

Tuesday, 15th October 2019

(10.14 am)

SIR BRIAN LANGSTAFF: I am very sorry, particularly to Liz, our first witness of the week, that you have been kept waiting this morning and that the glitches weren't discovered earlier than they were, but we are now in a position, aren't we, to begin? May we have Liz, please?

ELIZABETH GAIL HOOPER (sworn)

Questioned by MS FRASER BUTLIN

MS FRASER BUTLIN: Liz, you have lost two husbands, both of whom received infected blood and contracted viruses from that blood and blood products.

A. Yes, that's right.

Q. You have described Jeremy as your first love.

A. Yes, he was.

Q. And Paul as your soulmate.

A. That's right.

Q. And you have provided two pictures of them, which we'll have on the screen during your evidence.

A. Okay.

Q. You've said that Jeremy was loud, gregarious and larger than life.

A. Yes, he was. He was -- you always knew he was in a room. If you were in a party, you always knew that

1

A. That's right.

Q. And you were warned that he was joining.

A. Yes, we were. The headmaster had all of the third year in and basically told us that we had got this boy coming who had got special problems with his blood and we weren't allowed to fight him, because he would bleed and he wouldn't clot. So we'd all got to be very careful of this new lad that was going to be joining us.

As it turned out, Jeremy was the one that started all the fights, Jeremy was the one that was always in the middle of any problems and he was the one that was always there instigating the trouble. He was a proper little terror.

Q. You stayed on in school after your O levels.

A. Yes.

Q. Whereas Jeremy didn't.

A. Yes. He left as soon as possible.

Q. And then you met again when you were 16.

A. Yes. Well, I was 15, just coming up to my 16th birthday, and we had an end-of-year party and Jeremy gatecrashed. I hadn't seen him for 12 months or more. I had seen him round the village, because he lived in the same village as us, as me, but I'd seen him round the village, but not really, you know, very much, and

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Jeremy was there. He was always in the middle of everything, laughing and joking, proper charmer, he was, proper charmer, proper wide boy. Phil Mitchell. Think of Phil Mitchell. That's how he was, with his bald head and he used to wear his big leather jacket. He was a proper wide boy. He was from London and he always knew somebody who could do whatever you wanted, you know, whatever you needed.

Q. Jeremy had severe haemophilia B.

A. Yes.

Q. But he was not diagnosed until he was nine years old.

A. That's right, yes.

Q. He was treated in the Oxford Haemophilia Centre.

A. Yes.

Q. Under Dr Matthews and Dr Rizza.

A. Yes.

Q. In fact, his family moved house when he was 13 so that he would be closer to that centre.

A. That's right, yes.

Q. When Jeremy was given number Factor IX concentrate, was he or his parents ever warned about any risk of being exposed to any infection?

A. No.

Q. Jeremy joined your school when you were in your third year of secondary.

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then he walked into the party and it was just like something out of a love story. Our eyes met across the drunken teenagers and it was love at first sight. We were together from that moment on. We were -- we just didn't part. It was just incredible. He had gone from being this little fat, rotund kid with a pudding bowl haircut to this tall, lanky 16-year-old, and he'd got black jeans on and pointed boots on and he'd got a vintage German infantryman jacket on. Oh, he did look gorgeous. And he gave me his cigarettes at the end of the night and I kept them for weeks and week and weeks.

Q. You were together for five years and then you got married.

A. Yes.

Q. And had your son in 1993 --

A. That's right.

Q. -- who sits next to you.

A. Yes.

Q. Jeremy had worked his way up in a builder's merchants.

A. Yes, that's right.

Q. And ultimately became the sales and marketing director.

A. That's right, yes.

Q. You have described having a big house, nice cars, lots

4

1 of friends.

2 A. Yes. We were the epitome of an executive family.

3 Jeremy earned a good wage. We had a nice house. We

4 went on foreign holidays to America and, you know,

5 Egypt and all sorts of places. I had a new car.

6 Jeremy drove a Mercedes. You know, we were living the

7 dream.

8 Q. You have said Lewis's arrival was the icing on the

9 cake.

10 A. It was the icing on the cake. It was unplanned. We

11 weren't sort of -- well, I had been on the pill and

12 had to come off the pill, and God decided that that

13 was the time to strike. So after a couple of bottles

14 of wine, the following day I said, "I am not going to

15 have a baby, I don't want a baby", but it was too

16 late; I was already pregnant with my beautiful son.

17 Q. Just tracking back a little bit, when there were

18 reports on the television about blood being infected,

19 what was Jeremy's attitude towards that?

20 A. Initially we neither of us really paid that much

21 attention. Jeremy was very much a person that kept

22 the haemophilia side of him and the Haemophilia

23 Society and everything, kept it very much to one side.

24 It didn't interfere with our family life. We didn't

25 really discuss it, it was just something that we lived

5

1 A. No.

2 Q. Was any form of hepatitis discussed that appointment?

3 A. No.

4 Q. Was Jeremy given any advice at all about any risks of

5 transmission of viruses generally?

6 A. No.

7 Q. Lewis arrived in 1993.

8 A. Yes.

9 Q. In 1995 or 1996, Jeremy received a call from Dr

10 Matthews asking him to go in for an appointment and to

11 take you along.

12 A. That's right.

13 Q. What happened at that appointment?

14 A. He was quite mysterious about it because he wouldn't

15 tell -- well, it was his secretary who actually

16 phoned, and she wouldn't tell us what it was about.

17 She probably didn't know, truth be told. So off we

18 traipsed up to Oxford, after getting Lewis into -- mum

19 would have looked after Lewis whilst we were up there.

20 We went into Dr Matthews's office and he sat us

21 down and he explained that Jeremy had got hepatitis C,

22 and that it would attack his liver and that he could

23 have passed it on to me and, via me, to Lewis. Jeremy

24 asked him, you know, how long he had had it. "Is this

25 something new? Have I only just got it? What's

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1 with.

2 So when they started putting up the horrible

3 gravestone tumbling adverts, initially it was -- we

4 didn't really think much about it, but then I think it

5 was playing -- started to play on Jeremy's mind, you

6 know, obviously, he was a haemophiliac. So he

7 questioned his consultant with regards to whether he

8 could or would get HIV through this factor.

9 Q. From where you lived and your memory of the house, you

10 think that was in about 1987?

11 A. Yes, yes. We were living in a house in Waterloo

12 Close, because I remember that when Jeremy did ask Dr

13 Matthews on just a routine -- he went up for his

14 routine 12-monthly check and he just asked Dr

15 Matthews, and I just remember him telling me in the

16 living room of that particular house.

17 Q. What did Dr Matthews tell Jeremy about HIV?

18 A. He told him that he wasn't to worry, that because he

19 had haemophilia B the Factor IX had to go through an

20 extra heat treatment, which killed the -- as far as

21 they were aware killed the HIV virus off, because they

22 hadn't had any known cases of a haemophilia B

23 contracting HIV.

24 Q. At that appointment in 1987, was Jeremy told anything

25 about non-A, non-B hepatitis?

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1 happened? How has this come about?" Dr Matthews said

2 he had had it for about ten years and they had been

3 monitoring how things were developing in the system,

4 and they felt that his liver was showing signs of --

5 it wasn't working quite so well, which had prompted

6 them to have to explain to him why. But he also said

7 to Jeremy that one of the other reasons that they

8 couldn't tell him or wouldn't tell him before is

9 because they didn't know what to call it, and that

10 they knew it as non-A, non-B for a number of years,

11 and before they were able to -- they felt able to tell

12 people that they'd got this non-A, non-B hepatitis,

13 they had to have a proper name for it, to which, I

14 mean, Jeremy just erupted. His language was foul and

15 he said that he wanted to know how many hundreds of

16 thousands of pounds it had taken the committee that

17 decided to call it hepatitis C had got, because you

18 didn't need to be Einstein to think, "We have got

19 hepatitis A, we have got hepatitis B; oh, I know,

20 let's call it hepatitis C".

21 So, yes, that's...

22 Q. Dr Matthews said Jeremy had had it for approximately

23 ten years, which would put it back to about 1985 or

24 1986.

25 A. Yes.

8

1 Q. Before the discussion about HIV.
 2 A. Yes.
 3 Q. Jeremy also asked about the risk of passing the virus
 4 on and Dr Matthews said that was why you had been
 5 asked to come in as well.
 6 A. Yes. He explained that there was a possibility that I
 7 could have got it through seminal fluid or, you know,
 8 if I used his toothbrush, all that sort of stuff. So
 9 it was easier for me, because if I had it, Lewis would
 10 have it. So it was easier for me to be tested, and if
 11 I didn't have it, then Lewis wouldn't have it.
 12 Q. And Jeremy was absolutely furious?
 13 A. Yes. He was just -- he was beyond anger. I mean, he
 14 was just beyond anger. Jeremy was a big, big man. He
 15 was about 6 foot and he weighed 17/18 stone, a proper
 16 rugby player type, real big man, and you didn't want
 17 to stand in front of him when he got angry, and
 18 Dr Matthews was quite a petite man in comparison and
 19 I think he was a little bit scared, and I think he was
 20 a little bit glad when Jeremy just got up and said,
 21 "Come on, we're going home", and he just walked out
 22 rather than punch his lights out, I think.
 23 Q. And Jeremy was particularly angry because the centre
 24 had known you were pregnant.
 25 A. They had known I was pregnant, they had known I had

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1 reasons that he did it was because they had advised
 2 him he was going to be trialing this new drug, that he
 3 was going to be helping his fellow haemophiliacs that
 4 had got hepatitis C and others that had hepatitis C.
 5 I think that's what drove him to kind of think "Yes,
 6 I am going to be heroic here and do something fab".
 7 So he agreed to go onto this trial, six months, and it
 8 was six months of absolute hell, hell.
 9 He stopped communicating. He would only
 10 communicate in grunts and snarls. He shouted an awful
 11 lot. He spent a lot of time in his office playing on
 12 whatever computer game he'd got going at the time, and
 13 he would spend hours in there just keeping away from
 14 us.
 15 He wouldn't speak to Lewis. Lewis could do
 16 nothing -- I mean, Lewis would be downstairs or in his
 17 bedroom, playing in his bedroom, and he would come out
 18 of his bedroom and scream, "For God's sake, shut up"
 19 at his son, and Lewis wasn't doing anything, you know,
 20 he wasn't being particularly noisy. But he got
 21 really, really aggressive. It was the closest that
 22 Jeremy and I got to having a divorce, because he
 23 wouldn't eat with us, he used to take his meals
 24 upstairs and eat on his own; he couldn't sleep, so he
 25 was awake all night, he was taking drugs to try to

11

1 had a child, and yet they had not told us that he had
 2 got this disease that potentially he could have given
 3 to me and therefore to his son. He couldn't and
 4 wouldn't forgive them for that.
 5 Q. And you were in shock and feeling terribly confused
 6 about what you had heard as well.
 7 A. Yes. I mean, I was quite -- because I had always sort
 8 of been in Jeremy's shadow a little bit, and, you
 9 know, he was very much the man of the house and he --
 10 I just was the little woman in the kitchen doing the
 11 stuff, I hate to say it. I am not like that now.
 12 So, yes, I was very confused and didn't really
 13 understand what was going on, but we got home, talked
 14 about it on the way home, and, once Jeremy had calmed
 15 down, made an appointment for me to go back to the
 16 Haemophilia Centre to be tested. It was literally
 17 only two or three days after, and that came back
 18 negative.
 19 Q. Jeremy waited to have treatment for the hepatitis C
 20 until Lewis was about 11.
 21 A. Yes.
 22 Q. When he did undergo treatment, what were the side
 23 effects that he had?
 24 A. Oh, he had the interferon and Ribavirin treatment.
 25 They advised him that he was -- I think one of the

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1 make him sleep; he was taking -- he had a horrendous
 2 headache and the Oxford Haemophilia Centre told him to
 3 take paracetamol. You know, "Just take paracetamol,
 4 you can't take anything else, but just take
 5 paracetamol". And one day Jeremy was sat reading the
 6 leaflet out of one of the boxes of tablets he was
 7 taking, and it clearly said on the thing, "Do not take
 8 paracetamol with this drug". Yet he had been taking
 9 them for five or six weeks. It didn't get rid of the
 10 headache, but he was still -- Oxford had told him to
 11 take them.
 12 Oh, it was a nightmare. It was a nightmare.
 13 Q. You said after that Jeremy was never really himself
 14 again.
 15 A. No, he did change. It did change him. He became very
 16 short-tempered. He didn't have a lot of patience. He
 17 was tired all the time. He just -- no, he was
 18 a shadow of his former self.
 19 Q. And at the end of the treatment he was told he hadn't
 20 cleared the virus.
 21 A. He hadn't.
 22 Q. What was Jeremy's reaction to that?
 23 A. He was -- I mean, he was angry that it hadn't worked,
 24 sad that he had been through all of this and it hadn't
 25 -- you know, he had still got this disease. He was

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1 apologetic to us, because he had put us through such
 2 an awful thing for no reason and, yes, he became very
 3 depressed, very withdrawn.

4 **Q.** Jeremy began to get stomach pains, but nothing was
 5 found on an endoscopy. Then, on 7th December 2008,
 6 you were at work and a colleague interrupted a meeting
 7 that you were in --

8 **A.** Yes.

9 **Q.** -- to say that Jeremy was trying to get hold of you.

10 **A.** Yes, that's right. I went -- I didn't have my phone.
 11 It was in my handbag. So I went back to my desk and
 12 picked my phone up, and there was a voicemail message
 13 on my phone to say "Liz, please come home, you have to
 14 come home". So I basically just picked up my bag and
 15 went.

16 When I got home, I went up -- I shouted to him
 17 and he didn't answer me. So I went upstairs and first
 18 of all went into his office, because I assumed that's
 19 where he would be. He wasn't there. So I went along
 20 the landing into our bedroom and Jeremy was lying on
 21 our bed in a semicomatose state. He was able to say
 22 he had been vomiting blood.

23 So I went into the bathroom -- I don't know why
 24 I went into the bathroom, it's just one of those
 25 stupid things, you know, go and have a look and see

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1 ruptured entirely. Jeremy had an immediate cardiac
 2 arrest. They were able to start his heart again and
 3 they rushed him to surgery to try to repair the
 4 damage, but they weren't able to repair the damage.
 5 Jeremy bled to death.

6 **Q.** You meanwhile had contacted the family.

7 **A.** Yes.

8 **Q.** The family had driven down.

9 **A.** His one sister came all the way from Whitby. I phoned
 10 her to say that Jeremy had had a cardiac arrest and
 11 that he was in theatre, and she travelled down from
 12 Whitby to come to see him. She obviously didn't make
 13 it to see him, to talk to him, but she did make it
 14 down before he had finally passed, so she was able to
 15 see him.

16 There was only me -- they asked me if I wanted
 17 to see Jeremy, because there was nothing else they
 18 could do. His body was rejecting the Factor IX that
 19 they had given to him, and he had also had blood
 20 transfusions and his body was rejecting the blood as
 21 well. So, you know, there was nothing else they could
 22 do and it was only a matter of time before he passed.
 23 So they asked me and Lewis if we wanted to go in to
 24 see him in the theatre.

25 Lewis declined, and I am very glad he did, but

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1 what's in the bathroom, I don't know why. But I went
 2 into the bathroom and it was just -- oh, God, it was
 3 like the Texas Chainsaw Massacre. I have never seen
 4 anything like it. Blood everywhere.

5 I had phoned 999 obviously by that time and
 6 paramedics came and managed to get him out of bed and
 7 down the stairs, which proved quite difficult,
 8 because, as I say, he was a heavy man. They managed
 9 to get him down and into the ambulance and off to
 10 Warwick Hospital. I followed in the car. When I got
 11 there, they had managed to -- the bleeding had stemmed
 12 and it had stopped. They had got him in a little side
 13 ward and they said that they were going to do an
 14 endoscopy the following day. They couldn't do it in
 15 the afternoon, they had to do it the following day,
 16 because they needed to get the piece of equipment that
 17 they had used on a previous endoscopy that Jeremy had
 18 had at the hospital a couple of years previously, to
 19 which I thought, you know, why would you keep --
 20 Jeremy thought it was highly hilarious that they had
 21 kept this piece of equipment, as he said, in the loft
 22 in a bag with "Jeremy Foyle" written on it.

23 So the following day he went for this endoscopy,
 24 but they didn't -- they got the camera down his throat
 25 but it didn't go down very far before the pharynxes

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1 I went in to see him and his younger sister went in to
 2 see him. I wished I hadn't. It wasn't nice. It
 3 wasn't pleasant. There was this -- my big, strong,
 4 strapping man lying on a trolley in an operating
 5 theatre with blood basically coming from every
 6 orifice. He had blood in the corners of his eyes, it
 7 was coming out of his ears, down his nose, it was
 8 dribbling down his chin. So my last memory of Jeremy
 9 is, again, looking like something out of a horror
 10 film.

11 **Q.** You kissed him and told him you loved him.

12 **A.** I kissed him, told him I loved him. I told him that
 13 I couldn't stay, that I had got to go home to look
 14 after me and Lewis, and I walked out. I just went,
 15 got Lewis and we went home.

16 **Q.** And he died just before midnight.

17 **A.** Yes.

18 **Q.** You've said in your statement that before you could
 19 face up to the loss of Jeremy, you had to go into
 20 a survival mode.

21 **A.** Yes. My maternal instinct kicked in. On steroids, it
 22 was, because I knew that I was not going to be able to
 23 stay in the house that we were in. We were in this
 24 big detached house and I worked part-time for the NFU
 25 Mutual. My take-home wage a month didn't even cover

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the mortgage, let alone council tax and electricity and gas and all of that. So I knew I had to sell the house. So I rang our mortgage provider -- I mean, you have to bear in mind that Jeremy had done all of the mortgage himself. All I did was sign where he told me to sign. So I didn't know much about mortgages and all that sort of thing, but I rang them up and told them that Jeremy had passed away and they advised me that I had got a three-month mortgage holiday available. So I took that, but it meant that I had a three-month timeline. I had to sell the house and find somewhere else for Lewis and I to live within that three-month timeline.

So we did that. I did that. I got the house on the market. I organised a funeral. I packed up the house. I sorted out paperwork that was in the house. I sold Jeremy's car. I sold -- he had got a classic car. I got rid of that as well and all his fishing stuff, and even the fish out of the fishpond.

Lewis and I moved into a small, two-bedroomed semidetached house, and I had a small mortgage which I was able to afford to pay on my part-time wages, and because it was a much smaller house, so the council tax was less and the running costs were less. So it was tight, but we still managed.

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gone through his GCSEs -- and he did tremendously well. He still managed to get 13 GCSEs. They weren't to the projected levels, but he still managed to get through them after everything he had been through and helping me and reading mortgage stuff and things like that. We were sat having our tea one night. It was spaghetti Bolognese. I had a forkful halfway to my mouth and Lewis just said to me, "I think I am going to stop at such-and-such's on Saturday night", and that was it. It was just like somebody thumped me in the stomach and I just couldn't breathe and I started to cry and, boy, did I cry, and I did not stop and I could not stop. Lewis actually phoned Jeremy's other sister, Julia, and Julia came round because he didn't know what to do because I was just sat there wailing, weeping and wailing. I had a catastrophic mental breakdown.

Q. You have described it as: "I couldn't speak to anybody. I didn't want people

To talk to me. I just wanted to sit in a corner with a duvet over my head. It was a very, very dark time for me. It hurt even to make decisions, even whether or not I wanted Marmite on my toast. He had been my life. He was my everything."

A. Exactly. It was just the realisation he wasn't going

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Q. In terms of financial assistance, the consultant that signed Jeremy's death certificate told you about the Skipton Fund.

A. Yes.

Q. And you received a stage 2 payment.

A. Yes. I had never heard of the Skipton Fund until he mentioned it. We went in to get the documents, to get the death certificate, and he was just sat writing it out and then he just mentioned it. He said, "I think you'll find that you are eligible for a payment from I think it is the Skipton Fund, they call it, but I think you will find you are eligible for a payment because of how he's died", because otherwise I wouldn't have known.

Q. But only recently have you discovered you were also entitled to a bereavement payment.

A. Yes. I didn't get that. I have only just had that 11 years too late. But, yes, I just had that.

Q. The move of house was a huge emotional wrench for both you and Lewis.

A. Yes.

Q. You got Lewis through his GCSEs.

A. Yes.

Q. Then you said it was like you hit a brick wall.

A. Yes. Once we were settled and Lewis had, as I say,

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to come back. I suppose in the back of my mind there was always this, you know, "This is all just a bad dream and I am going to wake up. None of it is going to be real, you know, he is going to come in with a cup of tea and we are just going to carry on as we have always done". I just suddenly realised that that's not going to happen, and it was just -- I couldn't -- my brain was just -- it was just like I had got fog in my head and I couldn't see through the fog. I couldn't make my mouth work to say the words. People would speak to me and I would just look at them as if they were talking to me in a foreign language. I didn't understand. I didn't want to understand. I didn't want to understand and I didn't want to make decisions. I just wanted to sit and hoped it all went away, and if that meant that I didn't eat and Lewis didn't eat and the house went to rack and ruin, at that point in time, I didn't care.

