. Yes.
- 18 Q. But you've described a clear breach of 19 confidentiality.
- 20 A. Absolutely. That was my test result, not David's test 21 result. If, God forbid, if that test come back
- 22 positive, he would have been even more destroyed and
- 23 distraught than he was.
- 24 **Q**. You were advised by Dr Wensley to be retested every 25 six months but you declined, why was that?

- 1 A. Because he, David, gone through enough pain and enough 2 angst, worrying about the first lot of testing and 3 I just couldn't bear to have been tested every six 4 months because he would have known I'd been tested and 5 he would have wanted to know the results. So if
- 6 I wasn't tested I wouldn't have to tell him the 7 results.
- 8 **Q.** You were a young married couple with a very young 9 family. What was the impact on you and on David of 10 this news?
- 11 A. Well, we were thankful that I was negative and the 12 children were negative but for him it was just 13 destroying. Utterly destroying. He -- I remember 14 sitting -- he was sitting in the bath and I was, like 15 you do, sitting on the loo talking and he said, 16 "I just don't want to go on anymore".
- 17 Q. You have said in your statement he was already, at 18 that early stage, distraught.
- 19 **A.** Absolutely.
- 20 Q. A shadow of the man he used to be?
- 21 A. Yes.
- 22 Q. You weren't willing to put him through the possibility 23 of having to find out that he'd infected you?
- 24 That's right.
- 25 **Q.** You have expressed the belief in your witness

- 1 Q. And you've also identified from your consideration of 2 his records that he had been tested for hepatitis B?
- 3 A. Yes.
- 4 Q. You don't think he'd consented to that?
- 5 A. No, definitely not.
- 6 Q. Or knew anything about it?
- 7 A. No. In fact, hepatitis B had never, ever been 8 discussed with us.
- 9 Q. Now at this time David was working, we won't go into 10 precise details about his career because of the 11 anonymity, but he was working in a scientific
- 12 capacity. A. Yes.
- Q. In a job that he loved. 14
- A. Yes. 15

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- 16 **Q.** And as part of it he had to have blood tests every three months? 17
- 18 A. Yes.
- 19 Q. That gave rise to a dilemma for him?
- 20 A. Yes.
- 21 Q. What was that dilemma?
- 22 A. He was frightened that he couldn't disclose his
- 23 infection and he would put the nurses at risk taking
- 24 his blood. So he resigned from the job and took up --
- 25 and it was a well paid job with a very good prospect

- 1 statement that he might have been tested for purposes 2 of research.
- 3 A. Yes.
- 4 Q. At the time you wrote your statement, first of all, 5 what's the basis for that belief?
- 6 A. In the UKHCDO records his date of first positive is 7 a month previous to him being recalled. I don't know 8 where they've got that blood from but it must have 9 been stored and tested, so they knew he was positive 10 before they even sent the letter.
- 11 Q. You very recently obtained a document, I think it 12 arrived yesterday, from UKHCDO --
- 13 A. Yes.
- 14 **Q.** -- which -- and we haven't had time to get it scanned 15 and put on the system but it has a medical research 16 number in it; is that right?
- 17 A. Yes, it does, yes.
- 18 Q. What concerns you in particular about that?
- 19 A. When I've unravelled the codes on it, this is 20 a document that was produced ten months after he died,
- 21 a medical research document that was produced ten
- 22 months after he died. They were still trying to
- 23 research what was going on ten months after he died,
- 24 when they couldn't produce his medical records for the
- 25 coroner.

- 1 and a handsome pension and he gave -- he just couldn't 2 put them at risk, so he resigned and became
- 3 a salesman.
- 4 Q. He felt he couldn't tell them of his condition, the 5 nurses at work who take the bloods for the testing,
- 6 because of the stigma?
- 7 A. Absolutely.
- 8 Q. You have said in your statement this was the time of 9 the terrifying adverts on TV?
- 10 A. Yes, this was the tombstones time.
- 11 Q. You had been told at the point that he was given the 12 diagnosis not to tell anyone?
- 13 A. Yes.
- 14 Q. So he gave up the job he loved and took up a job 15 which, from what you said in your statement, he didn't 16 love?
- 17 A. He did it and he was very good at it but he didn't 18 enjoy it, like he had done being in the lab.
- 19 Q. It was a very tiring job his new sales job because it 20 involved an awful lot of travelling?
- 21 A. An awful lot of travel.
- 22 Q. At this point you went back to work a couple of nights 23 a week.
- 24 A. I was doing two nights a week, split nights, because 25 I didn't anybody to look after the children, so

