

Wednesday, 12 June 2019

1

2 (10.30 am)

3 **SIR BRIAN LANGSTAFF:** Good morning. Our first witness  
4 is -- wishes to be known as Martin, does he?

5 **MS RICHARDS:** Sir, yes, Martin Beard.

6 **SIR BRIAN LANGSTAFF:** Martin.

7 **MARTIN BEARD, affirmed**

8 **Questioned by MS RICHARDS**

9 **Q.** Martin, you were diagnosed as baby with severe  
10 haemophilia A?

11 **A.** Yes, that's correct.

12 **Q.** That was in July 1969?

13 **A.** Yes.

14 **Q.** Your mother wanted you to lead as normal a life as  
15 possible but you did sustain a lot of bleeds and end  
16 up spending a lot of time in hospital?

17 **A.** I did, yes. Basically, I went through the normal  
18 rough and tumble of any youngster at that time, but  
19 obviously with being a severe haemophiliac I had a lot  
20 of bleeds and where I lived the nearest hospital --  
21 well, the centre I was under was Birmingham  
22 Children's, which was a 30-mile journey from where  
23 I lived. So every time I had a bleed it was a trip in  
24 the ambulance to Birmingham Children's.

25 **Q.** And the available treatment at that time in your early

1 childhood was cryoprecipitate, but you had an allergic  
2 reaction to it?

3 **A.** I did. I used to have anaphylactic shocks,  
4 anaphylactic reactions to cryo.

5 **Q.** In about 1974 you and your mother were told there was  
6 a new treatment that was going to be made available  
7 for you, Factor VIII concentrates?

8 **A.** Yes.

9 **Q.** If we look on screen, please, at a document.

10 Paul, it is 0012003. It should come up on the  
11 screen in front of you in a moment. We can see this  
12 is a letter dated 16 December 1974 from the Lister  
13 Institute for Preventive Medicine to the Birmingham  
14 Children's Hospital and it says in relation to you:

15 "We can let you have some bottles of globulin  
16 concentrate to control his bleeds now that he has  
17 become sensitised to cryoprecipitate."

18 There is a reference in the next paragraph:

19 "We have recently encountered some difficulty  
20 with positive RIA hepatitis B antigen tests.

21 I suspect that some, possibly most, of these are false  
22 positives. The only concentrate we can send you is  
23 from a batch number HJ1025 which has given such  
24 a positive reaction which was 'diluted out'. Flewett  
25 knows of this problem and would probably retest this

1 batch for you."

2 Do you have any observation to make about that  
3 letter?

4 **A.** Apart from the fact they clearly identified  
5 a potential problem with it but they were still  
6 prepared to distribute it, which -- it is still  
7 shocking, but given the time back then in '74 and the  
8 fact that this -- Britain was very -- struggling to be  
9 self-sufficient in factor, but it still shouldn't have  
10 happened.

11 **Q.** Now you received the Factor VIII concentrates  
12 initially at hospital rather than at home.

13 **A.** Yes.

14 **Q.** Then in 1975 you had a particularly dangerous bleed.  
15 You had a lot of blood from a head wound. Is that  
16 right?

17 **A.** Yes. It was an innocuous injury. Me and my middle  
18 brother were having a snowball fight and he threw one  
19 at me and it had got a little stone in the snowball,  
20 which cut me on the top of the crown of the head,  
21 a very tiny cut, and we were outside a social club at  
22 the time where my parents were inside and I went in  
23 and there was blood running down my face, and my  
24 mother jumped up and screamed. I can still see it to  
25 this day, but she took me home, cleaned me up, put

1 a bandage on my head, and because it was such a small  
2 cut it, didn't really think it needed any treatment,  
3 but what happened was it kind of built up in the night  
4 the bandage came off and the following morning my  
5 brother described it as what he thought was like  
6 a murder scene. There was blood everywhere, and he  
7 went downstairs and said to my mum "I think Martin's  
8 dead", but because was a practical joker, my mother  
9 didn't believe him.

10            Luckily for me my eldest brother, he came down.  
11 He was the more sensible one at the time and he said,  
12 "It's true. I thinks' gone", and they rushed me in  
13 an ambulance to Birmingham Children's. I remember  
14 passing out in the ambulance, looking up through the  
15 frosted ceiling, and then I came round in a room in  
16 the hospital looking up at a nurse who was clearly  
17 cutting my hair away trying to find the wound, and  
18 then I passed out again and came round in a hospital  
19 bed, but they had to replace me with a few units of  
20 blood.