Q. And throughout that time Lewis provided you with huge support.

A. Lewis was the hero of the hour. Lewis and my parents, but Lewis primarily. He would go and do the shopping, he would make something to eat, he would bring me cups of tea, he would coax me to drink them. You know, he

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1 would berate me, he would cajole me -- anything to try
2 to break this wall that I'd built up in front of me
3 and I just didn't want anybody, not even Lewis, to get
4 past it and get to me, because I was too vulnerable,
5 fragile.

6 Q. During that time were you or Lewis ever offered any
7 counselling or psychological support?

8 A. No, nothing. The only time I -- Lewis had -- our
9 local GP did offer some counselling to Lewis as a
10 child, but I think he was so wrapped up in his life,
11 the fact that he'd lost his dad and the fact that he'd
12 got me sitting there like a big lump of marshmallow in
13 the corner that was no use to neither man nor beast,
14 he was having to do so much, so he declined that.
15 But, no, we didn't.

16 The only time that certainly the Oxford
17 Haemophilia Centre got in touch with me, I had a
18 letter from Dr Giangrande to say, yes, Jeremy was
19 eligible for the Skipton Fund and briefly at the end
20 to pass his condolences. But that was all. There was
21 never anything offered from them. They didn't advise
22 me to go anywhere, to try anything, nothing. We were
23 just cast adrift. That was it.

24 Q. In 2009 Lewis set up a profile for you on Facebook.

25 A. Yes.

21

1 uncanny.

2 Q. Paul told you he was a haemophiliac.

3 A. Yes, he did.

4 Q. What was your reaction to that?

5 A. "Is that all?" He said, "I am sorry, I have got to
6 tell you something. I'm not very well", and I said,
7 "What is the matter with you?" He said, "I am a
8 haemophiliac" and I went, "Oh, is that all? I have
9 been married to one for 23 years. Haemophilia?
10 I laugh in the face of haemophilia." So, you know,
11 that was that. He didn't tell me he was HIV or
12 hepatitis C until we met, I hasten to add. He didn't
13 tell me that over the phone. But it didn't matter.
14 I mean, I was smitten. He could have had leprosy and
15 I wouldn't have cared.

16 Q. Paul had severe haemophilia A and was treated at the
17 Haemophilia Centre under Dr Hill and then Dr Wilde.

18 A. That's right.

19 Q. He was treated with Factor VIII concentrate.

20 A. That's right.

21 Q. As far as you are aware and as far as he ever said,
22 was he ever warned of any risks involved in receiving
23 Factor VIII products?

24 A. No, he was never told.

25 Q. As you say, when you met, Paul told you he had HIV and

23

1 Q. You ended up connecting with Paul.

2 A. I did. It was just a comment, friend of a friend sort
3 of thing, and the comment -- we started to talk via
4 Facebook, via Messenger, and then from Messenger on to
5 texting and then from texting to phoning one another
6 up and -- yes, then I met him first of all in April,
7 and that was the first time I met him. We just -- it
8 was absolutely uncanny. It really was uncanny.
9 I picked him up from Stratford train station, because
10 he had -- first time I ever met him and he was coming
11 away with us to our friends' in Cambridgeshire to
12 celebrate Jeremy's birthday, actually. I always
13 thought, what a brave bloke to actually come and first
14 meet this woman that he's been talking to, although
15 we'd been talking for a few months and we'd got on
16 like a house on fire, you know, the first time you
17 clap eyes on her in the flesh was to go away and stay
18 with some people you hadn't met. We just literally --
19 I got out of the car and walked up to him and we
20 started to chat, and then we didn't stop chatting up
21 until he died, really. We just carried on. It was as
22 if we were carrying on a conversation that we had had
23 decades before. We both felt very much like we had
24 met one another in a previous life, if you will,
25 because it was just really, really special, really

22

1 hepatitis C.

2 A. Yes.

3 Q. And he had been infected for 25 years.

4 A. Yes.

5 Q. At the time you met, Paul was also emerging from what
6 you have described as a dark period of isolation after
7 an attack that was entirely unrelated to anything
8 involved in this Inquiry, just a random attack.

9 A. Just a random attack on the streets of Walsall. He
10 was badly beaten up by a group of young men and it
11 ended up with him having a burst -- his spleen burst.
12 They didn't think he would survive. He had to be
13 resuscitated a number of times on the way to the
14 hospital. He had to have his spleen removed. He had
15 come home from that. He had been mugged a couple of
16 times as well, just random, where they had knocked him
17 over and stole his wallet sort of muggings. So
18 basically he just sat in his house. He had stopped
19 all of the combination treatment for his HIV and he --
20 I think he was just sitting there waiting to die.
21 I think he just wanted to die. He didn't want to go
22 out. By his own admission he was quite reclusive. He
23 would go out to -- he would go to Flan O'Brien's on a
24 Friday night to have a pint and that was about the
25 limit. He would have a driving lesson with his friend

24

1 Lynne, but that was about it. He didn't mix. He
2 didn't go out.

3 Q. But when you met, he helped you come out of a horrible
4 place you'd been in.

5 A. Yes. We helped one another.

6 Q. And you ordered him back onto his combination therapy.

7 A. Yes, we saved one another. I am not particularly
8 religious and Paul wasn't particularly religious, but
9 we always said God brought us together because we both
10 needed saving for different reasons and, you know, we
11 did save one another quite literally. We saved one
12 another.

13 Q. You said that by the time you moved in together you
14 had settled into a routine of a happy middle-aged
15 couple.

16 A. Yes.

17 Q. But that Paul's illness had a much greater impact on
18 your lives together.

19 A. Yes. Paul was -- Jeremy had -- if you looked at him,
20 he was a big, hefty chap, but he didn't look
21 particularly ill. His mobility wasn't particularly
22 good. He struggled to walk very far. But he just
23 looked, you know, like a healthy bloke. Nobody would
24 know there was anything the matter with him.

25 Paul was a different kettle of fish. He was

25

1 in the notes, as they always did. I mean, I was there
2 with him. That was it. Carried on doing what they
3 did. Took bloods and, you know, just the normal
4 routine check in the centre. She didn't say anything
5 to us about how high his blood pressure was. Maybe we
6 should have asked. I don't know. We didn't think.
7 We naively assumed that if it was high enough to cause
8 her concern, she would either have gone and got one of
9 the doctors to look at him or at least would have said
10 to him, but she didn't say anything to him about going
11 to see the doctor. So he didn't. We just went home
12 and that was that.

13 Then a couple of months later, Paul said that
14 he'd got -- he woke up one day and he'd got a headache
15 and he couldn't get rid of the headache. He kept on
16 and on about, "This bloody headache is driving me
17 mad". So in the end I said to him, "Maybe it's
18 a migraine", because it sort of dragged for a little
19 bit, not developing but making him generally feeling
20 poorly. I had some Migrelief tablets, so he took
21 a Migrelief tablet and went to bed. That was that.

22 The following day he got up. The headache still
23 hadn't gone. It was no worse, it was no better. But
24 he had got squiggly lines in his sight. Again, we
25 just assumed that it was his first ever migraine. He

27

1 actually physically better than Jeremy in that he
2 could walk a lot further. We used to walk miles. As
3 Paul would say, we would go bimbly. We would go
4 bimbly around the shops and things like that, and he
5 loved to just bimbly about. He was a keen
6 photographer, so he was always -- I would lose him.
7 I would walk along and I'd turn around and he would be
8 miles back taking a photograph of a gargoyle on the
9 top of a church and things like that.

10 So he was an awful lot more able to physically
11 got out, but he looked a lot iller. He was only about
12 5 foot 8. He was a very slight man. He was only sort
13 of 10.5 or 11 stone. You know, you could see that
14 there was something -- he didn't look as healthy as
15 Jeremy had looked.

16 Q. Paul had liver cirrhosis --

17 A. Yes.

18 Q. -- kidney disease, arthritis and obviously ongoing
19 immune issues. Then towards the end of 2015 he went
20 into the Haemophilia Centre and had high blood
21 pressure.

22 A. Yes. He went in -- it was just again a routine trip
23 to the QE. One of the nurses took his blood pressure
24 and she just sort of said as a passing comment, "Oh,
25 your blood pressure is high today" and wrote it down

26

1 had never suffered from them before, but, you know,
2 because of the squiggly lines, we just seemed to think
3 that was more likely the case. But as the days went
4 on and the lights didn't disappear and things just got
5 worse and worse, in the end I said to him, "You had
6 better go and see the doctor". He went to see the
7 doctor and his blood pressure was astronomical.

8 He immediately went onto blood pressure tablets
9 and things, but they sent him -- referred him to see
10 an ophthalmologist because of the eyesight issues, and
11 it turns out that -- they did a brain scan and it
12 turned out that Paul had had a stroke from high blood
13 pressure. He had developed hypertensive retinopathy
14 because of the stroke.

15 Q. Over the next few months his eyesight deteriorated to
16 the point where he was registered blind.

17 A. He was registered -- yes.

18 Q. For Paul, that was terrifying.

19 A. Absolutely took the floor -- the ground from
20 underneath him. He had always liked -- we lived in
21 a small rural village and he liked to, you know,
22 bimbly, bimbly down the village to the shop and to our
23 local pub to have a pint of Guinness of a lunchtime
24 and pop home, you know, just live the life that he had
25 earned and we all want, you know. He used to go out.

28

He was very popular in the village. A lot of people knew him. So -- and that was suddenly taken away from him, because he could not do it on his own. Although he had support from Warwickshire Vision Support and they came out and helped him with the use of the white stick and encouraged him to try to go out on his own, because, as I say, it was only a small village, so, you know -- but the most he ever really got was he would go up to the doctor's, which was literally just the other side of a big Georgian house, but that was about it. If he went for a walk round the village, I had to be with him. He wouldn't go out on his own.

Q. His health also became more precarious.

A. His health started to deteriorate. Really from that moment, his health started to decline. He started to lose weight. He was a very picky eater. He would just have things like Cup-a-Soups and stuff. He didn't want to eat anything. You know, he started -- he got a big bloated tummy like somebody, you know, that was starving. His arms -- he was just wasting away in front of me. He was so, so depressed.

Then we started to -- I started to recognise that he was having some mood swings and his whole character was starting to change. He actually had a seizure. My dog woke me up actually, because by

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that time I was sleeping in the other room to Paul because he wasn't sleeping at night. I was caring for Paul and I was also caring for my mum, you know, who is elderly. I needed to sleep. So my dog woke me up and I went in. Paul was just on the floor fitting. So I called the ambulance out and he ended up in hospital, in ICU, for 24 hours until they stabilised him. He got round and he came out of it. He came home.

But I had actually spoken to the doctor whilst he was in hospital, and the doctor said to me that he felt that Paul -- he was very poorly. His words were that, "He could last five minutes, he could last five weeks, he could last five months, but you've got to prepare yourself that he isn't going to last forever". So I sort of had that warning, so I had the time to, you know, get myself, you know, aware of the fact that he was going to die.

Q. Did they ever say what was actually wrong with Paul, what the issue was?

A. No, not until he died, no. It was just a case of he had got HIV, he had got hepatitis C, and I think it was just a case of they just saw those and that was it, that was what was going to kill him. And they were right at the end but, you know ...

30

Q. Then one morning he said he didn't want breakfast.

A. Yes. I got up one morning. He had come home from hospital obviously. I went in and I said -- because obviously he had to take his meds after food. He couldn't take them on an empty stomach. So I went in to say, "What do you want for breakfast so you can have your meds?" and he said, "Actually, do you know, I don't really want to have anything to eat, I feel a bit bloated and don't want anything". So I said to him, "Right, I will go and walk the dogs and sort out my horses and then I will come back and we will get you something to eat then because you have got to have something because you have got to take your meds", nag, nag, nag.

When I went -- I went off, came back about an hour later and went upstairs. Paul had been sick and had had diarrhoea. So I went in to him and said, "Oh, crikey. Come on, let's get you up and cleaned". So we had an old commode that my mum didn't use anymore, so I had said to mum, "Can I have it, just in case?", because Paul was blind by this time obviously. "Can I have it so I can put it by the bed so if he is struggling, he can at least get up and use the commode so he doesn't have to walk to the bathroom". So I got him up, stripped him down, got him on the commode,

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stripped the bed, started to clean him and he basically started to slouch in his chair, and I thought, "This isn't -- I think I had better phone for an ambulance". Because, I mean, he was talking to me, you know, he was saying to me, "Oh, I am sorry about this, dearest", because he used to calm me "dearest", or "posh bird" was his other one. "I am sorry about this, dearest. I'm sorry that you're having to do this. This isn't right that you are having to do this. No wife should have to be doing this to her husband". So he was talking to me, but he was just -- this slouching, and I was thinking, "No, this is not quite right".

So I phoned the ambulance. We were very lucky, because the first responder actually lived in the village that we lived in. So -- and he had been to Paul before when he had had a seizure. So he was there within five minutes. He knew that I had got dogs and he knew that the door was open, so he literally walked straight in and straight up the stairs. I think he knew straightaway and he was already sending messages and whatever to the ambulance that was on its way. He took Paul's vital signs and they were obviously weak. He advised me at that point that the ambulance was on its way and would be

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1 imminent, but that he was going to get the Air
2 Ambulance as well, so just to warn me that the Air
3 Ambulance was going to come.

4 At this point I was sitting next to Paul,
5 crouching on the floor, and I had got Paul's head on
6 my chest and my arms around him, and he is still
7 naked. He was still naked and I still hadn't had a
8 chance to fully clean him up below. So there he was,
9 sitting on a commode in the nude with faeces all up
10 his back. I whispered to him as all these paramedics
11 started to come in, "Don't you be dying on me, Hoopy.
12 I am not ready yet, so don't you be dying on me", and
13 he said, "Don't be silly, don't be daft, you silly
14 woman, I am not going anywhere".

15 We heard the helicopter. The paramedics said to
16 me, "Can you go and guide them in". They were coming
17 in to land in the playing field at the school behind
18 the cottage where we live. So I gave Paul a kiss on
19 the head and I said, "Don't be too cheeky to them",
20 because one of them was a woman paramedic and he was
21 a bit of a flirt, and off I went and came back with
22 the Air Ambulance crew. They had a doctor on board.

23 I sat downstairs, because by this time I must
24 have had -- I think I had got four paramedics, the
25 first responder, the pilot from the helicopter and the

33

1 he wasn't going to survive and he was going to die,
2 basically, and could I have their permission to turn
3 the life support off. I said yes, they could, but
4 I needed to let his brother and his sister know, who
5 he hadn't -- he was estranged from his sister. I met
6 his sister for the first time at Paul's funeral. They
7 hadn't spoken for very many years. His brother he was
8 a little bit more, you know, closer to his brother
9 but, you know, they weren't a particularly close
10 family as such. So they waited until Vic and Maureen
11 came from Birmingham. Once they had been in and said
12 their goodbyes, then they turned off the life support.

13 Q. You have said in your statement that for the second
14 time in less than a decade the Contaminated Blood
15 Scandal had left you bereaved.

16 A. Yes.

17 Q. Paul hadn't worked since his HIV diagnosis --

18 A. No.

19 Q. -- because he had been made redundant after his
20 employers found out about his diagnosis, and you had
21 been Paul's carer, so hadn't worked for six years by
22 the time of his death.

23 A. That's right.

24 Q. You have said in your statement that EIBSS have been
25 nothing short of rubbish. Why is that?

35

1 two medics all in my bedroom, so there was hardly any
2 room. So I sat downstairs and I could hear them
3 talking. Then I heard all this banging and crashing,
4 and then it all went fairly quiet. Then the doctor
5 that was with the Air Ambulance came down and she sat
6 next to me and she held my hand and she said he'd had
7 a cardiac arrest, that they had brought him round, but
8 she didn't think he was going to survive. She said
9 they were going to get him to the hospital, but they
10 couldn't take him in the Air Ambulance, because they
11 had already brought him round with a defibrillator and
12 she was pretty much certain that they would have to do
13 it again on the way to the hospital, and they can't do
14 it on the helicopter, obviously, for obvious reasons.

15 I wasn't allowed to travel with Paul. I had to
16 go in separately. They wouldn't let me on the
17 ambulance. But when they brought Paul down, he was
18 alive, but he didn't -- he looked horrendous. He was
19 ashen. He had got no colour.

20 Q. He had two more cardiac arrests on the way to
21 hospital.

22 A. Yes, yes.

23 Q. There was not much more they could do for him.

24 A. They put him on life support. When I got to the
25 hospital, they said that he was on life support, but

34

1 A. Well, Paul died in the December and I phoned up EIBSS
2 to tell them that Paul had passed away, and their
3 immediate reaction was they were going to stop
4 payments. That was it. Paul had had monthly payments
5 from them as well as a couple of benefits from the
6 government, a Disability Living Allowance, an ESA,
7 that sort of thing. So everything stopped. We went
8 from having, you know, three grand a month coming in
9 to nothing. It just -- that was that. It just
10 stopped dead. It was actually one of the other widows
11 of the Tainted Blood group that told me about -- "You
12 are eligible for a top-up payment". They didn't tell
13 me. It was one of the widows who said, "You do know
14 you can have this top-up payment".

15 So the rigmarole began. Bearing in mind there
16 was no money coming in. We had a mortgage, we had
17 council tax to pay, we had electrics and everything to
18 pay and I had nothing. All I had was £179 widow
19 pension a month from Jeremy, one of Jeremy's pensions,
20 a frozen pension he had had years before. That was my
21 monthly income. I didn't have anything. I went to
22 the EIBSS and, "Yes, we will send you the forms".
23 I had to wait for the forms. Then it was, "Yes, you
24 fill this form in". Then they want this piece of
25 evidence, then they want that piece of evidence.

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"When you have done that piece of evidence you need to get this piece of evidence to back that piece of evidence up". That's how it feels. It is just constant, you know, "We want this, we want that, we want three bags full". Then you send it to them and they write back to you and say, "Right, we have had all of that but we now need this as well". It was just a constant round of jumping through endless, endless hoops, endless red tape, and it took from Paul dying in the December, I had my first top-up payment from them in the April. So I'd gone for those months with nothing, and the only way that I was able to survive again, up steps Lewis, paying for food, and my elderly mother, who is a pensioner, giving me money to put petrol in my car, to put food on my table, otherwise I would have had nothing.

Then the real bitch about it, and excuse my language, but the absolute bitch about it is that I had my first payment in April and then I had a letter from them in June to say I'd got to do my 12-monthly reapply, because every year you have to reapply. So I rang them up and said, "Why am I reapplying for something that I have only just had?" "Oh, well, because that's what we have to do, so you've got to reapply". I said, "So what are you

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- A. It took 12 months to sell it or thereabouts.
 Q. You have downsized to a leasehold property.
 A. I downsized to a leasehold. I was able to pay off the mortgage and the mortgage arrears, and with the money that I was left I bought a little maisonette, my mansionette as I call it.
 Q. What has been the emotional impact of losing Paul and all of that turbulence around finances?
 A. It's just been a nightmare. Last year was probably the worst of my life. I mean, losing Jeremy, it was awful and it ended so abruptly, and having to go through losing my house. But the actual transition, although it was heartbreaking, heart rendering and I was on autopilot, but I managed to get through it, and it felt like it was much more simple. The house sold for a start. You know, I put the house on the market one day and the following day, pretty much, it was sold. So it all seemed to sort of all drop into place. Fate helped me with Jeremy. Fate did not help me with Paul, and I was left destitute, because thankfully the mortgage suppliers were amazing and they didn't start any kind of repossession order on me for the cottage until it was -- my luck changed, because I finally managed to sell the cottage and about three or four days after accepting the offer on

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saying?" "We will send you a form".

So they send me the form. It was the same form that I had filled in a few months prior wanting all the same evidence. So I rang them up and said, "You've got all this, I have supplied all of this", and they wanted it all again. So I had to send the whole lot again. Even though they had got it on their files and they'd only had it for a few months, I had to send it all again. So it just -- so the rigmarole went on.

- Q. Because of your financial difficulties, you then lost your home again.
 A. Yes. I was unable to -- the top-up payment was not enough to cover mortgage, outgoings, house outgoings, food. So I am afraid my mortgage had to be put aside in order for me to simply survive to get through each day, and it was a day, because I was paid monthly, but there was never -- it didn't last. As soon as I paid out what I could on the bills that I had, I just didn't -- there was too much month at the end of each money. I think we have all said it. But literally the money would come in and a week later it was all gone. So I then had to wait three weeks with nothing again.
 Q. Eventually you managed to sell your home.