1 I would stay up, you know, I'd do one night and then 2 I'd stay up with them, then I'd sleep the next night, 3 stay up with them and then work the following night. 4 Q. That was as a nurse? 5 A. As a nurse, yes. 6 Q. By September of the following year 1986, you described 7 him as a mere shell of the man you married. 8 A. Yes. Q. What can you tell us about how he was? 9 10 A. He was distant. He wouldn't talk about things. He 11 was distant with the children. He didn't want to hug 12 them or -- and he was terrified if they went in the 13 bathroom without him, you know, watching what they 14 were doing. He was just broken, really broken, 15 psychologically he was shattered. 16 **Q.** Mentally in bits, you described him in your statement. 17 A. Yes. 18 Q. At that stage it wasn't so much the physical 19 ill-health but the diagnosis itself and the fear that 20 was destroying him? 21 A. Yes, absolutely. 22 Q. By 1988, his CD4 count was beginning to drop. 23 A. Yes. We had an incident where we were -- David had 24 gone for his six monthly check-up and Dr Wensley sat 25 there and said that his CD4 count had become low and 125 1 because they thought it was that that had caused the 2 problem. He'd been put on antidepressants by this 3 time and they wanted to stop them because they thought 4 that would cause the liver problems and then they said 5 it might be non-A non-B at that time. 6 Q. His AZT was stopped and he was told he might need 7 a liver biopsy. 8 A. Yes. 9 Q. And indeed told that he would need Factor VIII. 10 A. Yes. 11 **Q.** What were you told about how he could obtain 12 Factor VIII? 13 A. They said that they had some. Obviously, he said no 14 to Factor VIII, it wasn't happening, and they said, 15 "Oh well, we've got this really high specification 16 stuff, this really high purity. We reserve it for children and if you want it we can't prescribe it so 17 18 it's £30,000". 19 Q. Something you simply couldn't afford? 20 21 Q. Then there was some rigmarole surrounding the biopsy

1 had he thought about going on the Concorde trial, to 2 which I said, "Hang on a minute, if he needs AZT, he 3 needs AZT. He doesn't need a trial where he could get 4 a placebo. He needs the drug", and he sort of looked 5 at me a bit shocked and then he said, "Oh right, well 6 we'll just do some more blood tests", and they kept us 7 waiting for hours and hours and the CD4 count came 8 back and he said, "Oh, miraculously, it's raised so we 9 don't need to worry about AZT". 10 Q. David did start on AZT the following year, 1989. 11 A. Yes. 12 **Q.** You said in your statement he initially tolerated that 13 reasonably well. 14 A. Yeah. I mean, you know, as Richard said, it's 15 a constant reminder every time you take it. 16 **Q.** But then he started to suffer abdominal pains, weight 17 loss, loss of appetite and depression. 18 A. Yes. 19 **Q.** There came a point in time at which his liver and 20 spleen were discovered to be enlarged? 21 A. Yes. 22 Q. And then in December 1990 he was told that he might 23 have contracted hepatitis C. 24 A. Yes, they went through a bit of a rigmarole to start 25 with. They blamed the AZT. They wanted to stop that 126 1 charge of the Haemophilia Centre and he -- between the 2 hepatologist and the Haemophilia Centre there was 3 a lot of hooing and hawing whether they could fit 4 everybody in. Anyway, the night before, 5.00 the 5 night before the biopsy, by which time you have 6 arranged childcare, a dog sitter, the whole thing, to 7 be told that it had been cancelled. I wasn't very 8 happy and I said, "How come it's cancelled and they 9 said that we haven't got a protocol for treating this 10 sort of patient". 11 Q. Do you know what was meant by that? 12 13 14 15 16

A. Well, I assume that he meant if David was positive they didn't know what they could do about it. But my thought was, well, if we haven't got a diagnosis why are we worrying about treatment when we don't know what the problem is.

> So I did threaten the consultant who then rang me back at 7.00 to say that the biopsy was on and everything would be well.