21 **Q.** Now it was in 1976, the following year, when the  
22 hospital started to train your mum on administering  
23 the Factor VIII products to you at home?

24 **A.** Yes. Her training basically involved, she had to try  
25 and inject the veins in an orange. That was how she

1 was trained and it was quite bizarre as a 7 year old  
2 to watch my mum do this, but that was how she was  
3 trained and then -- but then we had to get permission  
4 from my local GP to be able to take Factor VIII home  
5 with me and initially my GP refused, so we changed GPs  
6 and the GP I went with was brilliant. He was a superb  
7 guy, who I was under for the next 40 years.

8 **Q.** And do you know why the first GP had refused?

9 **A.** He basically said that if he couldn't inject me, then  
10 there's no way my mum should be allowed to.

11 **Q.** Now, after you changed GPs and arrangements had been  
12 made for the home treatment, your mum would then store  
13 the Factor VIII in a fridge at home --

14 **A.** Yes.

15 **Q.** -- and would treat you at home?

16 **A.** Yes.

17 **Q.** And your mum kept meticulous handwritten records from  
18 1977 onwards of every time you had a bleed that  
19 required her to administer --

20 **A.** Yes.

21 **Q.** -- Factor VIII to you?

22 **A.** Yes. She -- she never really trusted doctors and  
23 although the hospital had their own records, which  
24 were basically a sheet of paper written down with what  
25 the bleed was for and how many bottles of factor that

1           you would have, my mum actually kept her own records  
2           and she wrote down the site of the bleed and when it  
3           was and roughly how many bottles you would have for  
4           that bleed.

5   **Q.** And it's clear from those records which you've shown  
6           to the Inquiry that you were having bleeds at least  
7           once a week, often twice a week?

8   **A.** Yes.

9   **Q.** Week in, week out for years?

10 **A.** Yes.

11 **Q.** And you required factor concentrates as the treatment  
12           for that?

13 **A.** Yes.

14 **Q.** You have also got an UK HCDO records which show that  
15           from 1977 onwards you received a range of different  
16           products: cryoglobulin, Factor VIII BPL, Cutter Factor  
17           VIII, prophylating Factor VIII?

18 **A.** Yes.

19 **Q.** As far as you are aware, was your mother ever given  
20           advice or information or warnings about any risks of  
21           infection associated with the use of those products?

22 **A.** No.

23 **Q.** As you grew into a teenager and continued to take  
24           those products, were you ever given any advice or  
25           warning or information?

1   **A.** No.

2   **Q.** Could we have up on screen, please, Paul, 0012004? If  
3       we could just have a close-up on the first part of it.  
4       Thank you. So this is a document from 1981. It shows  
5       a range of tests and you had some observations you  
6       wanted to make about this document?

7   **A.** Yes. I was watching another testimony and during the  
8       testimony this document flashed up and I thought to  
9       myself "I seen that before", and I went looking  
10      through my notes and I found this document and it is  
11      exactly the same document as another person was tested  
12      for in the same year. The only differences were the  
13      other person was about eight years younger than me and  
14      my test was done I think six months before his, and it  
15      just seems very strange that we were both tested in  
16      the same year for such a bizarre range of tests.

17   **Q.** And you've said in your at the same time you think  
18      that tests were undertaken without your --

19   **A.** Yes.

20   **Q.** -- you and your mother's knowledge and consent.

21   **A.** Yes.

22   **Q.** You would have been about 12 at this time?

23   **A.** Yes.

24   **Q.** As far as you're aware, was your knowledge -- was your  
25      consent, your mother's consent sought for these kind

1 of tests?

2 **A.** No. No.

3 **Q.** Now in 1986 your care transferred from Birmingham  
4 Children's Hospital to the Staffordshire North  
5 Infirmary?

6 **A.** Yes. Basically, I was too old to be classed under the  
7 Children's Hospital anymore and I thought that I would  
8 transfer to the Queen Elizabeth, as most of the  
9 haemophiliacs under Birmingham Children's did, and we  
10 were like a community. I knew a lot of the  
11 haemophiliacs at Birmingham Children's, and that's  
12 what I assumed would happen, but then Frank Hill said  
13 to me one day -- he says "I'm going to transfer you to  
14 North Staffordshire Royal Infirmary, because I think  
15 it will be more convenient for you". It turns out it  
16 wasn't. It was a longer journey, and it was also  
17 apparent that he had a friend there.