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- the cottage and getting things -- getting solicitors sorted and all of that, I had the letter from the mortgage supplier to say they were actually starting repossession to get the cottage away from me and I was able to ring them up and say, "It's sold". I mean, they had been -- I can't knock them. They had tried everything they could. They even put me in touch with somebody they use to try to sell a house on their behalf. So last year was just -- it was the year from hell. It was awful.
 Q. You finished your statement very happily. If I may, I will just read a paragraph from it.
 A. Yes.
 Q. "I have known and lost two of the best human beings ever to have walked this earth. For me, it is about answers. I want to know why. I am honoured to have known both of them, I really am. I have been a privileged, privileged woman. I had my first love and I had my soulmate. They will always be with me and I will love both of them equally. My heart overflows with love for the pair of them. They are amazing men and they need their stories told, both of them."

Those are the questions I have for you. I am just going to turn to Mr Snowden, who as you know

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1 represents you, and see if there is anything else he
 2 wants me to raise.
 3 Before we finish, I think there is something
 4 else you wanted to finish with?
 5 **A.** Yes. I wanted to be a little bit different from
 6 everybody else, so please forgive me. I have written
 7 a poem.
 8 I'd like to thank my son, Lewis, and my mum for
 9 their love and financial support, and to the Tainted
 10 Blood family for holding me up on the worst of days.
 11 But mostly I'd like to thank my husbands, for
 12 heros they are both,
 13 Never got the chance to tell their stories under
 14 oath.
 15 Two good men in every sense of the word,
 16 Taken away so cruelly before they could be
 17 heard. I would like to thank you for your love and
 18 for making me your wife,
 19 And to tell you both, my beautiful men, you
 20 really were my life.
 21 My first love and my soulmate, I couldn't ask
 22 for more,
 23 Maybe one last conversation, before you closed
 24 the door.
 25 So now I am sitting here in the capital of our

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1 **SIR BRIAN LANGSTAFF:** Theresa, please.
 2 **THERESA ANN SMITH (affirmed)**
 3 **Questioned by MS FRASER BUTLIN**
 4 **MS FRASER BUTLIN:** Theresa, you are here to tell us about
 5 your infection with hepatitis C.
 6 **A.** Yes.
 7 **Q.** In December 1983, you required an emergency
 8 appendectomy.
 9 **A.** Yes.
 10 **Q.** And you understand that you were given a plasma
 11 transfusion at that time.
 12 **A.** Yes.
 13 **Q.** About a year later you noticed you were becoming
 14 jaundiced whenever you got a cold or were poorly.
 15 **A.** Uh-huh.
 16 **Q.** And then at some point that jaundice became severe and
 17 you were admitted to hospital.
 18 **A.** Yes.
 19 **Q.** Can you tell us about that?
 20 **A.** The doctors weren't sure what was causing it, because
 21 you shouldn't randomly become jaundiced. So they took
 22 me in to do some tests to find out what they thought
 23 was causing it. They did a liver biopsy and a couple
 24 of days later came back to tell me -- I believe it was
 25 then -- I had got non-A, non-B hepatitis.

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1 land,
 2 And I am hoping that Sir Brian will take things
 3 into hand,
 4 And the justice that so much deserved can
 5 finally be found,
 6 Before any more casualties fall on this
 7 battleground. Thank you.
 8 **SIR BRIAN LANGSTAFF:** It is a great wonder to me that
 9 since you have every right to be bitter, some may
 10 think, you have shown no trace of that and you have
 11 described yourself instead as privileged. You've
 12 given us a remarkable account, full of detail, some of
 13 which is truly horrible, but you have given it in an
 14 undaunted way. I can only say I am in some wonder and
 15 I thank you very much.

16 **A.** Thank you.

17 **(Witness withdrew)**

18 **SIR BRIAN LANGSTAFF:** We will start again at 11.55.

19 **MS FRASER BUTLIN:** Thank you, sir.

20 **SIR BRIAN LANGSTAFF:** 11.55.

21 **(11.22 am)**

22 **(Short break)**

23 **SIR BRIAN LANGSTAFF:** How would our next witness wish to
 24 be known?

25 **MS FRASER BUTLIN:** She is called Theresa.

42

1 **Q.** During that biopsy a blood vessel was also nicked --
 2 **A.** Yes.
 3 **Q.** -- and so you needed further blood.
 4 **A.** I did.
 5 **Q.** You don't actually remember very much of that time at
 6 all.
 7 **A.** No. It's a blurry week that week. I was quite
 8 poorly, yes.
 9 **Q.** When you were told you had non-A, non-B hepatitis,
 10 what did you understand about the condition at that
 11 time?
 12 **A.** Nothing. I just knew it wasn't A or it wasn't B, but
 13 they didn't really explain what the difference was, if
 14 there was a difference, what it meant.
 15 **Q.** Were you told anything about managing the condition?
 16 **A.** Not at all.
 17 **Q.** Were you told anything about any precautions you
 18 should take?
 19 **A.** Not at all, no.
 20 **Q.** Did they monitor you at all?
 21 **A.** No. Not to my recollection, no.
 22 **Q.** In 1989 you gave birth to your son, Tom.
 23 **A.** Yes.
 24 **Q.** Who is sitting with you today.
 25 **A.** Uh-huh.

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1 Q. It was a difficult delivery --
 2 A. Uh-huh.
 3 Q. -- and your son was in distress.
 4 A. Yes.
 5 Q. When you asked about the chances of your son being
 6 infected with hepatitis, what were you told?
 7 A. I didn't actually think of that until I started
 8 treatment myself over at Derriford, but I was told it
 9 is quite rare for children of mothers with hepatitis C
 10 to be transmitted in the womb. However, it transpires
 11 that he was infected in the womb, we believe. So,
 12 yes, that's what they told me. He was infected with
 13 the same strain.
 14 Q. Your son was born with a rare illness called sacral
 15 agenesis. Can you tell us what that means for Tom?
 16 A. It basically means the bottom part, the sacral area of
 17 his spine, did not form properly. So all these nerves
 18 -- because they showed me a CT scan once and it is all
 19 bundled up like a ball of wool. So all of the nerves
 20 that should be kept in a line by his vertebrae are
 21 just protected by a bit of cartilage.
 22 So there are lots of different effects. It
 23 affects mobility. I think he had his first operation
 24 at nine months old to release the tendons at the back
 25 of his legs, because he had no heels, and he was born

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1 given the impression it would be extremely
 2 debilitating and he would never be able to walk and it
 3 might affect the length of his lifespan.
 4 Q. At that point, the doctors also said they wanted to do
 5 some tests.
 6 A. Yes.
 7 Q. What were those tests for?
 8 A. They didn't know what caused it, because it is a very
 9 rare condition. It usually only occurs if the mother
 10 has diabetes, and then only in 1 in 200,000 children,
 11 I believe, so they couldn't work out why Tom was born
 12 with it because I don't have diabetes and never have
 13 had. So they did a few blood tests, and they also
 14 said they wanted to check me for HIV because I had had
 15 blood transfusions, which was very unpleasant because
 16 at the time you used to wait quite a long time to hear
 17 back. So I was under the impression, as many women
 18 who give birth to children with any congenital
 19 problems, that you might have caused it.
 20 So I was wondering for six weeks if my baby was
 21 going to die, because I had heard what happened to
 22 babies born to mothers with HIV. They died routinely.
 23 They were always on the news at that time. I had to
 24 wait six weeks. Then I made a phone call to the
 25 clinic. She didn't want to tell me because you are

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1 with his feet inverted and inwards and crossed over
 2 his chest, which is why I believe it was quite a
 3 difficult delivery, because they thought he was
 4 breached, but he wasn't; he was just in that position.
 5 It meant he has had quite a few operations over his
 6 life. They had to build him some feet, effectively,
 7 over at Bristol Children's Hospital when he was 7. He
 8 had two within a year. They broke all the bones in
 9 his feet, because he was walking on the top of his
 10 feet. They thought he would never walk, to be
 11 truthful.

When he was first born, the doctor had to go and
 look it up in a book, because he had not seen it
 before, he didn't know what was happening. He came
 back, explained that it was this condition called
 sacral agenesis, and he explained to me that he would
 probably never walk, that he would crawl all his life,
 that he could get renal failure, that he could have
 hydrocephalous.

20 Q. Which is fluid on the brain?

21 A. Yes, which is common apparently in people with sacral
 22 agenesis. I don't know why, but so I am told. As it
 23 turns out, the doctor was incorrect. He took it upon
 24 himself to stand up and walk one day. But I was given
 25 the impression -- it is a severe disability, but I was

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1 not allowed to tell people over the phone, but
 2 I couldn't go in, so she said, "I am just going to say
 3 it's not as bad as what you think it is". I said
 4 "That's okay", because clearly that's not "You have
 5 got it".

They did want me to go back and have it done
 again six months later, but I didn't because I didn't
 think it was that in the first place and I didn't want
 to put myself back through that, to be honest. As
 they already knew I had got non-A, non-B, I don't know
 why it didn't occur to them either. It was a bit
 stressful, to say the least. It was a traumatic time.

13 Q. But at that stage nobody said anything to you about
 14 non-A, non-B hepatitis?

15 A. Absolutely not, no. Never came up.

16 Q. The tests were for HIV. They were negative.

17 A. Uh-huh.

18 Q. And that was the end of the investigations?

19 A. Yes. They had no idea. I saw a geneticist when Tom
 20 was about six months old and he couldn't explain it
 21 either. Nobody could.

22 Q. Then in about 2002 you realised that non-A, non-B
 23 hepatitis was, in fact, hepatitis C.

24 A. Yes.

25 Q. What was it that triggered that realisation?

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1 A. I had a conversation with somebody who said that what
2 I was describing with the repeated episodes of
3 jaundice and the fact that I had what was termed
4 non-A, non-B many years ago, he said, "That's classic
5 hepatitis C. Did you know?" I didn't know. So I got
6 in touch with the Lighthouse Trust and they confirmed
7 that, that hepatitis C is non-A, non-B. I still
8 didn't know at that point. That's what sort of
9 prompted me to go and have some tests to see if
10 I actually had got that and what I could do about it.
11 Q. And until that point you had no interactions with
12 anybody about your hepatitis C?
13 A. No, for 20-odd years, I suspect. It is about 20
14 years. Nobody had said a word about it.
15 Q. You then sought out treatment.
16 A. Uh-huh.
17 Q. And you went to see and asked to be referred to Dr
18 Cramp.
19 A. Yes.
20 Q. When you first saw him, you said he was excellent.
21 A. He was really good, yes.
22 Q. Can you tell us why he was particularly good?
23 A. Well, I do actually know that he's sort of like
24 a leader in his field, but at the time he was very --
25 he knew his subject. He explained to me what it

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1 A. After the first few weeks I was constantly nauseous.
2 They had to give me medication because I just wanted
3 to vomit all the time. At the time my dad was in
4 Derriford Hospital, because he was in renal failure.
5 So I was having to go there every day anyway, so ...
6 I have never really suffered from depressive
7 illnesses, but that treatment gave me such a
8 depression. I just woke up one morning and it was
9 like I was just crushed. I couldn't work out why.
10 For a day or two it didn't sink in, but I just
11 couldn't stop crying. I just felt like everybody
12 I knew had died overnight. It was just awful.
13 Apparently it was one of the side effects from the
14 treatment.
15 So I went along to the GP's and they treated it
16 with anti-depressants, but I also couldn't go --
17 I used to take regular exercise. I couldn't do that,
18 because you couldn't breathe, because your sort of
19 blood cell count was affected by it. It just -- it
20 wasn't very nice. It was very unpleasant. It was
21 worth it, but ...
22 Q. When you first realised that you were depressed, you
23 went to see a GP.
24 A. I did, yes.
25 Q. And they insisted you had to wait two weeks.

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1 meant. He explained to me there were treatments
2 available. He offered me the chance to be involved in
3 a trial that was running at the time, which was the
4 Ribavirin and interferon trial. So he put me on that.
5 And he also offered to check Tom. When I mentioned
6 Tom, he also offered to check Tom with a view to
7 getting treatment for Tom once he was of a legal age
8 to do so, because he was too young at the time. So he
9 had to wait until he was 18 to have it done.

10 He also mentioned the Skipton Fund. I believe
11 it was Dr Cramp who brought that up, because I had
12 never heard of that before either. So he was the one
13 that signed the forms and got it all sent in.

14 Q. You said he explained everything to you in a very calm
15 manner.

16 A. He was.

17 Q. And set everything out for you for the first time.

18 A. Yes.

19 Q. You went ahead with the trial --

20 A. I did, yes.

21 Q. -- for about six months, and you cleared the virus.

22 A. Yes.

23 Q. But you've described the side effects as "vile".

24 A. Yes, they were.

25 Q. Can you tell us anything about that?

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1 A. Yes, because that would be the normal -- that's their
2 normal sort of course of action if you have a
3 psychological depression. However, I knew it wasn't
4 a psychological depression, because it just -- I have
5 never had it before and it was just -- I went to bed
6 okay and when I woke up the next morning I wasn't
7 okay. So I left that with that GP and then the next
8 day I went back and saw a different GP in the same
9 practice and explained to him that I know what this
10 is, and he was kind enough to listen and provided me
11 with anti-depressants.

12 I am not sure how well they worked. I don't
13 know. I can't remember, truthfully, because it's
14 quite a little while ago. Maybe just the fact that
15 somebody listened might have helped a little bit, but
16 it had gone by the time I stopped taking the
17 treatment, so...

18 Q. Were you offered any counselling or psychological
19 support during the time?

20 A. No, no, no.

21 Q. You say in your statement the effect of the hepatitis
22 C on Tom has been tremendous, and you believe there's
23 a link between the hepatitis C virus and his sacral
24 agenesis.

25 A. I do.

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1 Q. Can you explain that for us?
 2 A. Okay. So because I have none of the normal risk
 3 factors that might indicate your child could be born
 4 with it if it does happen, even though it is so rare,
 5 I have wondered for so long what could have caused
 6 this. I started looking into it, and it appears that
 7 hepatitis C is what's known as a flavivirus, the same
 8 as some other big viruses like Zika, for example,
 9 which affects bone formation in the womb. Tom's
 10 physical problems are caused by a lack of bone
 11 formation in his spine. I am aware that they have
 12 done a little bit of testing, but not on humans yet,
 13 to find out if there's any link, but I do know that
 14 hepatitis C does do that in other mammals, such as
 15 cats. If you inject a pregnant cat with hepatitis C,
 16 its kittens will be born with deformed spines.
 17 So I feel, because I haven't got the risk
 18 factors in place, and because there seems to be
 19 evidence that suggests it could be that, that it's
 20 more than likely that's what caused it.
 21 Q. You said earlier in your evidence that Tom surprised
 22 everyone by getting up and walking.
 23 A. He did.
 24 Q. But he's needed a number of operations to rebuild his
 25 feet.

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1 day. He couldn't walk for days. It is just not
 2 practical, because he's putting himself through too
 3 much pain to go out and work. Although there's a
 4 downside to that in that you need to go out and work,
 5 not just for the money, but he's a young man. You
 6 don't want to be stuck at home all day. And he is a
 7 clever man, I have to say. It feels like it's a waste
 8 and it's been caused by that condition.
 9 Q. As you said, Tom was also diagnosed as hepatitis C
 10 positive and, once he was 18, he also underwent
 11 treatment.
 12 A. Yes.
 13 Q. With similar side effects.
 14 A. I don't know. I think he sailed through it slightly,
 15 but that could have been an age thing a little bit.
 16 I don't think it was quite so bad. They cleared it.
 17 It started to clear quite quickly again, didn't it, as
 18 well? So, yes.
 19 Q. He cleared the virus.
 20 A. Yes. We cleared it quite early on, after a few weeks,
 21 but they kept us on the whole six months obviously,
 22 just to see if it had gone.
 23 Q. Since then, what has been the effect on you in terms
 24 of your physical health since you have cleared the
 25 virus?

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1 A. Uh-huh.
 2 Q. And calipers as well.
 3 A. Yes.
 4 Q. He suffers constant pain in his feet.
 5 A. All the time. All your life, haven't you?
 6 Q. And hasn't been able to work.
 7 A. As he's got older, it's got worse, you see. It is
 8 progressive, because he is walking on plastic,
 9 effectively. It is rubbing away the fat underneath
 10 his feet, which is what you need to protect your bones
 11 when you walk. Tom basically has got no fat left
 12 underneath his feet now, so the illness is
 13 progressing, and it's so painful now that he can't
 14 work.
 15 Q. He surprised everyone by going to university and then
 16 trying to find work.
 17 A. Yes.
 18 Q. But just couldn't sustain it because of the pain.
 19 A. I think it was -- the last time was about a year ago.
 20 He started a new job, and after his shift, which was
 21 12 hours, 10 until 12, Tom doesn't complain about the
 22 pain in his feet, but he rang me because he was in
 23 agony and he couldn't make it to the bus stop, which
 24 was not very far from where he was working, and he
 25 actually lacerated his feet just by being on them all

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1 A. It's difficult to quantify. I don't have ill health
 2 per se. I have a suspicion that it may be having an
 3 effect on my blood vessels because I get really cold
 4 hands, and when I say cold, they are so cold that
 5 I can't hold the steering wheel of the car because it
 6 hurts. I can't grasp things. It is not so bad this
 7 time of year, even though they are cold today, but in
 8 the winter it is... it went away for a little while
 9 while I was on treatment and then came back again, so
 10 I'm not sure. I'm investigating whether there's
 11 a link in that. That concerns me slightly, because
 12 you can't see the blood vessels inside your body.
 13 I can see the ones in my hands, but all the blood
 14 vessels in the smaller parts can be affected. So
 15 I need to find out, just in case it is that, because
 16 it's a risk to your life. It's life-threatening. So
 17 I need to find out. Apart from that, I can't honestly
 18 say that I think it affects my health.
 19 Q. But it has had a huge emotional impact on you, and
 20 particularly the fact of Tom's illness.
 21 A. Yes. It is difficult to believe that it would have
 22 happened had I not had hepatitis C in the first place.
 23 So, yes, I think it's a guilt thing. Nobody has
 24 a baby expecting to give them something that's going
 25 to have a significant effect on their life, and

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1 I honestly believe that this did. I know it's not my
 2 fault I had it, but I still transmitted it. So, yes.
 3 **Q.** You said in your statement you have tremendous guilt
 4 over your son's illness following his birth and
 5 ongoing, as you thought you must be somehow to blame
 6 for it.
 7 **A.** Yes. Yes. When he was born I thought, "It has got to
 8 be me. How did that happen? What did I do?" I felt
 9 that way for quite a long time at the beginning. And
 10 really, to a certain extent, it is true; I may have
 11 passed on something that's had a considerable effect
 12 on the way his life has developed. So, yes, it does
 13 make you feel guilty. It does.
 14 **Q.** And you have ongoing fears of things in the future.
 15 You described it as continuing to live knowing you are
 16 a living experiment in this illness.
 17 **A.** I think we are. I think all of us who have been
 18 infected by it are, because they don't know -- even if
 19 they clear it, so we are living hepatitis C negative,
 20 this is a new thing. People used to get liver disease
 21 and they would pass, but with this we are getting
 22 liver disease and we are being treated and cured, but
 23 nobody knows what's going to happen in the future.
 24 For all we know, there could be a ten-year period
 25 where all of a sudden that treatment stops working

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1 a spider bite which had tracked, because it was
 2 infected, and the nurse assumed that was from
 3 intravenous drug use. So there was a lot of ignorance
 4 out there around it.
 5 **Q.** And now if you tell anyone that you have hepatitis C,
 6 you are very quick to say that you contracted it
 7 through infected blood.
 8 **A.** I always say that. I do always say that just to be on
 9 the safe side. But I think people are much more
 10 knowledgeable about it now, but I do tell people.
 11 I always tell people, because I work in the health
 12 profession, but yes.
 13 I am a little bit concerned that I was working
 14 with it for years and years and years without any
 15 knowledge of what was going on inside my own body and
 16 the risk of transmitting it to other people, because
 17 I will have worked with thousands of people over the
 18 years, and it does occur to me occasionally that -- it
 19 is difficult to know if you have infected anybody if
 20 somebody doesn't tell you to take precautions, because
 21 they didn't. So hopefully not, but ...
 22 **Q.** You are now a qualified nurse.
 23 **A.** Uh-huh.
 24 **Q.** Quite recently.
 25 **A.** Uh-huh.