- **Q.** You said you would happily go to the hospital and blow up the lot of them. You were angry.
- 22 A. Oh very. I was absolutely furious.

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Q. It was after that liver biopsy that it was confirmed that David did indeed have chronic active hepatitis, hepatitis C?

a biopsy and by this time it was Dr Lucas was in 127

A. Yes, for a year they'd been saying that he needed

itself. You received a call to tell you it had been

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cancelled?

- 1 **A.** Yes. There was the ELISA tests around that time and it was positive for hepatitis C.
- Q. It was in early 1992 that David was then seen bya doctor called Dr McClindon?
- 5 **A.** Yes.
- Q. You said he was a doctor who finally sat down with youand told you everything you felt you needed to know.
- 8 A. Yeah, he was absolutely amazing. He sat us down, he
 9 went through everything. He went through -- he talked
 10 to us like we were adult human beings who could
 11 understand, you know, we weren't being treated like
 12 small children. He was just amazing, absolutely.
- Q. He told you that non-A non-B was now known as
 hepatitis C.
- 15 A. Yes.
- 16 Q. He was honest with you, that they were uncertain about17 the management of the condition.
- 18 A. Yes.
- Q. He told you of particular potential difficulties
 because of the combination of David's HIV and
 hepatitis C.
- 22 **A.** Yes.
- Q. Again, I think in that same year, David was started onSeptrin; is that right?
- 25 A. Yes, yes. He'd been on the AZT but the Haemophilia

- 1 Q. Do you think that was because of the HIV?
- 2 A. Yes, I think so.
- 3 Q. He then embarked upon interferon treatment in 1992.
- 4 **A.** Yes.
- 5 Q. Again, he was admitted to hospital for that --
- 6 A. Yes. he was.
- 7 **Q.** -- because of potential side effects.
- 8 A. Yes, because of the potential side effects they
 9 decided that they would take him in and he sat there
 10 for I think it was about 48 hours he was in and waited
 11 and waited for these dreadful side effects of which he
 12 had none and it wasn't until some distance down the
 13 line that he actually started getting the flu-like
- symptoms and all the other side effects that people
 get with interferon.
 Q. There was even some debate about whose responsi
- Q. There was even some debate about whose responsibility
 it was going to be to fund the treatment, the hospital
 or Trusts or the GP?
- A. Yes. Basically, they said that -- and I think this
 was going back to the liver biopsy, I think this was
 what was probably at the root of it. They didn't know
 who was going to pay and in the end we were asked to
 go and see our GP and ask our GP if they would pay for
 David's interferon.
- 25 Q. In 1993, David had another liver biopsy. This time he

Centre hadn't bothered to put him on any prophylaxis for pneumocystis carinii pneumonia, and it was practice to put them on prophylaxis at the same time as starting anti-retroviral drugs.

5 So by this time they had started doing joint 6 clinics with the HIV specialist and he started David 7 on Septrin -- they started David on Septrin. 8 Unfortunately, David was violently allergic to Septrin 9 he ended up with Stevens-Johnson syndrome, which is 10 where basically you shed all your mucus membranes, so 11 his mouth -- itchy rash everywhere, his mouth was 12 completely raw. He was in a mess.

- Q. He was admitted to hospital and you've described the
 nursing care at that time --
- 15 **A.** Dire.
- 16 **Q.** -- as appalling?
- 17 **A.** Yes, absolutely diabolical.
- 18 Q. In what way?
- A. He was hallucinating because his temperature was that high. He was left in a bed. He was given three cotton wool bobs and a bottle of calamine lotion to cover himself in calamine, but he couldn't reach his back. He wasn't helped to have a wash. He was in there it must have been nearly a week, never had a wash, nobody would go near him.