18 So I got an appointment 1 September 1986 at  
19 North Staffordshire Royal Infirmary. Now, I wasn't  
20 driving at that point and my mother [redacted], so she  
21 was only just learning to drive again. So we went in  
22 an ambulance car for this appointment and were in the  
23 waiting room, unlike any other. My name is called out  
24 and my mum is on my arm, because she is struggling to  
25 walk and she open the doctor's door and I am not even



1 in his office. We are stood in the doorway, you know,  
2 and he doesn't even say, "Please take a seat. Hello,  
3 welcome to North Staffordshire. Hello, I am  
4 Dr Ibbotson". He doesn't say anything. All he says  
5 is, "Hello, I see you're HIV positive", and whether me  
6 being naive or the fact that I was a very healthy  
7 17 year old, I just batted it away and I said, "Oh,  
8 well, that's life", because I didn't really understand  
9 the implications of it.

10 He looks at me and says, "That's your life for  
11 the next two years". I said, "What do you mean by  
12 that?" He says, "You've got about two years to live".  
13 That's when it hit me, and I can't really remember the  
14 rest of the conversation I had with that man that day.  
15 I just remember going home and having to break the  
16 news to my brothers, but I don't know what their  
17 reaction was, whether they went away and cried.  
18 I honestly don't know.

19 **Q.** And that's how you learned that you had been infected  
20 by HIV --

21 **A.** Yes.

22 **Q.** -- in consequence of the treatment you had received.

23 You have said in your witness statement you were  
24 in a state of shock and disbelief. One of the  
25 particular concerns you have looking back at your

1           recollection of that consultation is that this  
2           information was delivered to you in a way that others  
3           in the waiting room could hear.

4   **A.** Yes, yes. He didn't whisper it. He said it in  
5           a normal voice and the door was open and the normal  
6           public were sat in the waiting room behind me.

7   **Q.** Now that was, as you have said, 1 September 1986. We  
8           are going to look at a couple of documents now.

9                    Could we have up on screen, please, Paul,  
10           0012005. If we could again have that highlighted.

11                   So we can see this is in relation to you. We  
12           see down the bottom it says:

13                    >Date of specimen: 1983.

14                    >Date of report." It is undated.

15                    The test result is:

16                    "HTLV-III antibody positive."

17                    But we can establish some kind of time-frame for  
18           this by your age, which is given at the top as 14.

19   **A.** Yes.

20   **Q.** So in what year did you turn 14?

21   **A.** That would have been 1983. January 10, 1983, I would  
22           have been 14.

23   **Q.** This was a result showing you were HTLV-III positive.  
24           You think it is most likely a result from 1983 --

25   **A.** Yes.

1 Q. -- because of the age that's given there?

2 A. Yes.

3 Q. And you weren't told of that test result?

4 A. No.

5 Q. Were you told that you were being tested?

6 A. No.

7 Q. If we can have a second document up on the screen,  
8 please, 0012002.

9 We can see, Martin, this is a letter from the  
10 Leicester Royal Infirmary dated 11 October 1985. It  
11 is addressed to a Dr Perry, Senior Registrar in  
12 haematology at Birmingham Children's Hospital. So  
13 this is almost a year before you had the consultation  
14 you have described in which you learned you were HIV  
15 positive?

16 A. Yes.

17 Q. We will just look at this letter together:

18 "Dear Dr Perry.

19 "Reach: Martin Beard.

20 "Thank you for letter to Dr Hutchinson which he  
21 passed on to me. We did ask Martin and his mother to  
22 call in and see us, but apparently they got lost in  
23 the hospital and did not make it to the Haemophilia  
24 Centre. However, he did turn up this morning when I  
25 was holding a haemostasis clinic and I met him then."

1           The next paragraph refers, Martin, to you being  
2           in Leicester for a couple of months learning  
3           electronic assembly work at the skill centre and  
4           refers to home treatment and to a bleed into your knee  
5           and explains that the sister, that's the nurse, at the  
6           work centre insisted on you coming to see them?

7   **A.** Yes.

8   **Q.** There's then a reference to your health in the  
9           following paragraph.

10           Then if we can have the next paragraph, please,  
11           highlighted, the one after that, Paul, it says this:

12           "We note that he is HTLV-III antibody positive,  
13           but is not aware of this and that you do not wish this  
14           to be divulged to him. We shall make every effort to  
15           comply with your wishes."

16           So that's a letter of October 1985, which may  
17           have been in any event a couple of years after you had  
18           been -- the test had been undertaken.

19   **A.** Yes.

20   **Q.** One doctor to another referring to your positive test  
21           result, to the fact that you are not aware of it, and  
22           that the doctor at the Birmingham Children's Hospital  
23           doesn't want you to be told.