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1 or... nobody knows.
 2 All the time there are new concerns coming out,
 3 because people are living longer. There's a special
 4 category mechanism, is it called, that's just been
 5 introduced, because the amount of people that have
 6 developed illnesses which are related to retrovirus,
 7 as hepatitis C, it's a new thing. They didn't know
 8 about it. People would have died before. Many people
 9 probably have died before, but the treatment is
 10 keeping us alive and the effects are sort of stacking
 11 up now.
 12 **Q.** You thought about bringing a legal case in relation to
 13 your infection and your son, but when you went to
 14 a solicitor, they assumed that you were an IV drug
 15 user.
 16 **A.** Yes, they did. They did. I mean, the first time
 17 I came across hepatitis C myself was when I was
 18 working in care homes. I came across a few patients
 19 who had it and they were described as drug users
 20 because of the hepatitis C. So I think that was
 21 a general sort of stigma that went along with it at
 22 that time. Bringing it out into the open in the form
 23 of an Inquiry and people coming forward has changed
 24 that, many people are aware now, but it happened --
 25 when Tom went to have treatment at Derriford, he had

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1 **Q.** But you still find it difficult at work that you were
 2 hepatitis C positive?
 3 **A.** It's something I have to bring up in the course of
 4 every job, because it's my responsibility, and also
 5 because I would anyway, because I'd hate to think
 6 I did infect somebody by accident. I can't now, I am
 7 hepatitis C negative, but all the same. As I say,
 8 I am never sure that we are hearing the whole truth,
 9 because at the beginning we didn't hear the whole
 10 truth. We clearly didn't, because they weren't
 11 explaining what non-A, non-B was, for example, whereas
 12 in other countries they knew what that was.
 13 Yes, I feel possibly things have been hidden
 14 from us for a long time and they might be continuing
 15 to be hidden from us, because it was a mercenary act
 16 to buy infected blood and nobody has taken any
 17 responsibility for it, and there's lots of stories out
 18 there where people have suffered.
 19 **Q.** And your fear is that that's continuing, which impacts
 20 your interactions with people at work and interactions
 21 with medical professionals.
 22 **A.** Yes, it does, yes.
 23 **Q.** You and Tom received money from the Skipton Fund.
 24 **A.** We did.
 25 **Q.** But then only very recently have you made a connection

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1 with EIBSS. How did you come to know about the EIBSS
 2 and why was there the gap?
 3 **A.** The gap could have partially been because I've moved,
 4 although I found out about the EIBSS payments through
 5 a documentary that was on the TV prior to the start of
 6 the Inquiry hearings and it mentioned payments, and it
 7 also mentioned within the course of that documentary
 8 that people with hepatitis C, they had made efforts to
 9 contact them. They had not made efforts to contact
 10 them unless I am an individual case that they didn't
 11 contact, because they would have contacted me, is the
 12 way I see it. So I found out about the EIBSS payments
 13 through that programme essentially.
 14 **Q.** So there were two issues that programme raised for
 15 you. One was why you had not been traced much
 16 earlier--
 17 **A.** Yes.
 18 **Q.** -- about having hepatitis C, having been previously
 19 diagnosed with non-A, non-B.
 20 **A.** Definitely.
 21 **Q.** You were concerned by that gap, that nobody had been
 22 in touch.
 23 **A.** Particularly because it was made as an explicit
 24 statement that there had been great efforts made to
 25 track people down so that they could inform them what

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1 illness, it is harder. They can often give you an
 2 idea.
 3 With Tom, I don't know that they can actually
 4 give me an idea, because they don't know what caused
 5 it in the first place. Therefore the prognosis that
 6 would normally accompany sacral agenesis that has been
 7 contracted through the mechanism of a diabetic mother,
 8 they don't apply. I don't know what will happen.
 9 I don't know how this will progress. That does
 10 concern me.
 11 **Q.** It also concerns you in terms of financial provision
 12 for Tom.
 13 **A.** Yes.
 14 **Q.** Very practically what will happen.
 15 **A.** Yes, yes, it does. It does. I mean, because we have
 16 talked about -- the pain is so bad, you've talked
 17 about having amputations on your legs, and he will
 18 definitely get arthritis in his feet, both feet. He
 19 had a lot of surgery on his feet. So there's a lot of
 20 pain in the future. I'd like to think that there's
 21 something in place to make sure that if he needs
 22 anything, then it's properly looked after, because you
 23 didn't do anything to deserve it. So, yes.
 24 **Q.** Those are the questions I have for you. Is there
 25 anything else you would like to say?

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1 was happening and explain about any finance they may
 2 be due or... I wouldn't go so far as to say it's
 3 a deliberate lie, but it's a misstatement, because
 4 they never bothered contacting me.
 5 **Q.** Secondly, in that programme you realised that Skipton
 6 had become EIBSS --
 7 **A.** Yes.
 8 **Q.** -- or replaced by EIBSS, and you realised you weren't
 9 in contact with EIBSS and were missing out on
 10 financial assistance.
 11 **A.** I rang them that afternoon just to check and they
 12 said, "Yes, you should have been paid from last year".
 13 So I did that and I let Tom know as well. So we did.
 14 **Q.** But as far as you are aware, there was no effort to
 15 trace you from your Skipton application to when EIBSS
 16 came into play?
 17 **A.** No, I don't think so.
 18 **Q.** You have said in your statement your real concern is
 19 Tom.
 20 **A.** Yes.
 21 **Q.** Especially once you have gone and the future effect on
 22 his own health.
 23 **A.** It concerns me. If you have an illness, they can give
 24 you a prognosis of how it's going to develop and
 25 what's going to happen in the future. If it's a rare

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1 **A.** No, not really, no. It's difficult, because it feels
 2 like I haven't been that affected, truthfully.
 3 There's some heartbreaking stories out there and it's
 4 had massive impact on people's lives, but at the same
 5 time when somebody said, "Would you like to give
 6 a statement?" I just think, well, we all need to
 7 really, don't we, because we need to get to the bottom
 8 of this and we need to prevent it happening again.
 9 That's it, really.
 10 **SIR BRIAN LANGSTAFF:** Well, I don't think you can possibly
 11 say that it hasn't affected you. It obviously has
 12 affected you and Tom. But you have given us a very
 13 lively account of living with uncertainty and looking
 14 for answers to the questions that you have, because
 15 they still -- I wouldn't say worry, but concern you.
 16 **A.** Yes.
 17 **SIR BRIAN LANGSTAFF:** And I would just like to thank you
 18 very much for that.
 19 Can I thank you both as well, Tom too, because
 20 you have come here today to describe the conditions
 21 from which Tom suffers and which you have mothered,
 22 and that's not easy. It's very brave, in my view.
 23 Thank you.
 24 **A.** Thank you.
 25

(Witness withdrew)

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1 **SIR BRIAN LANGSTAFF:** Well, we will take a break until
2 1.30.
3 **MS FRASER BUTLIN:** And after the break, sir, there will be
4 no live stream for the next witness, but we will have
5 a live stream for the fourth witness of the day.
6 **SIR BRIAN LANGSTAFF:** So if anyone is out there and taking
7 a stream, they might expect that the next witness will
8 be, what, about an hour and a quarter, we think?
9 **MS FRASER BUTLIN:** I think so, sir, yes.
10 **SIR BRIAN LANGSTAFF:** About an hour and a quarter. So it
11 may very well be some time around 3 o'clock that we
12 will resume streaming.
13 **MS FRASER BUTLIN:** That's correct.
14 **SIR BRIAN LANGSTAFF:** But for now I will see you again at
15 1.30.
16 (12.31 pm)
17 (Luncheon adjournment)
18 **SIR BRIAN LANGSTAFF:** As you were told at the end of this
19 morning's hearing, the next witness is anonymous and
20 there will be no live streaming. He will be known to
21 you and me as Mr AM. For those who are wondering
22 whether that's an M or an N, it is Alpha Mike in
23 phonetic.
24 The order in his case is this: the name and
25 address of witness W0125 -- that's Mr AM to you and me

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1 please. It should come up on the screen in front of
2 you. If we can have page 9, we can see there in the
3 bottom half of the page -- and this is from your
4 UKHCDO database records -- the treatments that you
5 received in the course of the 1980s. So we have
6 cryoprecipitate 1981 and 1982, then Factor VIII (BPL)
7 and Oxford Factor VIII in 1982, cryoprecipitate in
8 1983, Oxford Factor VIII in 1983 and BPL Factor VIII
9 in 1983.
10 **A.** Yes.
11 **Q.** So far as 1984 and 1985 are concerned -- and the
12 significance of that we will come back to -- you are
13 recorded as having received cryoprecipitate in 1984 at
14 Great Ormond Street, Factor VIII BPL in 1984 at Great
15 Ormond Street and Oxford Factor VIII in 1985.
16 **A.** Yes.
17 **Q.** It was in 1984 that you went on to home treatment.
18 **A.** Yes, around then, yes.
19 **Q.** Now, on 30th September 1985, you tested positive for
20 HIV.
21 **A.** Yes.
22 **Q.** You were only four years old at the time. If we keep
23 this document up on screen, Henry, but go, please, to
24 page 10, we can see in the top right-hand corner "Date
25 last negative: 15th December 1984". Then if we go to

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1 -- the name of any member of the witness's family and
2 any other identifying information, such as the
3 witness's image or a description of his appearance,
4 cannot be disclosed or published in any form unless
5 express permission is given by me or by the Solicitor
6 to the Inquiry acting on my behalf. Witness 0125 must
7 be referred to only as "Mr AM".

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

13 Now that that order is in place, Mr AM, please.

14 **Mr AM (sworn)**

15 **Questioned by MS RICHARDS**

16 **MS RICHARDS:** You have severe haemophilia A.
17 **A.** Yes.
18 **Q.** As do your two brothers.
19 **A.** Yes, they do.
20 **Q.** And your condition was diagnosed when you were a baby.
21 **A.** That's right, yes.
22 **Q.** Most of your treatment during your childhood was at
23 Great Ormond Street Hospital.
24 **A.** Yes.
25 **Q.** If we have up on screen, please, Henry, 0125002,

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1 the next page, page 11, please, you will see in the
2 top left-hand corner, "Date first positive: 30th
3 September 1985".
4 I understand from your statement that your
5 parents were not aware that you were being tested for
6 HIV.
7 **A.** No, I don't believe they were.
8 **Q.** They have become aware of another Great Ormond Street
9 patient being diagnosed with HIV at the same time.
10 **A.** Yes.
11 **Q.** One inference you have suggested in your statement is
12 there may have been some form of systematic testing of
13 patients going on.
14 **A.** Yes.
15 **Q.** Now, you believe the treatment which affected you was
16 in all probability the BPL Factor VIII you received in
17 1984.
18 **A.** Yes. You can see the window of opportunity for me to
19 be infected can be narrowed from the earlier negative
20 test. So between then and the positive test, there
21 was, I think, only one treatment during then. So the
22 likelihood is that that is when I was infected.
23 **Q.** One particular reason why in all likelihood it is the
24 November 1984 treatment, not a 1985 treatment, is that
25 one of your brothers was also given Factor from the

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1 1985 batch but was not infected with HIV.
 2 A. That's right, yes.
 3 Q. The late 1984 batch, which was given to you for
 4 a bleed in your left elbow, is the one treatment
 5 within the relevant window which was not shared by any
 6 of your siblings.
 7 A. That's right, yes. Back then, it is important to know
 8 we were very careful about batches, and until even
 9 recently with haemophilia we were very careful about
 10 batches because hospitals always told you never to mix
 11 the batch. Very occasionally, I think maybe once or
 12 twice, even with more modern treatment, I remember
 13 having a new batch and feeling a little unwell for an
 14 hour or so, dizzy, hot, that sort of thing. So you
 15 were strictly advised not to mix batches. So back
 16 then it was even more tightly controlled and advised
 17 not to mix batches.
 18 Q. Now, by the time you were given Factor VIII in
 19 November of 1984, and putting the case at its lowest
 20 on the basis of evidence the Inquiry has already
 21 heard, there is evidence to suggest that the risk of
 22 HIV from blood products was at least suspected.
 23 A. Yes.
 24 Q. What, as far as you know, were your parents told about
 25 the risks of the product they were giving to their

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1 advised that the NHS unheated product was likely to be
 2 safer than the heated commercial product and it is
 3 correct to say that we expressed a preference for
 4 [you] to stay on the unheated Lister product."
 5 A. Yes.
 6 Q. That's on the basis of advice that was being given to
 7 your parents at the time, based on this statement.
 8 A. Yes, probably based on the donor source that we knew
 9 -- in America where the donations were coming from,
 10 but in the UK it was felt that because donations were
 11 given on a more voluntary basis, it was likely to have
 12 come from a safer source.
 13 Q. Now, how did your parents learn of your diagnosis
 14 after this test that was carried out in September
 15 1985?
 16 A. They were told very quickly. The end of September,
 17 I think -- in early October they were contacted by
 18 Great Ormond Street, by the doctors, and asked to come
 19 in. They said one of the tests had come back and
 20 there was an irregularity about them. They asked my
 21 parents to come in as soon as possible. My dad was
 22 working away at the time in Liverpool and he flew back
 23 to London and my parents went -- sorry.
 24 Q. It is fine. Take your time.
 25 SIR BRIAN LANGSTAFF: Take your time, and there's water if

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1 children?
 2 A. I am not aware they were. I am not aware they were
 3 advised of any risks. I think probably, like many,
 4 the majority of the information came through the
 5 media. In a very different age to today, whereas
 6 obviously if something happens in America, you can
 7 find out within minutes here, that sort of information
 8 would have trickled through the print media, through
 9 television. So very little, if any, were they told
 10 about it.
 11 Q. We have a statement from your mother that was made in
 12 earlier litigation. Perhaps we will put that on
 13 screen. It is 0125003, please, Henry. If we go to
 14 the second page, we can see -- if we go a little bit
 15 further down the page, please, Henry -- thank you --
 16 we can see reference in that middle paragraph to there
 17 being -- towards the end of 1984:
 18 "By that time we were becoming anxious about
 19 AIDS."
 20 A. Yes.
 21 Q. Then your mother makes reference to a meeting at Great
 22 Ormond Street. We don't know the precise date of the
 23 meeting from this statement.
 24 A. No.
 25 Q. Which says this: "My recollection is that we were

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1 you want to drink it.
 2 A. And they went to Great Ormond Street. They speculated
 3 as to which one of us it was who was ill. My mum knew
 4 that it was me, because she said my glands had been up
 5 all year, so she knew it was likely to be me that the
 6 irregularity related to, and when she got there and
 7 they were told, she was right.
 8 MS RICHARDS: What were your parents told about your
 9 prognosis?
 10 A. They were told I would be lucky to make my tenth
 11 birthday.
 12 Q. Looking back, how did that diagnosis affect family
 13 life over the following years?
 14 A. It's only with hindsight I can look back, because
 15 I wasn't told myself then. I was told later, which
 16 I am sure we will come to. Life was -- I suppose life
 17 was tough. Was it difficult? Yes. But my father
 18 worked. My mother didn't. Having three young boys
 19 with haemophilia was quite enough to cope with. So
 20 she didn't work and looked after us, because you never
 21 knew which one of us would be on crutches, in a
 22 wheelchair or need tending to at school, all those
 23 sort of things. So Dad worked. He was self-employed.
 24 Coming to around the 1990s, the recession hit. He
 25 worked in the building industry. So things were

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1 incredibly difficult. But I think, understandably, my
 2 parents struggled to cope, as anyone would.
 3 My dad was diagnosed with depression and had
 4 some -- was given medication for that, but because he
 5 was driving to and from work and it made him nauseous,
 6 then he had to stop. That was back in 1986. You can
 7 imagine working in a male dominated environment it
 8 must have been impossible to talk about. We look now
 9 today and we talk about things like mental health and
 10 the fact it is okay not to be okay and the campaigns
 11 that are going on now. I can only imagine what my
 12 parents were dealing with back in the mid 1980s, not
 13 really being able to have any support. So they
 14 struggled and I think, having read their statements
 15 from previous litigation, I know that my mum said
 16 effectively they were living separate lives.

17 Q. I am just going to, if I may, read a couple of
 18 passages from those statements. Your mother in her
 19 statement said this:

20 "I have found it exceptionally hard to cope with
 21 the fact that [you have] been the unluckily one whilst
 22 his two brothers have mercifully been spared. After
 23 we found out about it, it had a devastating effect on
 24 our lives. My husband and I could not discuss it
 25 together and we had to deal with it as best as we

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1 As I say, we weren't rich by any stretch of the
 2 imagination, but we had the best of what they could
 3 afford.

4 Q. How and when did you learn of your HIV diagnosis?

5 A. I learned in the summer of 1993. I was 12 at the time
 6 and I was just moving schools. I was going from --
 7 the school system I was in had [redacted]. So I was
 8 at middle school and I was about to go to secondary
 9 school. My -- one of my other brothers and I went to
 10 a hospital appointment at Great Ormond Street, and my
 11 dad came, which was highly unusual. Dad never came to
 12 the hospital. As I have said in the statement, he
 13 struggled to cope, like so many that we have heard at
 14 the Inquiry, and many people buried their heads in the
 15 sand and I think that was largely speaking Dad's
 16 coping mechanism. Dad came to the hospital, so
 17 I thought something was up. As I said, he was the
 18 breadwinner, he worked, so coming to hospital for
 19 a day meant him not working.

20 I remember being in the waiting area with my
 21 brother and my dad. We were sat there for quite some
 22 time, I think probably well over an hour. My mum had
 23 disappeared for a time. Then eventually I was taken
 24 into a room with one of the doctors and my nurse from
 25 Great Ormond Street, and I sat down and I didn't know

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1 could separately. I tried to keep cheerful and do
 2 things with the children and he had to keep going with
 3 his work."

4 She talks about isolation and the devastating
 5 effect on lives. At the point in time at which she
 6 gave that statement, you still hadn't been told
 7 yourself of the diagnosis.

8 A. That's right, yes.

9 Q. She says this:

10 "My husband and I very much fear the day when we
 11 have to explain to him about his infection and how he
 12 will be able to cope with it."

13 Your father in his statement talks about
 14 wrapping up all the problems internally and going
 15 through a very difficult time.

16 A. Yes.

17 Q. You also say in your statement, looking back, that you
 18 think your parents, having been told in particular
 19 that you might be lucky to see your tenth birthday,
 20 tried to make sure you and your brothers had a good
 21 time.

22 A. Yes.

23 Q. To go away and trying to give you the best of things.

24 A. That's right, yes. We always had -- so it was only my
 25 dad who worked. We always had good family holidays.

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1 what was going on, quite frankly, but it all happened
 2 relatively quickly, so I didn't have too much time to
 3 think about it. So they sat me down and they
 4 explained to me that I was HIV positive.

5 Q. Can you recall what you thought and what, if anything,
 6 you said?

7 A. Immediately I burst into tears. I was -- it was
 8 a shock. I think my mum said in her statement that --
 9 previous statement that she thought I was the
 10 brightest out of the three of us and she thought there
 11 might come the day when I worked things out and put
 12 two and two together and asked the question, and if
 13 I did, they would inevitably tell me. But I didn't,
 14 because I was relatively fit and well. So it was a
 15 complete shock to me. I broke down into tears
 16 straightaway, and when I eventually recovered my
 17 composure, I think the first thing I said was, "Am
 18 I going to die?"

19 Q. Can you recall what, if anything, by this time the
 20 doctors were able to say to you about prognosis?

21 A. Probably more than what my parents were told, but
 22 probably less than what one might be told now.

23 I wasn't necessarily given a prognosis of sorts, but
 24 I was told that obviously there was more treatment
 25 available, and I think my first HIV doctor and maybe

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1 my second HIV doctor may have said similar things
2 along the lines of, "The longer you stay alive, the
3 more research and progress is being taken and the
4 better your life expectancy will be". Obviously we
5 are at a stage now where most people can expect to
6 live a relatively normal and full life. So it was
7 tentatively optimistic, I think, about my prognosis.

8 **Q.** You have said in your statement you felt very
9 supported on the day you were told.

10 **A.** Yes.

11 **Q.** This had been arranged between your parents and the
12 hospital that the news would be broken to you in this
13 way.

14 **A.** Yes. It was no accident like others have found out.

15 **Q.** You said in your statement that after the initial
16 response, you thought, "I haven't known for seven
17 years and I have been okay, so why can't I continue to
18 be okay?" and you just carried on.

19 **A.** That was largely my mindset. I did have a few
20 difficult days. I would be lying if I said I didn't.
21 And I don't know where that fortitude came from for
22 a 12/13-year-old either. But, yes, that was my
23 rationalisation of it, that I have been okay for seven
24 years and why shouldn't I continue to be okay? So, in
25 a way, the fact that I had not known to start with was

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1 bleeds. I think at one point I may have been told
2 that as a result of that my blood got thicker so I was
3 taking this medication to help balance it out. So
4 I think I was told various white lies to make sure
5 I didn't work out what was going on.
6 There were other things that, again, as I say,
7 I join the dots. I remember going to see the GP at
8 various times with my brother, my younger brother and
9 I, and at the end of the appointment at times my
10 brother and I would be asked to go and stand outside
11 in the corridor and I could hear on the other side of
12 the door my mum crying. Looking back, I realised that
13 was because that was the only person she could talk to
14 about it. That was the only other people who knew.

15 There were other situations, I think. Although
16 a dark subject, it sounds almost ridiculous, but we
17 would have quite lighthearted conversations sometimes
18 in the car on journeys about, you know, if you died,
19 what would you want to happen to you, would you want
20 to be cremated or buried? I always said I wanted to
21 be buried rather than cremated. I couldn't stand the
22 idea of being cremated. As I say, it was quite
23 a lighthearted conversation, but, you know, with
24 hindsight, it was clear that my parents were planning
25 my funeral in their own heads.