- 1 was given DDAVP.
 - A. Yes.
 - Q. You have said there that the treatment was an absolutedisgrace.
 - 5 **A.** Yes.
 - 6 Q. Again, in what way?
- 7 A. It's just, they can't -- the nurse that was giving the 8 DDAVP couldn't even set the drip rate on the IV. She 9 couldn't calculate how many drips a minute it was 10 supposed to run in over. She was supposed to be doing 11 observations every five minutes to start with but she 12 couldn't do that, so in the end I took over 13 administering -- well, running the drip and doing his 14 obs and making sure he was comfortable and then he 15 went down for the biopsy after that.
- Q. That biopsy confirmed that the interferon had not hadany effect?
- 18 A. No, no effect at all.
- Q. Did was also having to undergo various differentpermutations of medication for his HIV.
- 21 A. Yes.
- 22 Q. Some of which had a very bad effect on him?
- 23 **A.** Yes.
- 24 Q. What can you tell us about that?
- 25 A. He became really, really aggressive. For the first

- 1 time -- and he was a very proud man, a very -- a real 2 man's man, you know. He was quite old fashioned, the 3 woman's place was in the home, you know, preferably 4 tied to the kitchen, but he was very old fashioned about that and he -- I've lost my thread, I'm sorry. 5
 - Q. You said he became really aggressive.

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- 7 A. Yes, he'd never ever raised his hand to me but he did 8 then and one of the children became -- he lost his 9 temper with him and, you know, got hold of him.
- 10 Q. You've described that process of medication with all 11 these different drugs having to be taken at different 12 times and different intervals as an exhausting, 13 relentless process.
 - **A.** Yes. It was like being back in nursing doing a drug round but it was a drug round every hour because the combinations then were very difficult because they were all very, very new drugs. So some were with food some were without food, some were after food, some were before food, some were, you know, every so many hours and you'd wake up in the night to take them as well and it was a full-time job just managing. Oh, and some you couldn't eat certain foods with as well, so it was managing that whole drug regime was hard
- 25 Q. By 1995 in terms of David's physical condition he was 133

1 itching, jaundice, leukodystrophy?

- 2 A. Yes.
- 3 **Q.** He was referred with a view to a liver transplant?
 - A. He was, yes, he was referred to St James's here in Leeds. He was referred to see Dr Davis who was really brilliant. He was very good. He sat us down. He went in on -- I can remember it, he went on 7 May 1999 and we sat down and we spent the week in Leeds while he underwent all the tests and everything to see if he was suitable as a recipient and at the end of the week he basically said. "We've never done a transplant here for anyone who's got HIV as well as hepatitis C and he'll have to have a HIV drug holiday after the transplant", but they were willing to take him on. They were willing to take him on, to give him a liver transplant.
- 17 Q. You have said in your statement it was agreed he was 18 dying of the liver disease and not the HIV?
- 19 A. Yes, the HIV was under control by this time. His 20 viral load was undetectable.
- 21 Q. David had his transplant on 8 June 1999.
- 22
- 23 Q. You have said that medically the doctors did a really 24 good job --
- 25 A. Yes.

1 complaining of polydipsia and polyuria?

- 2 A. Yes.
- 3 Q. He had no appetite.
- 4 A. No.

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- 5 **Q.** But he had to try a high calorie diet to maintain his 6
- Yes, for his liver, because his liver was causing issues, they put him on a high calorie low fat diet to try and keep his weight up, which exacerbated the polydipsia and polyurea and when we went to the haemophilia joint clinic they took bloods like they 12 always did and failed to notice that his blood sugar 13 level was at 28, normal being around -- well, under 5.

They left him for several months like that and in the end I went to our GP and I said, look, I'm sure there's something diabetic going on. So she gave me strips to test and sure enough I graphed out his blood test results, did it every day and graphed it out, and I actually took it back to [redacted] by this time and said, "These are his blood test results. How come you didn't notice, you know, that's it's running high", and he just didn't take me on at all.

- 23 Q. David's liver continued to deteriorate?
- 24 Α.
- 25 He was experiencing, again, continuing weight loss,

- 1 Q. -- but the nursing --
- 2 A. Awful.
- 3 Q. -- was not so understanding.
 - A. No. They just didn't pick up on things that -- being a nurse, unfortunately, sometimes you can see things coming and they just didn't pick up on -- when he was even in intensive care I could see ectopics on his ECG and things weren't right that I couldn't explain. They sent me off to have a sleep for a couple of hours and when I came back he was on his way back to theatre

with a bleed, so they'd not noticed that.

They were really reluctant to nurse him, if you see what I mean. They wouldn't help him have a wash or anything and in the end I just did all the nursing care myself. I used to go in at 6.00 in the morning, get him up, make sure he'd had a wash and everything, make sure he ate something during the day, got him outside if I could, although he was on Tacrolimus by this time which you can't really go out in sunlight.