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1 a blessing.

2 **Q.** And you have explained in your statement that in the
3 year or 18 months following the communication of the
4 diagnosis to you, you started to look back on the time
5 before your diagnosis and to make sense of some
6 things.

7 **A.** There were lots of things that I started to join the
8 dots in relation to. As I said before, my mum thought
9 there might be times when I realised what my diagnosis
10 might have been and asked the question, but I didn't.
11 With hindsight, I can see where the opportunities lay.
12 I started on HIV medication when I was about 8 years
13 old. I remember vividly standing in the kitchen.
14 I think it was AZT and it was in a syringe and it
15 didn't taste very nice. I had to take it and I said
16 to my mum I didn't want to, so she said, "If you take
17 it, you can have a glass of Coke". So I did, and that
18 was that. I carried on taking it. Then years later
19 it turned into something else. But, of course, I was
20 taking the medication and my two brothers weren't.
21 So, as I say, there was the first opportunity for me
22 to say, "Why am I different to the other two?" but it
23 just never dawned on me.

24 I was given spurious explanations as to why
25 I was taking it. For example, I had lots of joint

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1 **Q.** You also mention in your statement a few occasions
2 where your mum would ask you if anyone had asked you
3 about being blood brothers at school --

4 **A.** Yes.

5 **Q.** -- because she was concerned there might have been
6 a sharing of blood.

7 **A.** Yes.

8 **Q.** You say:

9 "She never told me why or told me not to do it,
10 but it made sense why she asked in retrospect."

11 On one occasion you almost said yes just to see
12 what her reaction would be.

13 **A.** Yes, to see what her reaction was.

14 **Q.** You also say you always would see two doctors when you
15 went to Great Ormond Street in the years following
16 your diagnosis. There was a haemophilia doctor.
17 There was another doctor that was very nice but you
18 didn't know why she was there.

19 **A.** No, not in that sense. And that was normal. Every
20 appointment I went to, I saw two doctors. Now I know
21 one was my haemophilia doctor and one was my HIV
22 doctor. There was a special clinic downstairs at
23 Great Ormond Street where all the boys who were
24 infected with HIV would do. What Great Ormond Street
25 had done is they had got an HIV doctor from Mortimer

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1 Market clinic in London who came over and regularly
 2 held clinics with the boys who were HIV positive to
 3 make sure they got the best care.
 4 **Q.** You also recall in your statement a time when you were
 5 about ten years old and you had headaches. You were
 6 admitted to Great Ormond Street and had a lumbar
 7 puncture. Your parents were very upset.
 8 **A.** Yes.
 9 **Q.** In retrospect, you understand why.
 10 **A.** Yes. Obviously every parent is upset when their child
 11 is unwell, but I had had headaches for about a month
 12 and I couldn't shift them, and I was still going to
 13 school. Eventually they became excruciating. So we
 14 went to the hospital and they carried out various
 15 tests, and it resulted in a lumbar puncture. I think
 16 a small percentage of people then have back pain as
 17 a result of the lumbar puncture, and I had that back
 18 pain. I was bent double for about a week. I couldn't
 19 eat anything. Well, I could, but if I ate it, I would
 20 immediately bring it back up. So I was in hospital on
 21 a drip for a good week or so. I remember actually
 22 I went home for a time after the lumbar puncture.
 23 Then I think I had been playing in my bedroom with
 24 some Lego and I bent over. That's where the pain
 25 really started, so I went back to Great Ormond Street,

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1 about what has happened to them. One of the lyrics
 2 talks about, "I have served my sentence but committed
 3 no crime". I think many people feel like that.
 4 **Q.** You later learned that you had also been infected with
 5 hepatitis C.
 6 **A.** Yes.
 7 **Q.** Can you recall anything about that?
 8 **A.** No. I don't know when I was told I had hepatitis C
 9 and neither does my mum, and neither does she in
 10 relation to my other siblings. I simply don't know
 11 when that happened. As crazy as that sounds, because,
 12 of course, if you were told, you would like to think
 13 you would remember, but I think in the scheme of
 14 everything, HIV, hepatitis, haemophilia, you would put
 15 it in that hierarchy. And later on, things like
 16 variant CJD as well would be some way down the list
 17 compared to everything else you were told about.
 18 So I am not sure if it was something I was
 19 specifically told about at some point or my parents
 20 were and it paled into insignificance because of my
 21 initial diagnosis, but no, my parents don't remember
 22 and I don't remember. I remember when I moved my care
 23 from Great Ormond Street to the Mortimer Market clinic
 24 for my HIV, at some point having a conversation with
 25 my doctor about it and then receiving treatment later

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1 where I was an inpatient for a week or so.
 2 I think my parents were always worried anyway
 3 because of my HIV, but that really caused them to
 4 worry.
 5 **Q.** During your childhood and teenage years, in terms of
 6 physical symptoms, you have described having swollen
 7 glands, oral thrush, but that was all relatively
 8 minor.
 9 **A.** Yes. Yes.
 10 **Q.** But you recall that sometimes you would cry yourself
 11 to sleep thinking you were going to die.
 12 **A.** Yes, a couple of times. As I say, I didn't come to
 13 that realisation quickly. In the first few months
 14 there were some dark times when I was worried.
 15 I think I said in my statement, I remember back to
 16 people like Freddie Mercury, who died in 1991, which
 17 was incredibly recent in terms of when I had just been
 18 told about my diagnosis. You would think if someone
 19 like that, who -- presumably with all the money he
 20 had, he could have been -- he would have been able to
 21 get private health care with effectively the best
 22 health care in the world, he still succumbed to it.
 23 That was something that was a constant reminder, and
 24 I suppose Freddie Mercury and Queen music generally,
 25 that it sums up I think what a lot of people feel

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1 on.
 2 **Q.** You have since noted in your medical records in around
 3 1984 a record of abnormal liver function tests.
 4 **A.** Yes.
 5 **Q.** As far as you are aware, nothing was mentioned at the
 6 time to your parents about hepatitis?
 7 **A.** No. You saw from the UKHCDO record there are two
 8 hospitals mentioned, Great Ormond Street and Wexham
 9 Park, and in my medical records there's a letter from
 10 Great Ormond Street to Wexham Park hospital with my
 11 ALT level, which is significantly elevated, but that
 12 may or may not be an initial indication of hepatitis C
 13 at the time, and that was in April 1984. But as far
 14 as I am aware, there was certainly no conversation
 15 with my parents prior to them learning of my HIV
 16 diagnosis that I may or may not have been infected
 17 with what would have then been non-A, non-B hepatitis.
 18 **Q.** At a later stage what, if anything, did you learn
 19 about the risk of vCJD?
 20 **A.** I was written to, like most people, I think, in 2004
 21 to advise, "You may have been exposed to variant CJD".
 22 I think from memory I probably was. But, again, it
 23 paled into insignificance with my other diagnoses.
 24 **Q.** How was your health physically during your teens and
 25 adulthood? What treatments did you receive for HIV?

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1 A. My health was good despite anything. If anything, my
2 haemophilia has caused me more problems and issue than
3 certainly my HIV and hepatitis in terms of joint
4 damage. I can't touch my left shoulder and both my
5 ankles are severely arthritic.

6 Initially we talk a lot about CD4 counts and
7 viral loads for those people with HIV, and I had no
8 CD4 count whatsoever, which is one of the reasons why
9 my parents were so incredibly worried about me getting
10 ill, things like chickenpox at school, for example.
11 So I had no CD4 count whatsoever, so I wasn't able to
12 fight off any viral infections. And my viral load --
13 I am not sure they were even testing it then.

14 I moved on from the liquid AZT to tablets in
15 AZT, and then I think I went through several different
16 medications. One was called DDI, which was a tablet
17 which was dissolved in a bottle of water. Then
18 I moved on to triple therapy, three different tablets
19 I think twice a day then. I now take triple therapy
20 once a day.

21 Around the age of 17 I started to develop a CD4
22 count. So rather than get ill, I actually started to
23 get better. At the time I had a lot of warts, or
24 a couple, maybe four or five on my hands, and a lot on
25 one of my big toes and on my feet. I had been sent to

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1 removed under local anaesthetic. The registrar who
2 had removed it told me at the time when he removed it
3 that he thought it was a lesion. I forgot -- you will
4 be able to prompt me.

5 Q. Kaposi's sarcoma?

6 A. Kaposi's sarcoma, thank you. A Kaposi's sarcoma
7 lesion, which meant nothing to me. I was then to go
8 back two weeks later for a follow-up appointment.

9 Two days later I happened to be doing some
10 summer work at a particular place and I was reading
11 some papers in relation to something, and there was
12 somebody I was reading about who also had HIV and also
13 had Kaposi's sarcoma. The doctor had written in his
14 notes that that meant his HIV had progressed to
15 a diagnosis of AIDS.

16 I went home that night -- I was still living at
17 home with my parents -- and spoke to my mum, who had
18 been at the appointment with me. She had understood
19 the import of what the doctor had said when he said
20 it, but she had not told me so as not to worry me.
21 But I then had 12 days thinking I had progressed from
22 having HIV to AIDS, which of course was an absolutely
23 petrifying time.

24 I went back to that appointment and I saw
25 a different doctor, a different registrar, who told me

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1 the dermatology clinic. I had had them frozen with
2 liquid nitrogen and that didn't work. But I started
3 on this new medication, I started to get a CD4 count
4 and my warts disappeared almost overnight. So it was
5 apparent to me that I was seemingly, with the
6 medication, getting better.

7 Q. You did, I think, have a reaction to one HIV drug with
8 a rash all over your body in your childhood.

9 A. Yes. 3TC. It was a little diamond tablet. Yes, it
10 was either that or a jar of Chicken Tonight which mum
11 cooked for dinner. Either way, we didn't have Chicken
12 Tonight again for dinner, which was a bonus. But,
13 yes, we think it was the 3TC.

14 Q. You had an occasion during your adulthood where you
15 thought for a period of time that your HIV may have
16 developed into AIDS. Can you tell us about that?

17 A. Yes. In around -- I think from memory around 2004
18 I had a mole on my back just by my right scapula, and
19 I had been on holiday and it had started to hurt.
20 Obviously I couldn't see it myself, so I couldn't tell
21 whether it had got bigger at all, but it had started
22 to hurt and be a bit painful, so I was again referred
23 to the dermatology clinic. By this time I was at
24 University College Hospital. I was referred to the
25 dermatology clinic, and I was -- I went to have it

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1 it was benign and nothing to worry about. But it was
2 quite clear -- and the new doctor, as it were, the one
3 I hadn't seen previously apologised to me because it
4 was quite clear what the doctor had done is he had
5 seen the lesion, seen my diagnosis and added two and
6 two together and come up with five. But that didn't
7 help me at the time.

8 Q. Did your parents tell many other people of your
9 infection?

10 A. No. No. It was a secret. It felt like a dark and
11 guilty secret. But no, it was our family secret and
12 still largely is. There are very few people who know.

13 Q. That remains the case to this day?

14 A. Yes.

15 Q. This is probably the first time you have spoken
16 publicly --

17 A. Yes.

18 Q. -- about what you are describing. You have explained
19 in your statement that you

20 Yourself first told somebody that you had HIV as
21 a teenager. You told your first girlfriend and your
22 best friend around the same time.

23 A. Yes, I was about 16 when I told my first girlfriend
24 and best friend.

25 Q. What was their response?

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1 A. Didn't bat an eyelid. They were teenagers and just
2 got on with life.
3 Q. In terms of your work life, you don't tell people you
4 are HIV positive.
5 A. No.
6 Q. You explain in your statement that merely disclosing
7 the fact of your haemophilia in early years had led to
8 discrimination, to you not getting work.
9 A. Yes. My brother and I were both applying for weekend
10 jobs. At the time we were teenagers and wanted a bit
11 of part-time work and money in our pockets so we could
12 go out with friends. We were both applying for jobs
13 and we'd fill out forms, and under the disability
14 section at the end we would fill out we had
15 haemophilia, and you wouldn't get a thing back. You
16 wouldn't get a phone call, letter, nothing. You might
17 think once or twice that your application form got
18 lost or there was someone better, but after four or
19 five times you start to realise there's a reason they
20 are not getting back to you.
21 So we both decided to apply for a job and not
22 put on our haemophilia diagnosis, and two days later
23 we both had a job.
24 Q. It is that experience and your own knowledge of the
25 stigma associated with HIV and AIDS that has led you

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1 MS RICHARDS: In terms of your personal and family life,
2 you met your wife while you were still a university
3 student.
4 A. Yes, I was at the end of my first year at university.
5 Q. You later married. Your wife was fully aware of your
6 HIV diagnosis. There then came a time when you
7 discussed having children. What process did you go
8 through?
9 A. We went through the only process that you could really
10 at the time, which was sperm washing. We were
11 fortunate on the one hand to be living in London. The
12 only place that I am aware in the country that did
13 sperm washing was the Chelsea & Westminster hospital.
14 We had to go to -- I spoke to my HIV doctor about it,
15 who referred me to the GP because we then had to go
16 and make an application to our local London borough at
17 the time for funding. We eventually did get funding
18 and we went through a round of sperm washing at the
19 Chelsea & Westminster.
20 Q. That was not successful.
21 A. No, it wasn't, and one of the side effects of the HIV
22 medication is it reduces significantly your sperm
23 count. So, no, it was unsuccessful the first time.
24 Q. And then you had difficulty or you weren't able to
25 obtain funding for any further rounds because of

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1 not to tell people about that.
2 A. Yes.
3 Q. You have described in your statement an incident in
4 the course of your working life when you overheard a
5 discussion about someone with HIV or AIDS. What can
6 you tell us about that?
7 A. Yes. There was a client I was supposed to meet in my
8 working life and there were some other people who knew
9 about that client and they were speaking about his
10 diagnosis quite freely in front of me, not in front of
11 him, but then when I was due to see him, they made
12 various comments to me about being careful, et cetera,
13 which I internally laughed at, because I obviously
14 knew that my diagnosis was the same as his.
15 Q. And you have said this in your statement:
16 "My experience has done nothing to disabuse me
17 of the notion that attitudes towards the virus had or
18 were changing."
19 A. Yes.
20 SIR BRIAN LANGSTAFF: Did you mean attitudes weren't
21 changing?
22 MS RICHARDS: Yes, I'm sorry.
23 SIR BRIAN LANGSTAFF: I think that's what you meant to
24 say.
25 A. Yes.

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1 a change in NICE guidance. Can you tell us about
2 that?
3 A. Yes. I think initially we decided that we weren't
4 going to go through a second round of applications.
5 I think the first time you apply it is almost a given
6 that you will get it, but the second time it is
7 I think a bit more of a battle. My wife and I took
8 the decision that having children was never something
9 that was going to make or break us. We were together
10 for each other rather than having children
11 necessarily.
12 It was around 2008 I remember going to see my
13 HIV doctor. I think he mentioned it first or I may
14 have read it in the press before, but at the time
15 there was something that became known as The Swiss
16 Statement in 2008, and The Swiss Statement was
17 a statement by a number of Swiss doctors about the
18 fact that if you had an undetectable viral load, then
19 you couldn't pass it on. We are now of course talking
20 about the U=U campaign. It was relevant I think
21 mainly in Switzerland because of the law in relation
22 to criminal law about whether or not you could consent
23 to being infected with HIV, effectively, and people
24 having sexual relationships. So it was of interest in
25 that respect. The NICE guidelines changed and it felt

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1 contradictory in the sense that it still said that if
2 one of you was infected, you should have protected
3 sexual intercourse, but it also said that if you
4 wanted to conceive children, then you should consider
5 doing it naturally.

6 **Q.** And you understood that that would be problematic in
7 terms of obtaining any further funding for any further
8 rounds of sperm washing.

9 **A.** Yes, I think that was part of it. That was obviously
10 a limiting factor in any consideration for any further
11 funding.

12 **Q.** You have said this in your statement:

13 "It felt cruel that we were not able to conceive
14 children naturally due to NHS treatment but then would
15 have to fund anything more than one round of
16 treatment."

17 **A.** Yes.

18 **Q.** You also in your statement, discussing the impact,
19 practical impact of stigma, talked about issues
20 relating to travel to the USA. What can you tell us
21 about that?

22 **A.** I think that's probably where I have experienced the
23 most stigma in relation to HIV. I think I have been
24 to the US maybe -- as a child I went a couple of times
25 with my family but knew nothing of what was going on.

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1 questions, and then they started again and asked me
2 the same series of questions to see if I gave
3 a different answer.

4 I don't think I had any issues when I entered
5 the US that time, but on other occasions when my wife
6 and I have been, although I don't need a visa anymore,
7 there is always a marker on my passport. So when
8 I went to New York, I remember spending about an hour
9 trying to get through customs. Immediately my
10 passport -- they didn't let me through, I was taken
11 off into a room. My passport was taken away. They
12 carried out various investigations. They didn't
13 really say much, if anything, to me. I eventually
14 said to them, "Is this why you are checking, because
15 there is a marker on it?" They said there is.

16 I think the worst experience was when my wife
17 and I were in Canada and then went to US. We had been
18 travelling to see some family. We had been to
19 Vancouver and over to Victoria Island. When we were
20 there, we got the boat from Victoria to Seattle, and
21 the procedure is that you clear US customs before
22 getting to Seattle so you can get straight off the
23 boat and get on with the rest of your holiday. My
24 wife and I got there early because the boat trip
25 itself is part of the journey, in the sense that there

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1 Back then my parents would have had to apply for
2 a visa for me to enter the country. When Barack Obama
3 was president, he changed the law in America in
4 relation to people with HIV having to apply for visas,
5 so I no longer had to apply, but there was one
6 occasion before the law changed when I was in my early
7 20s. My best friend had been off travelling around
8 the world for several months. I was just about to
9 start a new job and I was going to go out to meet him
10 in Los Angeles for a couple of weeks for us to meet up
11 and have a bit of a holiday before I sort of settled
12 down with work. I had to go to the American Embassy
13 for an application. It was just before the summer.
14 When I got there, there were lots of other people in
15 their early 20s. They were going on sports camps and
16 the like, so they were applying for visas, and they
17 were sat in the waiting room. I was petrified that
18 people were going to ask me why I was there. Where
19 was I going? What fun was I off to have? Why was I
20 getting my visa and things. So I kept my head down.
21 I think I might have had a newspaper with me and
22 buried my head in the newspaper.

23 When I did go through, I had an interview with
24 an immigration officer from the US. It felt like
25 a police interview. They asked me a series of

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1 are whales and dolphins and nice things to see, so we
2 thought we would get there early and try to get a good
3 seat on the boat and sit near the window. So we did,
4 and I think we were one of the first ones there, but
5 we were the last ones on the boat because, again,
6 there was a marker on my passport. I was taken off,
7 pulled into a separate room with my wife. There was
8 another man sat there. He was Australian. In some
9 sort of search he tested positive for gamma radiation
10 because he had terminal cancer. He was on
11 a round-the-world tour with his wife before he
12 eventually died, so he was in the room as well. There
13 was no privacy whatsoever. We both knew -- not that
14 either of us were going to go and shout about each
15 other's diagnosis, but we both knew exactly the other
16 person's diagnosis. And we sat there like criminals
17 in a police station custody suite. It was horrific.
18 And having been, as I say, the first ones there, we
19 were the last ones on the boat, and I don't think we
20 got a seat if at all. It soured what had been
21 otherwise a very good holiday.

22 **Q.** In terms of medical care, what effect has the
23 potential exposure to the risk of vCJD had, if any, on
24 medical care you have received?

25 **A.** It's had an impact. One particular example -- I have

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had two inguinal hernias. The first time I had the operation at the Royal Free Hospital it took place without incident. The second time I had it, I had been for my preliminary appointment and seen the consultant, and on the day I think his registrar was carrying out the surgery. I had gone in on the Thursday night. I am self-employed, and so I had deliberately taken time off work and managed my diary. Because of my haemophilia, I knew that, unlike most people who have hernia operations, who can go in and out on the same day, I would have to stay in for a couple of days to have my Factor VIII levels monitored. So I deliberately did it with the weekend in mind so as not to miss work.

I was woken up in the small hours of the morning by the phlebotomist and had a cannula put in me, which even as a haemophiliac, having injected myself thousands of times, it's never a pleasant experience, especially at that time of the morning. Then at 8 o'clock I had been nil by mouth since the night before. The registrar came round to inspect my hernia and said to me I was going to be first down the next morning -- that morning in terms of surgery, which I thought was quite unusual, because I think most other people at the Inquiry have talked about being

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and he didn't accept that for a moment. He is a very mild-mannered man, but he said, "I don't believe for a second that a major hospital in London like that did not have the equipment to carry out the operation" on me. I suspect that the registrar -- he was struggling to find the hernia. The consultant had found it, but the registrar was struggling when he came to see me. My feeling is that he was scared to operate on a haemophiliac, not being able to find the hernia. But at least the ostensible reason I was given for the operation was they didn't have disposable equipment for the operation.

Q. Your treatment for your HIV over the years, you say in your statement, has been very good.

A. It's been excellent.

Q. And you have said you wished others had been as fortunate in that respect.

A. Yes.

Q. You have identified two particular respects in which your HIV care has been good. First, as you have already alluded to, you had specialist HIV care from an early age.

A. Yes.

Q. Rather than simply being cared for by a haematologist for your HIV?

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the last one down because of their infection. But for whatever reason I was put to the front of the list. He said, "You will be down shortly around 8.30".

So 8.30 came and went. 9 o'clock came and went.

By this time I was starting to get a bit anxious and wondering why I had not been taken down to surgery. I spoke to one of the nurses. She said, "Oh, I don't think you are going to be taken down now". I said, "Do you know why not?" She said, "No, but let me try to speak to the surgeon". By this time I was getting quite angry, because I felt I was being fobbed off. I demanded to see the surgeon and I was told, "You can't, he is in surgery".

So in my gown, I think with the cannula in, I walked off the ward and I walked down to the Haemophilia Centre. I walked in and I spoke to my doctor there and I said, "I am being taken for a fool upstairs". I said, "You need to go and find out what's going on, please". It transpired the reason I wasn't being -- or at least the reason I was told I was not being taken down for the surgery is because the Royal Free didn't have any disposable equipment to carry out my operation that day, and so I would be sent home and my operation would be rescheduled.

I subsequently spoke to my HIV doctor about that

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A. Yes. The haemophilia doctors at Great Ormond Street, I understand from my mother, were incredibly proactive about getting that care. As I say, it wasn't just someone else from the hospital; they got a specialist HIV doctor in from the Mortimer Market Centre, and they set up a specialist clinic for all the boys at Great Ormond Street who were infected to be treated and looked after and to fight to get the first medication.

Q. And that's continued over the years; you have had specialist HIV care.

A. Yes. I have the option of having my HIV care at the Royal Free Hospital, but I choose not to; I go to a specialist HIV centre for it.

Q. A second factor about your care identified in your statement is the continuity of care you have had, especially for your HIV. You have only really ever seen two doctors.

A. Yes, and my second doctor is about to retire, which shows you how long I have been with him. So, yes.

Q. What was your experience of treatment for hepatitis C?

A. My hepatitis C treatment was also treated through the Mortimer Market Centre, through my doctor there, Dr Ian Williams, and the hepatitis C medication was horrific. I had my first injection at the clinic.

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1 I went there on a Friday morning to be injected.
 2 I then went to work that day and I went out that
 3 evening. I had been warned about the side effects and
 4 how debilitating and crippling they were, but I had
 5 also been given several other warnings prior to other
 6 medication and none of the side effects had really
 7 materialised. So I think there was probably an
 8 element of naivety from me that I felt it is fine, you
 9 just have to tell me all these things and none of them
 10 or not many of them are actually going to be real.
 11 But it was horrific.

12 I was out in central London at the time, and it
 13 was about 8 o'clock when it just came over me. I was
 14 living in south-west London at the time. I just had
 15 to hail a black cab and get in the back of a black cab
 16 and get home. When I got home, I got undressed and
 17 I got into bed and -- it is impossible to explain to
 18 somebody who's never experienced it really. It's the
 19 worst flu you have ever had multiplied by ten. I was
 20 hot. I was cold. I felt sick. I felt suicidal --
 21 all in one night.

22 I think it was quite a warm evening, but there
 23 would be times when I would be under the duvet
 24 shivering and then there would be times when I would
 25 have the duvet off and wearing hardly anything and I'd

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1 during this Inquiry --
 2 A. Yes.
 3 Q. -- that you have continued to suffer with brain fog
 4 and memory issues.
 5 A. Yes. Lots of people have spoken about that. I used
 6 to have an incredibly sharp memory, being able to
 7 remember names, faces, where I had met people, but now
 8 -- last night, for example, I went out to dinner with
 9 my wife and I can tell you what food we had and
 10 roughly where it was, but I can't tell you the name of
 11 the restaurant. Those sort of things just escape me.
 12 It is only after several times of maybe doing
 13 something or being somewhere that I will eventually
 14 remember the name of where I was or that sort of
 15 thing.
 16 Q. To what extent has counselling or psychological
 17 support been made available to me?
 18 A. I think there are probably two aspects to that. When
 19 I was at Great Ormond Street, again, Great Ormond
 20 Street had a counsellor, a lovely lady called Candy
 21 Duggan. For much of the time I didn't know she was
 22 a counsellor. I spoke to her, but it wasn't --
 23 I wouldn't describe it as a formal counselling session
 24 where I went in, it was a case of, "Right, we are
 25 going to sit down and talk about things". It was

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1 be sweating. I couldn't eat. I struggled to sleep.
 2 My wife effectively nursed me, and on Monday morning
 3 I got up and went to work.
 4 Q. You have said in your statement, and I think this was
 5 around 2006 that you had this treatment, you would
 6 inject the treatment at home after that first weekend
 7 on a Friday evening. You would be ill for the
 8 weekend.
 9 A. Yes.
 10 Q. You'd just about start functioning by the Sunday and
 11 then you would try to get to work on the Monday --
 12 A. Yes.
 13 Q. -- and work through to the Friday again.
 14 A. The nature of my work meant that I always had
 15 preparation to do over the weekend, and so on a Sunday
 16 I would need to prepare. As you say, I would be just
 17 about functioning. On Monday I would still feel ill,
 18 but I was self-employed. I had no choice.
 19 Q. You took that treatment for how long?
 20 A. About six months, I think.
 21 Q. You did clear hepatitis C after that first round of
 22 treatment.
 23 A. Yes.
 24 Q. But you say in your statement that you realise, and it
 25 is only through hearing evidence that you have heard

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1 a general friendly chat to see how things were going,
 2 that sort of thing.
 3 I know that -- I think one piece I haven't
 4 mentioned previously, but when I was at Great Ormond
 5 Street, I know I was monitored and tested because of
 6 my HIV. There were various psychological testing that
 7 took place with my parents' consent, obviously, and
 8 I had CT scans on my brain and things to monitor me.
 9 When I had my hepatitis C treatment, I think
 10 I was offered counselling before that by my doctor,
 11 Dr Ian Williams, and I think once or twice afterwards,
 12 but it was never something I felt I wanted or needed.
 13 I remember another witness saying previously
 14 that he felt counselling should have almost been
 15 something that was thrust upon you. I think
 16 I wouldn't disagree with that. I think it is
 17 something that undoubtedly does help, but it was
 18 offered to me, but not very -- not overly, not
 19 persistently, but it was there if I wanted it.
 20 Q. In terms of your parents, who were told in the 1980s
 21 that their 4-year-old had HIV, were they offered any
 22 form of counselling or psychological or other support?
 23 A. I don't think directly, no. I think they -- like so
 24 much of the NHS, one part was left to fill in for the
 25 other. I think the haemophilia doctors did most of

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1 it. I know when my dad was suffering from depression
 2 it was a conversation with the haemophilia doctor at
 3 Great Ormond Street that helped him to go and see
 4 somebody about it. So I don't think they were ever
 5 formally offered anything, no.

6 **Q.** Your parents participated in the group litigation, the
 7 HIV litigation.

8 **A.** Yes.

9 **Q.** What is your understanding and view of the way in
 10 which that litigation was compromised, having spoken,
 11 I think, to your parents about this issue?

12 **A.** Yes. My parents were at lots of the meetings in
 13 London and it was -- from what I understand, those
 14 meetings were incredibly difficult, because on the one
 15 hand you had young boys, and they were boys, who were
 16 dying, who were being promised this money from the
 17 government, and on the other hand you had people like
 18 my parents, who had a young son, for whom to a degree
 19 they could provide for and care for and look after,
 20 who wanted to go to court and seek a better settlement
 21 in relation to everyone's infections, and I think the
 22 words I am sure have been used before, but there was
 23 a form of emotional blackmail that went on in all of
 24 this. It wasn't just government pressuring the people
 25 into accepting it; it was because of that promise that

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1 r the extent or the potential damage that would have
 2 caused.

3 **Q.** You applied, I think, only once to the MacFarlane
 4 Trust for a discretionary payment.

5 **A.** Yes.

6 **Q.** That was for a laptop for study or work-related
 7 reasons.

8 **A.** Uh-huh.

9 **Q.** What was the response from the MacFarlane Trust?

10 **A.** Reluctantly they gave me the money. They said that
 11 they knew how much people in [redacted] earned, so
 12 "Don't be asking again", effectively.

13 **Q.** You have described that again as disgraceful. You
 14 were made to feel guilty for asking for anything.

15 **A.** Yes, yes. Despite everything that had gone on, I had
 16 gone to university. I had studied, I had worked hard
 17 and I had achieved well, I thought, and despite all of
 18 that, they simply said to me, "Don't ask again",
 19 effectively.

20 **Q.** Your witness statement says that you have by and large
 21 been fit and well.

22 **A.** Yes.

23 **Q.** And that you have tried to live your life by looking
 24 forward, but also this, appreciating, as you do, that
 25 you are lucky to be alive, and fortunate, you say, in

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1 was being held out to those people, those people were
 2 indirectly putting pressure on the others who wanted
 3 to remain resolute and say "No". My mum firmly
 4 believes that if the waiver hadn't been signed back
 5 then, we probably wouldn't be where we are now.

6 **Q.** Then you I think a number of years later approached
 7 solicitors about the possibility of challenging the
 8 waiver.

9 **A.** Uh-huh.

10 **Q.** What were you advised?

11 **A.** Yes. The solicitor that represented my parents at the
 12 time -- I was going to be one of the test cases when
 13 the case went to court, because it was thought I was
 14 infected through British product rather than American
 15 product. The solicitor had since left the firm of
 16 solicitors and I think was teaching in Nottingham.
 17 I contacted him about challenging the waiver, but his
 18 advice to me was there was no way to challenge the
 19 waiver.

20 **Q.** You have termed the way in which the litigation was
 21 compromised in this way in your statement:
 22 "A disgraceful sleight of hand".

23 **A.** Yes, especially with the hepatitis C infection, the
 24 fact that that was added so late on, seemingly, when
 25 people didn't know of the fact that they were infected

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1 some respects in terms of the care you have received.

2 **A.** Yes.

3 **Q.** "Living with my infection is like having a constant
 4 cloud hanging over."
 5 Is that right?

6 **A.** Yes. I think despite everything, so many people have
 7 described themselves as lucky. I think I was
 8 discussing this with my parents and family recently
 9 and I described myself as one of the lucky unlucky
 10 ones.

11 **MS RICHARDS:** Those are the questions I have for you.
 12 I am just going to ask Ms Gollop if she has any
 13 questions.

14 No, there is nothing further. Is there anything
 15 more that you would like to say?

16 **A.** Just one or two bits. I won't be particularly long.
 17 It has become customary, Sir Brian, for people to
 18 Make closing remarks. I don't want to shy away
 19 from that custom.

20 **SIR BRIAN LANGSTAFF:** It is not obligatory.

21 **A.** No, I know. I want to start by publicly saying thank
 22 you to
 23 Several people. First and foremost my parents.
 24 I can't begin to imagine what you have gone through,
 25 and your strength and courage continue to inspire me.

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1 I dare say you often ask yourselves if you did the
2 right thing, and the answer to that is a resounding
3 yes.

4 Next to my brothers. Growing up wasn't always
5 easy, and at times we had to grow up a little quicker
6 than others. It was always fun and continues to be.
7 So thank you for being there.

8 Then to my wife. Many would have run the other
9 way. You ran into my arms. I still ask myself why,
10 and I am forever grateful that you did. Words can't
11 express my gratitude to you, so I will simply say
12 thank you.

13 There are many healthcare professionals that
14 I would like to publicly say thank you to, but due my
15 anonymity, they would never hear it. There are many
16 doctors, nurses, physios and others who have got me to
17 where I am. One of the great things about the
18 haemophiliac community is because it is a lifelong
19 condition, many of those people also become friends,
20 and it is my privilege to know them all.

21 I want to turn then to what I call my piece of
22 the jigsaw, and I hope you will forgive me for
23 trespassing on what might be considered exclusively
24 your territory, but something I have struggled with
25 whilst listening to others give evidence is where my

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1 position than they are.

2 In terms of where I believe my piece of the
3 jigsaw sits, I believe I am an example of what could
4 have been achieved had a coordinated and comprehensive
5 response been instituted. Instead, what happened was
6 the most egregious dereliction of duty by a country to
7 its citizens in modern times. The government made us
8 more vulnerable with deadly infections. Whether that
9 could and should have been prevented is a matter for
10 this Inquiry. What is abundantly clear, however, is
11 that of the government's response was worse than mere
12 apathy. The government actively compounded our
13 community's plight with campaigns, such as the AIDS
14 tombstone campaign.

15 Much is talked about in relation to money and
16 compensation. Many people who had money have spent it
17 filling the gaps left by a lack of government
18 response, on hepatitis treatment, for example.

19 But what we as a community want is about so much
20 more than money. Day after day, week after week, the
21 Inquiry has heard accounts of people's personal
22 battles with their viruses. In reality, we have been
23 waging a war, not just against our viruses but against
24 government. Government has tried to subdue us. They
25 continue to ignore us and continue to do battle with

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1 piece of the jigsaw fits. I wanted to make some
2 observations about how I feel my account fits into the
3 bigger picture of the Inquiry generally.

4 So many people have given evidence of how they
5 have been let down and the catastrophic impact it has
6 had on their life. Whilst my story is not all good,
7 overwhelmingly I have had a good experience in terms
8 of the response to what has happened, which begs the
9 question: what should have happened?

10 In my view, a comprehensive database of those
11 infected should have been set up. Haemophiliacs
12 should have been systematically tested and
13 a comprehensive look-back exercise undertaken to
14 ascertain those infected from the whole blood
15 community. Specialist clinics should then have been
16 developed with the leading experts treating those
17 infected, experts in HIV, experts in hepatitis,
18 counsellors, dentists and anything else the infected
19 were struggling to cope with.

20 Had that happened, I firmly believe many more
21 people could have ended up in my position, namely
22 having been able to lead a fulfilled life, despite the
23 devastating infection which had befallen them. I am
24 not naive enough to think all could have been saved,
25 but undoubtedly many more should be in a better

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1 us. Why? Where is their recognition of our struggle?

2 We today see the public health campaign U=U,
3 meaning undetectable means untransmittable in relation
4 to HIV. We all remember those tombstone adverts. We
5 should now be celebrating the U=U campaign, and its
6 principal champion should be government. They should
7 be endeavouring to undo large aspects of the harm they
8 themselves created, but instead it is left to
9 charities like the Terrence Higgins Trust to promote
10 such news. Again, where is our government in all of
11 this?

12 We are tired of meaningless apologies. We are
13 tired to platitudes in relation to this being
14 something that should never have happened. As
15 a community, in future we will judge you by what you
16 do, not by what you say. If you want a list, here is
17 a starter for free.

18 Start a public health campaign backed by
19 government in relation to U=U.

20 Secondly, level out the support payments across
21 the UK as a matter of urgency, by the end of this year
22 at the very latest.

23 Thirdly, start a look-back campaign now. Do not
24 wait until the end of the Inquiry. More lives will
25 have been lost if you do.

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1 Then I turn to my country and I ask: why have
2 you forsaken us?

3 Sir Brian, you said last week in your opening
4 comments that no-one could fail to be moved by what
5 they have heard. Sadly, I don't believe enough
6 politicians are listening. Why when Diana Johnson MP
7 writes to the Prime Minister, Boris Johnson, is a
8 letter received from Oliver Dowden MP? Is the death
9 of over 3,000 of his country's citizens not important
10 enough for the Prime Minister to respond?

11 I don't believe it is an accident that when
12 David Livingston was Cabinet Office minister and
13 attended the opening last September, he remained
14 engaged. Politicians must engage now, but not just
15 politicians. Our Royal family and celebrities. With
16 some notable exceptions, politicians of all hues have
17 ignored our plight for decades. But not just
18 politicians. Why have our Royal family never
19 acknowledged this immense tragedy. Haemophilia is
20 known as the Royal disease. Why the dis-ease about
21 acknowledging us?

22 Perhaps the Queen will see fit to mention it in
23 her Christmas speech this year. Perhaps Princes
24 William or Harry would like to meet some of the
25 victims of this tragedy and gain a true understanding

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1 health may be devolved, responsibility cannot. It is
2 further evidence of the government's lack of humanity,
3 which is in stark contrast to that shown by you,
4 Sir Brian, and your team.

5 The manner in which we have been treated by you
6 and your team has been exemplary. The hearings
7 themselves are so much more than allowing people to
8 tell their personal stories. They have allowed people
9 to come together and share experiences they thought
10 only they had been through. Alongside the recognition
11 it provides, it has allowed people to realise they are
12 not alone. There will be more difficult times ahead,
13 but I feel we are in safe hands.

14 So, finally, let me thank you, Sir Brian, and
15 all of your incredible team.

16 **SIR BRIAN LANGSTAFF:** Can I, before I respond to your
17 thanks to us, just ask you one question, if I may.

18 Despite the clarity of everything else you said,
19 there was one expression you used which was a little
20 Delphic. It was your mother's saying to you: "If
21 things had been different, we wouldn't be where we are
22 now."

23 What do you think she meant by that?

24 **A.** I think she feels that if people hadn't signed the
25 waiver and things had gone to court, things wouldn't

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1 of the stigma our community has endured. And
2 celebrities who use their profile to try to end the
3 stigma around HIV. Why has no-one ever championed our
4 cause? We have no celebrities queuing up to write
5 a song and raise money to support our community, or to
6 highlight our profile to the public or to ensure we
7 are at the top of the political agenda. Only last
8 weekend Sir Elton John said, "The traumatic thing is
9 still the stigma". As a community we seem to have
10 a stigma all of our own.

11 Lastly, money. Since July I have been in
12 receipt of the higher rate of payments from the
13 English infected blood support schemes. I now work
14 part time and [redacted], and at the moment that is
15 becoming somewhat of a part-time job, for which I am
16 not allowed to be remunerated. The additional
17 payments have given me a significant amount of
18 breathing space in terms of being able to balance my
19 work with the other demands on my life. The impact
20 for others who have not been as fortunate for me is
21 surely immeasurable.

22 Why then does government continue to ignore the
23 plight of those in Wales and Northern Ireland in
24 particular? What happened happened on the Westminster
25 government's watch. Westminster must respond. Whilst

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1 be as bad for the community as they are now. I think
2 she feels had the case eventually gone to court and
3 been litigated, people would be in a better position
4 now.

5 **SIR BRIAN LANGSTAFF:** So she would be looking to the
6 litigation and success from the litigation, that's
7 what she had in mind?

8 **A.** Yes, and of course it then wouldn't have barred any
9 further claims in relation to hepatitis as well, which
10 was one of the big issues which transpired after that.

11 **SIR BRIAN LANGSTAFF:** Thank you for that. It remains for
12 me to thank you, and particular thanks, I think,
13 because you have delivered a very clear account and,
14 indeed, made at the very end those very clear
15 recommendations, the comprehensive -- coordinated,
16 compassionate and comprehensive response you are
17 calling for. I have heard that and I shall remember
18 that, even if I had difficulty in putting the words in
19 the right order.

20 But particular thanks because it is obvious that
21 you have managed to give us a very clear account
22 despite the emotional rawness which this has to you,
23 and despite what is obviously, as you put it, a very
24 private family matter, although I see the front row,
25 who are here to support you, and that makes it all the

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1 more courageous for you to feel, I think, that it was
 2 your responsibility to come, rather than your
 3 pleasure, to tell us about what you have. So thank
 4 you.
 5 A. Thank you.
 6 (Witness withdrew)
 7 SIR BRIAN LANGSTAFF: We will hear our next witness at
 8 3 o'clock.
 9 MS RICHARDS: Yes, sir.
 10 SIR BRIAN LANGSTAFF: 3 o'clock.
 11 (2.36 pm)
 12 (Short break)
 13 (3.05 pm)
 14 SIR BRIAN LANGSTAFF: Our next witness would like us to
 15 call him Robert, would he?
 16 MS FRASER BUTLIN: That's correct, sir.
 17 SIR BRIAN LANGSTAFF: May we have Robert, please.
 18 ROBERT IVAN HODGKINS (affirmed)
 19 Questioned by MS FRASER BUTLIN
 20 MS FRASER BUTLIN: Robert, you were diagnosed with severe
 21 haemophilia A when you were a few months old.
 22 A. Yes, that's right.
 23 Q. As a child, you were usually treated at the
 24 Hammersmith Hospital --
 25 A. Yes.