Then I'd stay with him until 11 o'clock at night and then our caravan was parked in the middle of the park in Leeds, at Roundhay, so I used to go back to the caravan, catch a bit of kip and then go back again the next day and that went -- it was about three weeks he was in.

- 1 Q. David had been put in a side ward on his own due to 2 his HIV status --
- 3 A. Yes.

- 4 Q. -- and the nurses didn't want to go near him.
- 5 A. No, they wouldn't go near him. I did his dressings. 6 I did this obs. I did everything. It was guite funny 7 actually because he was the only one that didn't get
- MRSA, so there was some irony to it all. 9 Q. As you have said, he ended up going back to theatre 10 because he was bleeding.
- 11 **A.** Yes, and then he went back again after that.
- 12 Q. Because his bowel was blocked?
- A. Yeah. 13
- 14 **Q.** He was suffering from hypothermia; he was 15 hallucinating?
- 16 A. Oh yes, he was away with the fairies. He could see 17 Labrador dogs sitting on the opposite bed.
- 18 Q. He was discharged home but by this time he was down to 19 about 7 and a half stone.
- 20 A. Yes.
- 21 Q. He had been a big man.
- 22 **A.** Yes, he was 15 stone at his fighting weight.
- 23 Q. Then he had to have a stent put in in his bile duct?
- 24 A. Yeah, the anastomosis where they join the bile duct 25 together sort of collapsed on itself so they did an

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- 1 lost more weight. There's a photograph of him on New 2 Year's Eve 1999 and he looks like he's just walked out 3 of Auschwitz except that he's orange he's that badly 4 jaundiced.
- 5 Q. He was so ill by this time that doctors and nurses had 6 to come to the house to run tests there. He couldn't 7 get to hospital?
- 8 A. No, we couldn't get to Leeds. There was no way we 9 could have got down the M62.
- 10 Q. There was a discussion about the possibility of 11 a further liver transplant?
- 12 A. Yes, and they were -- they talked about another liver 13 transplant but he -- there was almost like conference 14 call before conference calls happened. Our GP was sat 15 at our house and he'd spoken with Dr Mandel and 16 actually it was Dr Schmidt by this time, and he'd 17 spoken with Dr Davis in Leeds and Dr Schmidt at North 18 Manchester General and they'd come to the conclusion 19 that they would give him another liver transplant, but 20 David said that he'd had enough and he couldn't go on 21
- any more. He couldn't have another transplant because 22 he just couldn't go through that anymore.
- 23 **Q.** He just wanted them to leave him alone?
- 24 A. Yes. That was on the Thursday.
- 25 **Q.** What happened over the weekend?

- 1 endoscopy, and that's not without risk, and put 2 a stent across to open the bile duct up so that the 3 bile could flow then because he'd gone jaundiced 4
- 5 **Q.** Then in late 1998 you say his HIV reared its head.
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- 7 **Q.** He had herpetic ulcers and had to be put on medication 8 for that?
- 9 A. Yes. The other thing that I've only found out 10 recently, I don't know whether I put it in my 11 statement actually, was I got some medical records 12 from North Manchester General and it turns out that 13 the liver that he got and I -- if he hadn't had that 14 liver he wouldn't have had those six months and 15 I appreciate that, but it was cytomegalovirus risk, so 16 he had an extra drug added. So he had to have 17 ganciclovir as well as all his other drugs and the 18 anti-rejection drugs and everything else so he got 19 quite a cocktail and we think that's what had tipped 20 the HIV.
- 21 **Q.** Physically he continued to deteriorate?
- 22 A. Yes.
- 23 Q. You said that by the end of 1999 the hepatitis C was 24 rearing its head again.
- 25 A. Yeah, that had come back. He was jaundiced. He'd

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1 A. He stopped taking all his medication, he was up and 2 about, just couldn't get downstairs very well. He 3 came downstairs on the Sunday, wasn't eating, he went 4 back up Sunday dinner time and he got up a couple of 5 times in the afternoon just to go to the loo and back 6 and then he -- at 2 o'clock in the morning I had to 7 ring the GP because he was in so much pain and the GP 8 came out and he said -- the GP had given me his phone 9 number, his home phone number, to ring him and he said 10 the only thing I can give him is morphine and we both 11 know that that's the beginning of the end.