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1 A. Yes, I did.
 2 Q. You have looked at your medical records and you think
 3 you received something in the region of 3,500
 4 injections between 1969 and 2003.
 5 A. I think so, yes.
 6 Q. And your Factor VIII treatment covered the full range
 7 of products: Cutter, BPL, Armour, Immune, Hyland
 8 products.
 9 A. I had it all, yes.
 10 Q. In late 1974, you were on holiday with your parents
 11 and became unwell. When you got home, your father
 12 noticed your eyes looked yellow.
 13 A. Yes.
 14 Q. What were you then told?
 15 A. Actually it was the local GP came out. I had started
 16 to get very sick, vomit. I wasn't a chubby child, and
 17 I wasn't fat, I was sort of in the middle. I couldn't
 18 keep any food down apparently. I had a cramping pain
 19 in my stomach, abdominal area. I was just really
 20 quite unwell. They called the local GP, who was the
 21 family GP and they had known me from birth. My
 22 parents had lived in the house for quite a long time.
 23 They weren't locals, but they were known. He came out
 24 and he said -- he looked at my eyes and said, "I think
 25 your son has hepatitis".

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1 Q. -- needing treatment about once a week.
 2 A. Yes.
 3 Q. You were on cryoprecipitate until 1973, when you
 4 started to be treated with Factor VIII.
 5 A. Yes.
 6 Q. At that time, when you changed to Factor VIII, what
 7 were your parents told about it?
 8 A. Nothing, really. My mother, who was the one that
 9 looked after me mostly at hospital, I apparently had
 10 a bleed -- and I have very little memory of this
 11 personally -- she took me into the hospital,
 12 Hammersmith, and, in fact, when I was going to be
 13 injected, they brought out this syringe of clear
 14 treatment, whereas before -- cryoprecipitate is in
 15 bags. It is literally like a bag of plasma, but it
 16 was a yellowy colour, but you had vast amounts.
 17 I think even as an infant I used to have about 60 ml,
 18 which is an enormous syringe, whereas the freeze dried
 19 is tiny by comparison. She was worried. She told me
 20 she said, "That's not enough, that's not good enough".
 21 They literally laughed and said, "Oh, no, this is new
 22 treatment, this is much better, he will be fine, this
 23 is all he needs", and that was it. There was no
 24 information, no leaflet or discussion.
 25 Q. You went on to twice-weekly prophylaxis in about 1976.

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1 Obviously my parents were -- they weren't
 2 medical people, but they were both reasonably quite
 3 well read. My father had been in the forces,
 4 actually, so he knew a bit about certain illness, and
 5 he said "Hepatitis? But he's a kid. How did he get
 6 that?"
 7 Obviously then they contacted the Haemophilia
 8 Centre at Hammersmith, went in. I don't really
 9 remember much about this, but they obviously did
 10 tests. I got pretty ill. In fact, I believe I lost
 11 over a stone in weight through vomiting and not being
 12 able to eat anything. For my parents --
 13 a 4/5-year-old, that's a lot of weight. The hospital
 14 was obviously very concerned. Over the period,
 15 I think for something like six weeks, six/eight weeks,
 16 I was ill, really quite ill, but slowly started to
 17 recover.
 18 I believe they told my parents then, the doctor
 19 at the hospital, that it was confirmed to be
 20 hepatitis. I thought hepatitis B. My parents were
 21 really pretty -- well, you know, pretty staggered and
 22 it became clear -- it was in treatment with the doctor
 23 at the time, who was actually quite angry. In fact,
 24 I believe she tried to take it further, actually, to
 25 her credit really. She made a complaint and even

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1 talked about compensation. My father was angry. My
 2 mother was angry. How the hell could this happen?
 3 She said, "It is completely unacceptable", I remember.
 4 But it is a long time ago. I don't have a clear
 5 recollection. But that's basically what happened.
 6 So from Hammersmith it was taken up, but nothing
 7 happened. She was told, I believe, to the best of my
 8 mother's memory, that it couldn't go any further.
 9 Obviously being pretty naive then. We all know why
 10 now, but at the time it was just a horrible thing that
 11 happened. It was an accident. I don't think I really
 12 questioned that, really. In a lot of ways, I don't
 13 think I really thought about it. I was like five
 14 years old, so...

15 Q. You have looked through your records. At that point
 16 there is a diagnosis of hepatitis B. Your
 17 recollection in your statement is your parents were
 18 also told you had hepatitis non-A, non-B at around
 19 about the same time.

20 A. That's right. That's right, actually. Probably
 21 further blood tests. It was called -- there was
 22 something called Australian antigen.

23 Q. Which is the hepatitis B.

24 A. Right. So that is that. The non-A, non-B was talked
 25 about. Frankly, I don't remember a lot about it. My

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1 A. The doctor I was seeing at the time for my liver at
 2 Churchill Hospital, Oxford, said that my -- some
 3 functions, as you said, were not 100%. I wasn't --
 4 I mean, I like to drink, but I didn't have a problem
 5 and I wasn't a big drug user, I wasn't anything that
 6 put me in say a high-risk category.

7 Again, to my recollection she said, "I'd like to
 8 run some other tests. I have obviously some thoughts
 9 about it". So I said "Fine", you know. She did run
 10 those tests, and I saw her again for the next
 11 appointment and she told me that they had come back
 12 and it confirmed what she had a suspicion, that I had
 13 another hepatitis virus known as delta virus or hep D.

14 Q. What did she tell you about hepatitis D?

15 A. She told me that it was a very unusual hepatitis and
 16 she said, "You are unlucky". She said, "Even in your
 17 community it is very rare". She had come across it as
 18 a hepatologist before, but it is a bizarre virus. To
 19 survive, it has to use hepatitis B. In other words,
 20 it is like a parasitic virus of a virus. That then
 21 damages your liver. There is no treatment. It is
 22 progressive, but it needs hepatitis B to survive, and
 23 I had been exposed to hepatitis B, as we were
 24 discussing. So in my liver, where some of the virus
 25 was, there was this delta virus doing what it

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1 parents obviously knew it wasn't good and my liver was
 2 being checked. If I went into the hospital for my
 3 haemophilia appointment, they would take extra blood,
 4 and they used to prod me like they do and examine
 5 where the liver is, and they would be saying things
 6 like "Oh, that's okay, you know, that's not
 7 a problem", that sort of thing.

8 Q. Your recollection is that in about 1995, you think you
 9 were told you had hepatitis C.

10 A. Yes.

11 Q. But until then you hadn't been told that non-A, non-B
 12 was hepatitis C.

13 A. No, no, I hadn't been.

14 Q. The connection was only put in place for you in about
 15 1995.

16 A. Yes, yes.

17 Q. You weren't told you were being tested for hepatitis C
 18 at that point.

19 A. No. No.

20 Q. But then since then you've cleared hepatitis C
 21 naturally?

22 A. Yes, I did, yes.

23 Q. But then in about 2012 your liver function tests were
 24 abnormal, and the doctors ran further tests. What did
 25 they tell you about those results?

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1 shouldn't do, basically. That was about the extent.
 2 I didn't get offered any counselling. It was like
 3 a routine appointment.

4 Q. And she told you there was no treatment for it?

5 A. Yes.

6 Q. There were no options?

7 A. No, she did, yes, yes, yes.

8 Q. You were also told in the early 1990s that you had
 9 received blood products from someone who had died of
 10 vCJD. Your recollection is you have not been told
 11 anything since then.

12 A. Yes. I don't have any letters at home I could find.

13 Q. Your statement has been provided to the Churchill
 14 Hospital and they have provided a response to your
 15 statement, which will be published on the Inquiry
 16 website in due course, but they have also provided
 17 some letters that they say were sent to you about
 18 vCJD. We are just going to put a couple of them up on
 19 the screen.

20 A. Okay.

21 Q. Henry, please can we have 3063002, please. It's
 22 a letter from 3rd December 1997 and it sets out some
 23 information about vCJD. Then if we go over the page
 24 to the final paragraph, it says this:
 25 "We would have preferred to have been able to

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1 have spoken to you personally about this issue.
 2 However, we hope you appreciate that the requirement
 3 to inform so many people in a short period of time
 4 does not permit this. Should you wish to discuss this
 5 further do not hesitate to call the centre to speak to
 6 us at the numbers above. In order to ensure that
 7 patients have the fullest possible information on all
 8 the issues and the reasons that we have taken this
 9 step, we have arranged for a meeting in lecture
 10 theatre 1 [and the date is there] to present the
 11 evidence and discuss the matter, to which you are
 12 invited."

13 Do you have any recollection of receiving this
 14 letter?

15 A. No, I don't.

16 Q. And you have obtained your medical records and
 17 substantial quantities of them. Is this letter in
 18 your medical records?

19 A. No, it is not.

20 Q. A further letter they say was sent in 2001. 3063004,
 21 please, Henry. We can see in the third paragraph that
 22 the records show that you had received some of the
 23 implicated batches. Then the final paragraph:

24 "It is regrettable that the Department of Health
 25 did not follow the unanimous advice of the UK

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1 patients more regularly in the routine clinic, and
 2 particularly those on home treatment who do not often
 3 get seen by a senior haematologist, as they have few
 4 problems. We are concerned about the acquired immune
 5 deficiency syndrome which has been seen in haemophilia
 6 sufferers in America and has now been documented in
 7 one patient in England with haemophilia who was
 8 treated with imported American Factor VIII. The main
 9 signs of the syndrome are fever, weight loss, rashes,
 10 diarrhoea and repeated infection."

11 They have noted earlier in the letter that you
 12 had some enlarged glands, lymph nodes. If we look
 13 just above the last paragraph:

14 "I rechecked his serum virology, but do not have
 15 the results yet.

16 "I am uncertain as to the significance of his
 17 slightly enlarged lymph nodes, but otherwise he seems
 18 to be extremely fit. We shall see him again in 6
 19 months' time for another routine check, though if he
 20 should have any further infections, I would be
 21 grateful if you would get him to come up and see us
 22 earlier."

23 Were you aware of them checking for HTLV-III?

24 A. No.

25 Q. Were your parents aware of it?

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1 Haemophilia Centre directors' organisation and adopt
 2 the use of recombinant Factor VIII some years ago as
 3 this problem could have been avoided. It remains a
 4 matter of concern to us that recombinant Factor VIII
 5 and IX are still denied to most patients with
 6 haemophilia in England, although these products are
 7 now available to all people with haemophilia in Wales,
 8 Scotland and Northern Ireland. We shall continue to
 9 lobby on your behalf to obtain these products for all
 10 of our patients."

11 Again, do you think you ever received that
 12 letter?

13 A. I have no recollection of that letter.

14 Q. And is it present in your medical records?

15 A. No.

16 Q. You are also HIV positive.

17 A. Yes, I am.

18 Q. And I just want to look back at some of the
 19 documentation in the early 1980s to look at when you
 20 were told and what you were told.

21 Could we have document 0009002, please, Henry.

22 This is a letter from August 1983. If we look at the
 23 third paragraph, we can see that the haematology
 24 registrar to your GP is telling them:

25 "We have decided to see all our haemophilia

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1 A. No.

2 Q. You recall seeing a letter in your records in the
 3 context of the American litigation, a letter later on
 4 in 1983, saying you had tested positive to HTLV-III?

5 A. That's right.

6 Q. But that's not in your records anymore.

7 A. Well, it was in the original records I got a few years
 8 ago from the GP, and it was from the Department of
 9 Health. It was a letter to my GP saying basically
 10 that I'd been exposed to a virus called HTLV-III and
 11 that I was not a significant public health risk, but
 12 they were obviously informing them that this had
 13 happened. But I think it was October 1983. I had
 14 a copy. Because I, like a lot of the people involved,
 15 didn't think it was going to have the chance -- didn't
 16 think we were going to have the chance to have
 17 a public inquiry, I got rid of the letter. I don't
 18 remember getting rid of it, but I got rid of it. But
 19 it was a definite letter that existed.

20 The reason I remember it was different from this
 21 letter is because it actually stated on there HTLV-III
 22 and it was from the Department of Health. It wasn't
 23 from the Haemophilia Centre, but the Department of
 24 Health saying that I wasn't a severe health risk.
 25 I don't know what that meant. Presumably they would

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1 come round in hazmat suits to collect me, but they
 2 were not going to do that now. I had no idea the
 3 letter existed, that's why I kept a copy, because
 4 I showed my mother, because at the time I would have
 5 been 15, and they had no information from anybody
 6 about that whatsoever. I mean, I had never heard of
 7 HTLV-III. I didn't know what the hell it was or
 8 didn't want to know what the hell it was. You know,
 9 I was fit and hanging around with my friends at the
 10 time.

11 **SIR BRIAN LANGSTAFF:** May I just ask you how sure you are
 12 about the date being 1983. Let me tell you the reason
 13 I ask. My general understanding is HTLV-III was
 14 labelled in that way after the virus had been isolated
 15 for the first time in April 1984, although there had
 16 been a similar virus identified known as LAV about
 17 a year previously. So if you perhaps might be
 18 mistaking October 1983 or October 1984, that --

19 **A.** The thing is, I don't have the letter, but it
 20 definitely did not say HIV.

21 **SIR BRIAN LANGSTAFF:** No.

22 **A.** It definitely did not say HIV.

23 **SIR BRIAN LANGSTAFF:** But it is the date I was really
 24 asking about.

25 **MS FRASER BUTLIN:** Sir, it might assist to look at the

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1 said -- a TV programme, documentary. I recalled it
 2 was Panorama, but I can't -- I think it was the BBC
 3 and it was about the infections for HIV in America.
 4 That was in the '84. So I heard that for the first
 5 time. It caused -- obviously it was pretty
 6 overwhelming. My parents were obviously shocked, and
 7 then got a call from Hammersmith saying, "We just want
 8 to give you a call. A lot of people are worried.
 9 It's been on TV". The irony is they were actually
 10 angry at the BBC. They said, "We are thinking of
 11 taking an official complaint about the BBC because
 12 they are talking about a virus in America and being
 13 infected with it". So obviously they were angry that
 14 that information had come out.

15 **Q.** In your statement you have placed that at about
 16 November 1985, when you then went in for an
 17 appointment with your parents.

18 **A.** It was -- yes. I found out from the doctor at the
 19 time, who basically had done a test -- I thought it
 20 may have been actually 1984. It could have been the
 21 '84, but I --

22 **Q.** If we look at 0009007, we can see an entry from
 23 26 November 1985, which says you were advised of your
 24 status then.

25 **A.** The reason I say that is because my -- the doctor that

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1 next document that we were about to go to in relation
 2 to dates, if I may.

3 **SIR BRIAN LANGSTAFF:** Please.

4 **MS FRASER BUTLIN:** 0009005, please. This is a medical
 5 record from 15th January 1984. It will come up on our
 6 screens in just a moment. We see in the top left
 7 corner the date, 15th January 1984. If we go down
 8 towards the bottom, there is in brackets:
 9 "Started heat treated Factor VIII (HTLV-III
 10 antibody positive)."

11 **SIR BRIAN LANGSTAFF:** And the date?

12 **MS FRASER BUTLIN:** The top of the letter says 15th January
 13 1984.

14 **SIR BRIAN LANGSTAFF:** Yes. Can you just scroll down
 15 again. Thank you very much.

16 **MS FRASER BUTLIN:** In the margin, which is highlighted --
 17 just above that, Henry, if we go up a little, we can
 18 see, "FBC profile", full blood count profile,
 19 "virology and store HTLV", what I think is shorthand
 20 for "antibodies".

21 **SIR BRIAN LANGSTAFF:** Yes.

22 **MS FRASER BUTLIN:** Again, in 1984, were you or your
 23 parents aware of this?

24 **A.** Not at all. I think the first I have ever heard or
 25 remember hearing was off -- which I know others have

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1 was looking after me at the time had a colleague who
 2 had been training or partly trained, if I can
 3 remember, at Professor Robert Gallo's laboratory at --
 4 in the American Cancer Institute, which is partly
 5 credited with discovering HIV. The test had become
 6 available, and that was in the '84. What I remember
 7 is that they took mine and so many others -- I think
 8 about 12 people's blood and flew the blood sample to
 9 America to have it tested at the laboratory to confirm
 10 whether it was HIV and then the results would be faxed
 11 back, and that is what happened.

12 I went to Hammersmith Hospital with my parents.
 13 I thought it was the '84, but it might -- I thought it
 14 was, because the tests had only just become available,
 15 and I know officially, or what I believe was
 16 officially, it wasn't really recognised until the '85,
 17 but I got an early window, as it were, on it, because
 18 this colleague had done a favour to the doctor, which
 19 is possibly why there isn't any direct record, because
 20 it was a bit under the radar.

21 **Q.** Whenever that appointment was, what was your
 22 understanding of what you were being told?

23 **A.** That I had been exposed to HIV. That was basically
 24 it.

25 **Q.** What did your parents understand that they had been

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1 told?
 2 A. My mother -- by the time I was told, I was 16, so my
 3 mother wasn't in the room. The doctor said to me --
 4 I can remember she said, "We are not asking anybody to
 5 say do you want to know, but if you'd like to know,
 6 I'm prepared to tell you", and I said, "Well, there
 7 isn't much doubt that I've been exposed to it, is
 8 there?" and she just smiled and said, "No, you have
 9 been exposed". And then I said, "Well, I think my
 10 parents should be told", and because she had known,
 11 obviously like a lot of haemophilia doctors, the
 12 family and knew my mother, she just nodded and said,
 13 "Okay, that's fine". I said, "Can I go and get her?"
 14 and she said yes. So she went and got her.

15 My mother sat there, and we had obviously been
 16 talking about it, and the doctor said, "I am afraid
 17 Robert -- it's come back and he has been exposed to
 18 HIV". Unfortunately my mother, I don't think she
 19 understood what that meant. She did not understand
 20 that I was HIV -- she just thought I had been exposed
 21 to it like you have been exposed to a flu virus and
 22 that was it. I had a pretty good understanding what
 23 she was talking about, so I did realise that that was
 24 pretty catastrophic.

25 Within about a year, with an incident at home,

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1 the consultant that much. He came in -- or I came in
 2 and he said -- he was an African guy, actually, very
 3 black skin. He was training. He was going back, so
 4 he wasn't here permanently, and he said -- he looked
 5 up and he said "Oh, hello. Sit down. I am very sorry
 6 for your situation".

7 So I thought, okay, that's good of him, but
 8 I have been living with it for quite a few years, and
 9 he obviously saw my expression that was sort of
 10 puzzled and he said, "Haven't they told you?" I said
 11 "Told me what?" He said, "Your immune system is very
 12 low. I am very sorry about that. There isn't a lot
 13 that I can do for you, but we will try and do what we
 14 can", or something like that.

15 Q. At that point you asked for your care to be
 16 transferred elsewhere.

17 A. Well, yes, that's right. So I spent -- at that time
 18 obviously I went back home. It was pretty
 19 devastating. I think I then actually went back again
 20 and there was a doctor that saw me who realised my CD4
 21 count was very low and immediately suggested that I go
 22 -- because by this time it had gone down to -- when
 23 I went back again, it had gone down to about 50, and
 24 anybody that knows the immune system knows the normal
 25 count, which I have heard other people say should be

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1 I told my mother and she found out, which was --
 2 obviously it was an emotional moment, but it wasn't as
 3 emotional, because she knew of the virus, but she
 4 hadn't any idea for about a year, maybe a year and
 5 a half, that I was actually positive, and the same for
 6 my father.

7 Q. You have said in your statement that the doctors
 8 didn't tell you very much about what it actually meant
 9 and what you should be doing.

10 A. Not really, to my recollection. There wasn't any
 11 great advice. I do appreciate there wasn't a lot
 12 anybody knew about HIV. But I wasn't offered
 13 counselling, and actually neither were my parents
 14 offered anything.

15 Q. You were registered at the Oxford Haemophilia Centre
 16 from 1987. Were you given any treatment for your HIV
 17 from the time of your diagnosis until the mid 1990s?

18 A. No.

19 Q. How did you come to start treatment in the mid 1990s?

20 A. I was going to a routine haemophilia appointment,
 21 which for a lot of people would be the normal thing
 22 and where you seem to find out everything, routine
 23 appointment. There was a six-monthly house doctor
 24 there, who was obviously finishing her training, who
 25 I used to see generally. I didn't really get to see

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1 800, 1,200 is normal, below 100, as one of the doctors
 2 said, there is not much point counting really. The
 3 count was 50. The doctor I saw there was quite
 4 shocked and said, "Why haven't you been put on
 5 antibiotics to stop the disease PCP?"

6 At that time I felt taken aback and I was quite
 7 angry, and that's actually when I went back and
 8 decided to take my care elsewhere because I thought
 9 these people aren't taking care of me. This is --
 10 because I had also got -- additionally to that I had
 11 been having a newsletter from a group called the
 12 National AIDS Manual called Update, and it was a very,
 13 very good publication. It gave you a lot of
 14 information largely about diseases. It was a bit
 15 depressing, but it then also started to talk about how
 16 to prevent yourself. There was a very good
 17 straightforward antibiotic you could take to prevent
 18 PCP. So I thought: I am out of here. There is no way
 19 they are going to look after me properly.

20 I went to a local clinic I had read about in
 21 another bit of information. It is a GU clinic run by
 22 a Dr Stephen Dawson, and that was the best bit of
 23 decision-making I made for my health, because they
 24 were great.

25 Q. And in their response, the Churchill Hospital have

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1 said your CD4 levels were good until October 1994, but
2 they then failed to check your levels in April 1995
3 before noting they had dropped very substantially in
4 November 1995, and they have apologised for the
5 failure to check your CD4 count in April 1995.

6 When you went to the new clinic, you went on to
7 experimental treatments for the HIV.

8 A. Yes.

9 Q. And you suffered quite significant side effects.

10 A. Yes. I mean, over the years -- the thing about --
11 I made a decision to take some of this early
12 treatment, because my CD4 count was low. The drugs
13 that were then available, the antiretroviral drugs,
14 were about stopping the virus replicating in you.
15 They weren't about rebuilding the immune system.

16 With HIV, the thing at that time particularly
17 that everybody understood was that you died and became
18 ill because of the lack of immune system, not because
19 of the virus. With my CD4 count -- I think it went
20 down to about 20-something -- I knew that probably
21 that was going to be it. The drugs were not going to
22 rebuild my immune system, but I felt that I should do
23 something. I felt I wanted to do something.

24 So I had the chance to try some of these early
25 drugs. They were quite toxic and subsequently they

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1 because of a drug that I have now changed from again.
2 I am currently awaiting an appointment with the renal
3 team specialist to look at my kidneys again, because
4 there is something not quite right.

5 Q. You have struggled with severe fatigue and depression?

6 A. Yes. I am not a naturally depressive person, but
7 I have had -- it has obviously worn me down, yes, and
8 definitely I have had fatigue, which I know is an
9 effect of perhaps not a liver that's very good and
10 kidneys, yes.

11 Q. In terms of your mental health, you have had help from
12 a psychologist for about the last three or four years.

13 A. Yes.

14 Q. And you have said that has been a great help.

15 A. Yes.

16 Q. Were you ever offered any support before that time?

17 A. No, not in the early days, to my recollection, no.

18 Q. And you have had to actively seek out that support --

19 A. Yes, yes.

20 Q. -- over the last couple of years.

21 A. Yes, yes.

22 Q. One of your main concerns is about the effect of the
23 hepatitis D in the future.

24 A. Yes.

25 Q. What can you tell us about that?

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1 have given me various problems. I mean, one of the
2 problems that continues now is the lipid fats in your
3 blood. It destroyed a process in the liver that
4 allows you to metabolise properly, so it gives you
5 higher blood fats, basically, which is not a good
6 thing.

7 Q. You also had problems with your kidneys, which
8 continue.

9 A. That's right. I mean, in the longer term, the very
10 first -- one of the drugs that has done this blood
11 lipids is D4T, which is one of the very early drugs,
12 which was really quite toxic. One of the other drugs
13 a bit later on, I think you would probably call them
14 the second generation of drug, gave me what they
15 called kidney grit, which was really like kidney
16 stones, pretty painful, uncomfortable. I had to come
17 off that. I have had quite a few -- I mean, later on
18 I had a drug that gave me neurological effect or
19 damage. So over the time, I mean, there's been quite
20 a few, quite a few.

21 Q. You have also -- some of the medications affected your
22 bone density.

23 A. Yes, that's very recently.

24 Q. Causing osteoporosis.

25 A. Yes, I was diagnosed with osteoporosis quite recently

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1 A. For a lot of people, the hepatitis C -- which I did
2 obviously get exposed to, but I was very lucky.
3 I seemed to clear it myself, which a small portion of
4 people do. The effective treatment there is now for
5 hep C at least gives people something. Unfortunately
6 for me this delta virus, there doesn't seem any
7 effective treatment at the moment. The only chance
8 I have to really deal with that is if they have more
9 effective treatment for hep B, which is what this
10 virus actually uses to survive on. So there isn't
11 anything at the moment. Possibly in the future they
12 may be more effective. If I could get the equivalent
13 of treatment for hep B that people can for hep C, it
14 would be much better for me, but there is nothing at
15 the moment. That is an anxiety, because it is
16 progressive.

17 Q. And you are having regular liver biopsies and tests to
18 see what's going on.

19 A. Yes, I am.

20 Q. In terms of your education and work life, you were
21 obviously diagnosed with HIV as a teenager.

22 A. Yes, I was.

23 Q. Can you tell us what impact that had on your
24 education?

25 A. Pretty severe, really. I mean, I was at the age where

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1 I was right at the beginning of deciding what I was
2 going to do. Obviously finding out that you've got
3 that problem, I mean, it's hard to -- lots of people
4 have been talking about it, but for me it was really
5 almost just like -- I don't know -- falling into
6 a bottomless pit, you know. There was just no way of
7 dealing with it. There was just -- the media, the
8 opinion of what people were that were positive, the
9 social effect as well as the medical effect was pretty
10 devastating.

11 So it did make me feel really what is the point
12 of doing -- in a lot of ways I didn't -- I have never
13 stopped having ambition and doing things. What it
14 really did almost is make me I think panic, and that
15 is I thought to myself: how much time have I got left?
16 There are things I want to do. Do I really want to
17 waste so many years training for this, so many years
18 studying for that, get to the end of that and then
19 start to get ill? It sort of shortened my life view
20 dramatically.

21 I mean, in the mid 1980s, when you found out,
22 I mean, this is the era of Rock Hudson dying and
23 people that were in the public were literally dying.
24 Psychologically, obviously, it affected me a great
25 deal. I didn't just stop, but I did think, "If I go

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1 other training as well, as well as some other
2 educational stuff through that time.

3 But obviously when people get the knowledge
4 about the fact you were positive in the 1980s, and
5 this was something that people living with the problem
6 will understand, I imagine, is that when somebody knew
7 about you, you could never tell what that person would
8 be like, and in a community, one of the difficulties
9 is although I am fit and I put a lot of effort into
10 that, I couldn't go so far without telling somebody
11 about the haemophilia. I mean, you can't not say
12 about that, because it's severe. For insurance
13 purposes, for all sorts of other reasons, you need to
14 say. At that time, people connected it quite
15 strongly. So that in itself gave me problems.

16 Later on, I was in Hollywood, I was in America,
17 and I met with a producer. I talked to a guy about a
18 collaboration. I couldn't stay out there, because of
19 my positive status, and in America, that's where they
20 gave it to me or it came from.

21 So in a practical sense, yes, there are lots of
22 places and lots of opportunities that I've lost, but I
23 think above all it is the -- as other people have been
24 saying, it's the knowledge. You can't tell what
25 somebody is going to be like. Once they know that, it

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1 back in" -- at the time I had actually left education
2 and what I wanted to do was to go back in to do some
3 additional training, which later on I did do. For
4 those first two or three years, I mean, my career was
5 blood tests and urine tests and hospital appointments.
6 It wasn't really feasible -- if I had been in
7 education at the time, I don't think I would have come
8 out. I want to say that. But I do think it made me
9 think, "What do I really do?" I mean, there wasn't
10 anything you could do.

11 Q. So from about 16 to 21, you weren't in education and
12 you weren't able to work particularly?

13 A. By the end of the 1980s I had gone back into full time
14 -- I did a full-time college course. Before that
15 I had done some additional training for the creative
16 stuff that I really wanted to make a career of, but it
17 was very disruptive. It was not a good time.

18 Q. And ultimately those plans and hopes of doing creative
19 work didn't --

20 A. Well, I have done some things. My thing was
21 filmmaking. I had a relative who was a cameraman.
22 I had an interest in writing and directing. In the
23 1980s, actually, that was one of the first bits of
24 training -- I managed to get on a course that involved
25 basically filmmaking, and I subsequently then did

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1 was potentially pretty devastating.

2 Q. So your paid work life has been very limited.

3 A. Yes.

4 Q. But you have been able to do a lot of charity work.

5 A. I have. I mean, having severe haemophilia, I mean, I
6 was getting -- because I wasn't on prophylaxis, I was
7 getting a bleed probably every week, and trying to do
8 regular -- I mean, my big ambition was to do
9 filmmaking, but trying to do almost like the
10 intermediate work was where it was a problem, because
11 if you turn up to apply for a job and they say, "Have
12 you got any problems?" and you say, "Well, I have
13 a few" and then you say you have severe haemophilia,
14 then they say "What's that?" and they say, "Do you
15 have to have any time off?" and you say, "Probably
16 a day a week", they say, "Oh, yeah, that's not
17 a problem", then you never hear from them again,
18 because you're going to be -- I mean, I was making
19 sandwiches at one point, like a lot of kids do. For
20 me, I have ankle damage, so I couldn't do something
21 that was involving a lot of standing. Obviously,
22 having severe haemophilia, I couldn't do anything like
23 go and work on a building site. So the intermediate
24 thing was pretty difficult.

25 I went along to the careers service. She was a

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1 specialist with people with problems and she just
2 said, "I don't really know what to suggest".
3 I thought "I don't know what to suggest either". So
4 she made me a cup of tea, and I used to go back every
5 three months. That was about it, really. That was
6 about all anybody could do.

7 Q. In your statement you said your illness has proved
8 a real challenge for you and it's been difficult to
9 form any long-term relationships.
10 A. Yes. If you are a teenager in the 1980s and you had
11 HIV, that was not a great calling card. Obviously for
12 people that are adults, I mean, I don't really need to
13 explain that much further. It was not fun. It was
14 very difficult. I mean, when I found out, I was
15 15/16. I hadn't really seriously considered about
16 being married, about having a family. Everything was
17 what I wanted to do.

18 But over -- it is funny, actually. I have never
19 had a long-term relationship past very intermediate
20 stuff, and as I've got older, the last I guess 10
21 years, maybe 15, I wish I had been able to have
22 children. I wish I had been able to have a long-term
23 relationship. I am heterosexual. My parents were
24 married for 50-plus years. I grew up in a household
25 like that. It is what I wanted to do. But I wasn't

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1 a lot better than they did.

2 On a personal note I, because of my HIV status,
3 even if I had been able to find regular work,
4 I couldn't get a mortgage. That's what everybody knew
5 that was positive. It was made clear. So I was stuck
6 at home, which is not what I wanted. I had to
7 obviously tolerate that and I was quite lucky, really,
8 because my parents owned their own home, they were
9 stable. At least I had a place to live. But I never
10 had the chance to own my own home.

11 It is a little bit complicated. My father
12 became ill. He had a stroke, which is in 1990. He
13 developed Parkinson's and dementia, which for my
14 mother was very difficult, because both of them knew
15 about me, so she had to give up her work really to
16 look after my father. Then it went to another level
17 and we had to have nursing staff coming in day and
18 night.

19 Slightly ironically, my parents were worried
20 about me and I wasn't getting ill, but my father was,
21 who had no health issues before that time really, he
22 had always been strong and fit.

23 When my father died at the end of the 1990s, we
24 needed a new boiler, which is not a sexy thing but it
25 is quite important when you don't have much of an

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1 a good bet, really. So that didn't ever really work
2 out.

3 Q. In terms of finances, you participated in the American
4 pharmaceutical litigation.

5 A. Yes, I did, yes.

6 Q. And signed the settlement agreement in that.

7 A. Yes.

8 Q. You have also received a lump sum payment from the
9 MacFarlane Trust and annual sums, but you have said in
10 your statement you have not found them very helpful to
11 you because you don't own your own home. You live
12 with your mum.

13 A. I do, yes.

14 Q. Can you tell us what the issue with the MacFarlane
15 Trust has been?

16 A. How long have you got? The person that was on before
17 me I think spoke very

18 Well and they said a lot about some of the
19 things that I feel, and that is that really for a
20 community of people like us, who were vulnerable --
21 not that I like to think of myself like that, and I
22 don't think anybody else does, but we were vulnerable
23 -- I think really in a country like Britain, which at
24 the time was something like the fourth wealthiest
25 country in the world, they could have done a hell of

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1 immune system and your mother is of retirement age.
2 I thought: I know, there is this MacFarlane Trust.
3 I: had never really asked anything of them because
4 they had always said, "If you are a homeowner you can
5 get this, if you're a homeowner you can get that" and
6 I thought there is not much I can get out of them
7 anyway.

8 I contacted them and said, "We need a new
9 boiler. Can you help out?" They said, "Well, you are
10 not the homeowner. Do you pay rent?" I said, "It is
11 my parents' home. No, I don't pay rent". They said,
12 "I am really sorry, no, there's nothing we can do".
13 So the first major application I had was turned down.

14 In part, some of my problem with the MacFarlane
15 Trust is the fact that I didn't make many applications
16 to them, because they didn't give me the impression
17 I could get anything out of them. The only thing
18 I ever remember getting out of them was a grant to get
19 hold of a computer and a payment for a massage, which
20 I did use, but I am not explaining that any further.
21 That was it. Literally, that was it. They weren't
22 very helpful.

23 The criterion -- you know, there are other
24 people here and other people are probably going to
25 speak that can spend a lot more time explaining the

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technicalities of it, but they were not an organisation that was very helpful to anybody. I have never -- because I have been connected with this community for a long time, some guys I have known for 20 years, I have never met anybody of the infected, the affected, ever that has ever had anything good to say about the MacFarlane Trust or Skipton Fund or any other organisation that was meant to be there. They were useless, worse than useless.

Q. In terms of the Skipton Fund, because you had cleared the hepatitis C naturally --

A. Oh, yes, yes, yes.

Q. -- you couldn't have any payments from them on that.

A. Right.

Q. And they also didn't recognise hepatitis D.

A. That's right. Well, I am not a trained scientist, though science was quite an interest of mine. So I had a test that said you are PCR negative for hepatitis C. I was very relieved. I didn't need any of the therapy that a lot of people have had to tolerate. I thought: God, that's something good. I was then told that, because of that, I didn't qualify for any payment whatsoever from the Skipton Fund. So I didn't receive the initial £20,000, no recognition at all or anything.

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Q. Robert, those are the questions I have for you. Is there anything else you would like to say?

A. Yes, there is. There is. I have written down a load, but I am not going to be able to say it all. There are others that have said it very well as well.

You know, one of the problems is that for most of my life, and I know for a lot of people that live with haemophilia in my generation, we have been seen as essentially a failure, and it makes me angry because in my generation, when I was born in the late 1960s, the revolution that gave me everything that I have now -- and I have been able to do many things, I have been able to travel around the world, I have been able to pursue interests, I have been able to walk here and walk out -- all because some remarkable people developed a treatment that solves my dilemma. But unfortunately those people got betrayed I think as much as we did, and that is they perverted this treatment for profit.

The original discovery of cryoprecipitate I believe was done in America at Stanford, and it was done by public money. It was people that cared enough to do these things. The drug companies got hold of this stuff and it has been a nightmare.

In the press they always say -- which I know we

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I felt angry about that, because any of the other guy's I know, I think everybody was sort of puzzled, because we all thought that everybody that got exposed to -- what that initial payment was, was saying, "This is to help you deal with the fact that we basically infected you with a virus". I didn't expect recognition at the same level as some people have had with severely affected livers, but I expected some recognition and got nothing.

What is really puzzling is a few years later I was told I was PCR negative for hepatitis B, but apparently PCR negative wasn't good enough to stop the hepatitis D, which they had also passed into me, and still no recognition. So on the one hand I was PCR negative and excluded, but on the other hand I was PCR negative and had a virus because there were still traces of it in my liver.

The Skipton Fund Trust don't recognise hep D. I know it is very rare, but I have it. They don't recognise if you have PCR negative tests, so I didn't qualify for any help there. That is the end of it. I applied for it and they simply turned me down. And I got one of the doctors to back me up, but it wasn't enough, so I have no relationship with them whatsoever.

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all understand -- it was one of the greatest disasters in NHS history, but to me it was one of the greatest successes that became the greatest disaster. That adds to the problem. It adds to the catastrophe, because it was all good. When I was born, things were getting better. For the first few years of my life, I had a treatment that my parents couldn't believe even existed, and it gave me the ultimate achievement, which is normality. I can walk around and people don't even know there's anything wrong with me. I went to a local school. I played with my friends. I rode a bike. I climbed a tree. I even competed in sport. And I could not have done that without the treatment.

So I can't say anything else anybody else hasn't already said up to now. I mean, one of the things, I have done training as a filmmaker, and somebody else before me mentioned it, and I don't understand why we haven't had in this community our Philadelphia. We haven't had our Dallas Buyers' Club. We haven't had any recognition within culture really at all apart from a disease of the week, where a load of us get sick and everybody gets sad.

If I had to pitch an idea, a script, I would say our story is somewhere between Watergate and a

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financial film like Gordon Gekko's film. He would be a character in that story. Because it is far more than just a sad story. It is a catastrophe, and it involves a level of political scandal that is as deep as Watergate, and Watergate was one of the big political scandals in America. That's the calibre of film we should have. That is the calibre of story we should see, and it should have an impact.

I mean, recently they have done a show on Sky, I think it is, called Chernobyl, and it got a lot of acclaim and it was very tragic. We can match what happened in Chernobyl, because if you were positive in the 1980s, you were radioactive. Nobody wanted to come near you. And it would make a powerful story, and I think one that would help the community, for us, and also to explain it. So few people even understand what this catastrophe is about apart from now, and that is because of the limited press coverage. I mean, having like, you know, 35 seconds on Newsnight is powerful for the person there, but then somebody watches Love Island and it's all gone away. It should be something more than what it is. So that is I guess the main part that I want to say.

I also feel as I have got older how awful it must have been for my parents to see their child being

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SIR BRIAN LANGSTAFF: I suspect, with your rather relaxed manner, it is telling a tale which is somewhat understated. That may be part of its power.

A. Well, I have a lot of emotion, but, I mean, one of the other things that actually I was talking about just before I came on is that, you know, in some ways, this is a huge event and I feel a bit edgy about being up here, because it would be unnatural not to be, but it is almost rehearsed, and that's what the tragedy of it is. I mean, I have been talking about this problem -- so many people have -- for 35 years. It's difficult to feel fresh.

The fact I can talk about it without really getting that emotional is probably a measure of how damaged maybe I am or it's almost -- when you write scripts, it is like first, second person. It is almost talking like a second person. It is like I am detached about what happened.

It happened to me in the early 1970s. I can't even remember that period really. It has gone on for so long. I have never had any period of my life where there has not been any infection there. It is tragic, but if I could get more emotional about it, I would, but I am just burned out. I don't have any left. I am like an actor that's burned out, really.

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made ill by a country that they had been a part of. I mean, my father fought in the Second World War and he ran a factory. He made a lot of contributions. My mother worked. And all they saw was me getting worse and worse, and I should have been getting better and better.

As I have got older, if I had had a child that went through what I went through, I would have found it very, very difficult to cope with. I think that that should be recognised, as other people have said, as well.

So I have a lot of other things, but that's basically, I think, pretty much what I want to say.

So thank you very much.

MS FRASER BUTLIN: I am just going to turn to Mr Snowden, who as you know represents you, to see if he wants to ask anything. No.

SIR BRIAN LANGSTAFF: You are the first person who has made a plea for a film. Some have given me poetry, some have made recommendations. Yours is the first to deal with what is obviously your great love.

A. Yes.

SIR BRIAN LANGSTAFF: Can I thank you very much for what was a fascinating account, a pleasure to listen to.

A. Thank you.

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I haven't got anything more to feel about it anymore.

My father died in the late 1990s and, you know, he never saw me get better. He never saw any of that, which makes me sad. But I'm still alive. So I feel -- I haven't stopped wanting to do things. I haven't stopped pursuing things.

One of the other things is that it's a bit like in a way a civil rights movement. With bigotry, you can't take that bigotry away, but you can match what it is. So if you can pursue what you want to do, you have made that contribution in and you have not given up, and in that way maybe that's a victory for me.

So thank you very much for your efforts too, and, I mean, you know, it is an amazing experience that this is actually happening, because I have waited and my parents have waited and everybody else I know has waited for at least 30 years, and now for me 47 years or whatever. So I hope we get the conclusion.

Thank you very much.

(Witness withdrew)

SIR BRIAN LANGSTAFF: Tomorrow we start at 10.00 again and all our witnesses tomorrow are anonymous, are they not?

MS FRASER BUTLIN: No, sir. The first two are anonymous and there will be no live stream. The third witness

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1 after lunch is Amanda Beesley.
2 **SIR BRIAN LANGSTAFF:** Ah, thank you very much. So
3 anonymous in the morning and those who wish to follow
4 us on live streaming should tune in, if that's the
5 right expression, after lunch.
6 **MS FRASER BUTLIN:** After lunch.
7 **SIR BRIAN LANGSTAFF:** Thank you very much.
8 **MS FRASER BUTLIN:** Thank you.
9 (4.05 pm)
10 (Adjourned until 10.00 on Wednesday, 16th October 2019)
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(50) hindsight... - incident

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(58) see... - sperm

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