At 8.00 in the morning he passed away with me and the boys in the room.

- 14 Q. How old was David at the time of his death?
- 15 A. He was just 40.

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- 16 **Q.** Those years between his diagnosis and his death, how 17 had they been for David?
- 18 A. Awful. Absolutely horrendous. He'd had -- we tried 19 to do everything we could to give the boys good 20 memories of him. Every time we went away, we tried to 21 go away, we went in caravans, in the end I towed the 22 caravan and set it up and everything so that we could 23 get away just for a few days. Every time we went we 24 had -- we made scrapbooks. We saved tickets and we 25 kept everything, so that he would still be there.

Tried to pick out the good things that happened and not dwell on the horrible things.

And I personally made some horrendous mistakes.

I didn't tell the children that he was dying.
I didn't know how to. Nobody came up with a magic recipe of, you know, this is the speech to have with your children, you know, and we couldn't tell them because it was HIV and it was hepatitis and if the school had found out then, you know, some horrendous stories of children being excluded from schools and, you know, they had enough problems in their lives without anything else, you know. They both [redacted] and they were trying to forge their -- and I made

mistakes.Q. David died at home.

16 A. Yes.

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17 **Q.** There was due to be a coroner's inquest into his death.

A. There was. The GP said that from what he'd read,
I mean he knew as well, he wanted a coroner's inquest
because it needed to be out in the open what had
happened.

My first thought was, "Oh my God, the press will be there". Strange the things you think, so we did have a coroner's inquest but because there was

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1 Q. You had a nervous break down after his death --

A. Yes.

Q. -- in late 2000. What, if anything, would you like totell us about that?

A. I was -- there was -- when he died everything stopped.

You've been so busy -- I mean, I still had the

children and thank the Lord I did because I wouldn't

be here if I hadn't had them. All the caring stops

9 and you feel like you've got no purpose anymore and

then I got to the point where I actually -- I couldn't

11 read, I couldn't write, I couldn't string a sentence

together, I was treated at a psychiatric hospital.

I used to go once a week and my task was to colour

14 a picture and to actually have the concentration to

colour a child's picture was just hard, really hard.

16 **Q.** So you had given up work to care for David?

17 **A.** Yes, I gave up work in 1992.

Q. And pretty much since 1992 you had been isolated in terms of social life and other interactions?

20 A. Yes, I couldn't go out. I couldn't leave him at all.

Q. You have said in your statement David never got to seehis sons grow up.

23 A. No.

24 **Q.** To get to degrees.

25 **A.** No.

1 a coroner's inquest I had two burly policemen parked

on my door. I had to identify his body formally and

3 then they came and took him away.

4 Q. The inquest conclusion was that he died of liver5 failure.

6 A. Yeah.

7 Q. Hepatitis C diagnosis was recorded.

8 A. Yeah

9 Q. Secondary to -- and then HIV infection.

10 A. Yeah

11 **Q.** And a verdict of misadventure?

12 A. Yes.

17

13 Q. You have touched on the impact that the medication

14 David had on his mood and his behaviour. How overall

15 did that impact upon you and the children?

16 A. I tried to minimise it for the children as best

I could. I think our eldest lad got more flak.

Sometimes you end up referee, you know, in the middle.

19 I'm sorry, I've lost my mind again.

20 **Q.** The David who behaved like that was the David who

21 behaved like that because of his medication --

22 A. Absolutely.

23 Q. -- and not because that was the man he was or the

24 father that he was?

25 A. No, not at all.

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1 **Q.** He never got to see them marry and he never got to hold his grandchildren.

3 **A.** No.

4 **Q.** You were left as a widow looking after two boys and

5 you were very substantially in debt.

6 A. Yes, significantly.

7 Q. You have been left, you explained in your statement,

8 with ongoing mental health problems in terms of

9 depression.

10 **A.** Yes.

11 **Q.** You continue to take antidepressants?

12 **A.** Yes. I have to be very -- I have to be quite careful.

You get used to the symptoms after a while and you know when things are going a bit pear-shaped.

Q. You have remarried and your husband is extremelysupportive?

suppoA. Very.

25

18 **Q.** You have said that if it wasn't for him you don't

19 think you would be alive now.

A. No. About five years ago I had another breakdown and
 that was work-related. I'd just lost, my mother had

22 died at home and we nursed her and when I went back,

23 people, they weren't very sympathetic and everything

just went downhill from there.

I ended up being performance managed. When

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- 1 you're being performance managed it's all right as 2 long as the goal posts stay in one place but they kept 3 moving them and in the end I took ill-health 4 retirement, but because I had had so much time off 5 looking after David, my pension's nothing.
- 6 **Q.** David had been involved in the 1991 litigation?

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- 8 **Q.** And you have recorded in your statement that he had to 9 sign a waiver and it was very much take it or leave 10 it.
- 11 **A.** Yes. It was take it or leave it and, not only that, 12 if you don't sign it then nobody gets anything.
 - Q. What was yours and David's experiences of the trusts and schemes?
 - A. The Macfarlane Trust were a nightmare. You needed reams and reams of evidence to extract anything out of them. I do remember when David died Ann Hithersay was the -- I don't know whether she was the director or something. She was very nice.

In fact, her letter saved my skin not that long ago. She sent me a lovely letter after David died enclosing the funeral grant which was £1,000 then and that letter I had to use for EIBSS because somewhere along the line from David dying in 2000 I received money from them until 2002 when I went back to work.

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1 with the schemes as jumping through hoops and having 2 to fight for everything.

- **A.** Absolutely. You fought for everything. You know, I remember once applying for a washing machine and they said what do you want one for? I thought I'd grow flowers in it, you know. It's just ridiculous. You needed the medical form, some medical forms have come back with some of the notes from North Manchester General and the form that they actually filled in is in the case notes, you know. It's just crazy, you
- Q. A couple of years after David died, you and some other widows of haemophiliacs who had been infected with HIV and who had died made a complaint about the treatment that they had received at Manchester Royal Infirmary.
- 16 A. Yes.
 - **Q.** You have touched on a number of your concerns about the overall care at Manchester Royal Infirmary and it's right I should say that the documents you have given us also contain Manchester Royal Infirmary's response.

You had a particular concern, you and others in your position, about what had been -- the behaviour of a nurse counsellor called Meg Openshaw?

A. Yes.

So they -- I was given a sort of monthly income until I got my number back, because by then by number had lapsed and I had to retain as a nurse, but once I was back working then everything stopped and they, basically, at that point, they must have thrown my file in the bin because when EIBSS was invented nothing was transferred, so I knew nothing about the EIBSS money that had been given to widows. I didn't even know anything about it.

When I had to fill the form in for that and produce all the evidence, you know, his will, his death certificate and everything else, they wanted proof that I was living with him when he died and they suggested perhaps bank statements might be useful but I don't know anybody who keeps bank statements for 19 years. So I was really, really struggling because they weren't going to pay the 10,000, they weren't going to pay it out, until I happened to speak to Victoria Prowse who was winding up the Macfarlane Trust and she said -- I said have you got anything in my file and she sent me a letter that -the letter that Ann Hithersay had written and that was the only thing I've got that says that I cohabited with David.

Q. You have described overall your experience of dealing

- Q. Can you just give us a flavour of what the concerns were?
- A. David and I with a few others had been to the weekends that Richard was talking about and we'd found this group called the Birchgrove Group and they were amazing. So we decided that it would be a really good idea to have something similar to that in Manchester. So we approached the nurse counsellor, because she was the one that knew everybody, if she would help us with it, which she gladly did.

Anyway, it came down to later on that, as she was going round doing her counselling she was taking titbits from one person to the next so, for example, if I got a washing machine she'd tell everybody else I'd had a washing machine and how I'd got it and what I'd done. There was some horrendous things that she -- she divulged so much personal, very, very personal information.

- Q. Such as HIV status?
 - A. Oh, yes. HIV status of a widow -- not a widow, a wife had been divulged to everybody who would listen. She been raped by her husband. She was just obnoxious, horrendous.
 - Q. The complaints that were made by, it was you and four

claimed that one of the wives who was HIV positive had

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1		other families, were of breaches of confidentiality	1		of taking it any further and I got a letter she
2		and that was, in particular, your concern but also	2		said put your questions in a letter, which I did, and
3		inappropriate treatment or lack of treatment and	3		I got a response back from one of the consultants that
4		unprofessional conduct	4		was basically, you know, he didn't answer my
5	A.	Yes.	5		questions.
6		specifically towards this group of haemophiliacs	6	Q.	
7		who had HIV.	7		there anything you would like to add?
8	Α.	Yes.	8	Α.	Yes, if that's all right.
9	Q.	Without going into the detail of the documentation	9		I would like to say thank you to those who have
10	-	because you have supplied it all to the Inquiry, you	10		helped us on this long and horrendously difficult
11		and the others made a complaint to the	11		journey. My Dad: he was the first to know about
12		Macfarlane Trust or asked the Macfarlane Trust to	12		David's infection and wanted to sell everything, his
13		investigate the complaints?	13		business and everything, to obtain whatever treatment
14	Δ.	Yes, the Macfarlane Trust and the Haemophilia Society	14		there was for him. David's brother, who would draw
15		were there at that meeting and we'd raised concerns so	15		cartoons for him, and who spent many hours talking to
16		they got us all together and they Ann Hithersay was	16		him, driving me and the children to and from a variety
17		there and she put together the report which then went	17		of hospitals. Sadly, neither of these wonderful men
18		to the Chief Exec.	18		lived to see us get this far.
19	Q.	It ultimately went to Manchester Royal Infirmary?	19		My husband and two boys, their wives, our
20	A.	Yes.	20		wonderful grandchildren and the rest of our family who
21		You said in your statement that you're not really	21		have steadfastly supported us through the dark times.
22	Œ.	clear what happened to it after that.	22		Self-help groups and, more recently for me, Tainted
23	Α.	No. The last I heard this matron contacted me whom	23		Blood and Factor 8, Collins Solicitors, Sir Brian, and
23 24	A.	I met and who said, "There, there, dear", you know,	23 24		the Inquiry team. There was some clinicians who were
25		it's just a complete whitewash. They had no intention	24 25		shining stars: Dr Azawi, who was swimming against the
23			23		•
		149			150
1		tied of apathy at Manchester Royal Infirmary; Dr John	1	SIR	R BRIAN LANGSTAFF: Thank you very much indeed, Ms Q.
2		MaClinton, hepatologist; Dr Bibak Mandell, Dr Bridget	2	•	That's it for you for today, even though you go on
3		Maier, and Dr Schmidt from North Manchester General;	3		living with what you've told us about but thank you
4		Dr Davis and his team here at St James's, they gave	4		for telling us.
5		him a chance of life with a liver transplant, and	5	Δ	Thank you.
6		I want to thank the donor and their family.	6		R BRIAN LANGSTAFF: Now, we have a 10.30 start to morrow,
7		I'd like to thank our GPs, obtaining the	7	0	do we?
8		interferon treatment when MRI wouldn't pay; the	8	MS	RICHARDS: We do, sir.
9		district nurses who helped after David's transplant	9		R BRIAN LANGSTAFF: What do we have tomorrow?
10		and at the time of his death; and the psychiatric	10		RICHARDS: We are hearing from Peter Burney and from
11		nurse who latterly helped me back from the edge.	11	IVIO	Ann, Sarah, Eleanor and Jennifer Dorricott.
12		During our journey, we've met some diabolical	12	SID	R BRIAN LANGSTAFF: Thank you. So 10.30 tomorrow.
13		clinicians, and I include nurses, some who didn't	13	Silv	Thank you all.
14		understand and were afraid of the viruses our loved	14	(4.1	19 pm)
		ones had been given, some incompetent, some who	15	(4.1	(Adjourned until 10.30 am the following day)
15 16			16		(Adjourned until 10.50 and the following day)
16		downright lied, hid, and are still hiding evidence,			
17 10		kept us isolated, alone and ignorant, and were	17 18		
18		prepared to let our loved ones die.			
19		Please, Sir Brian, with your team at your side	19		
20		uncover the facts, the omissions, the lies and the	20		
21		greed. Leave no stone unturned and let us understand	21 22		
22			77		
22	_	the whole truth of why and how this tragedy happened.			
23	Q.	Thank you. I am just going to ask if there's anything	23		
	Q.	• • • • • • • • • • • • • • • • • • • •			

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(40) MS FRASER BUTLIN: - acquaintances

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