24   **A.** Yes.

25   **Q.** Now, when did you first see this letter?

1 **A.** I saw that in 2006 when I got hold of my medical  
2 records.

3 **Q.** And what was your reaction to seeing that letter?

4 **A.** Stunned. Absolutely stunned. Total blatant disregard  
5 for me and disappointment, the fact that I had been  
6 under Birmingham all those years and while I was under  
7 Birmingham I was always very open to medical  
8 examinations, because I was blind in one eye and they  
9 liked examining me and I was always open to questions  
10 and things like this, but they never had the decency  
11 to tell me about this, and what also staggered me was  
12 the fact that they were prepared to put other people  
13 at risk, the people who I was working with.

14 **Q.** In terms of the work that's described there, the work  
15 that you were doing in Leicester, was that very  
16 physical work?

17 **A.** Some of it was. Some it I was doing sheet metal  
18 working, riveting working and then I moved on to the  
19 electronic assembly work which was less demanding, but  
20 when I was doing the sheet metal working and things  
21 like that, they were -- for a severe haemophiliac, it  
22 was very dangerous work and if I had have had a bad  
23 incident, people would have been at risk, and that is  
24 just staggering.

25 **Q.** And in this period, 1983 to 1986, before you

1 discovered your infection, did your mother continue to  
2 administer the Factor VIII to you at home or were you  
3 doing this by yourself by now?

4 **A.** I was doing that by myself. I started treating myself  
5 at the age of 11, I think. Basically, I was  
6 an in-patient at Birmingham one day and the  
7 haemophilia nurse came along and see said, "You're  
8 going to inject yourself today", and I said, "No, I am  
9 not". She says "You have got two choices. You either  
10 put the needle in yourself or you stick it in me", and  
11 I was that petrified at the thought of putting  
12 a needle in somebody I just grabbed it and did it.  
13 That was my initiation over, so from then on I treated  
14 myself.

15 **Q.** Dr Perry and Dr Mitchell, so the person to whom that  
16 letter was addressed and the author of that letter,  
17 have both been asked for their response. I know you  
18 have seen those responses, Martin. Dr Perry simply  
19 says:

20 "I cannot comment upon the screening for  
21 HTLV-III antibodies. I was during this period  
22 a trainee under the supervision of Dr Frank Hill,  
23 consultant haematologist, and whom I would advise is  
24 contacted to discuss this in detail."

25 Do you have any observations to make about

1 Dr Perry's response?

2 **A.** One way or another they know more than they're letting  
3 on. They were either ordered from higher up to keep  
4 it a secret or they made their decision on their own.  
5 I can't see any other way round it.

6 **Q.** And Dr Mitchell --

7 **SIR BRIAN LANGSTAFF:** Before you go on to Dr Mitchell,  
8 what you have dealt with thus far is his reaction to  
9 the screening.

10 Does he say anything about what is said in the  
11 letter about him not wanting to tell Mr Beard what he  
12 knew about his HIV status?

13 **MS RICHARDS:** Sir, no. I have read out verbatim the one  
14 paragraph of Dr Perry's statement which addresses the  
15 substance.

16 **SIR BRIAN LANGSTAFF:** So he simply doesn't engage with the  
17 criticism at all?

18 **MS RICHARDS:** The Inquiry team are going back to Dr Perry  
19 to ask for further responses.

20 **SIR BRIAN LANGSTAFF:** It might be useful when you do to  
21 confirm what date he knew there had been an actual  
22 positive test for HIV, because 1983 was before HTLV  
23 was identified. That wasn't until, as I understand  
24 it, May 1984.

25 **MS RICHARDS:** Yes, sir.

1     **SIR BRIAN LANGSTAFF:** So the test result you have shown us  
2           must be a retrospective test, but it is plain from the  
3           letter that they knew by the date of the letter.

4     **MS RICHARDS:** Yes, sir. It is not clear, as Martin knows,  
5           from that test result, because the report itself is  
6           not dated. Unusually, most of the reports in Martin's  
7           medical records are dated. That one is not.

8           Martin, you have also been shown Dr Mitchell's  
9           response. Dr Mitchell was the author of that letter  
10          saying they would do their best to comply with  
11          Dr Perry's wishes not to divulge your HIV status to  
12          you. What Dr Mitchell has said is:

13                 "It is unbelievable that the doctors at  
14          Birmingham Children's Hospital Haemophilia Centre  
15          intended that Mr Beard should be kept in permanently  
16          in ignorance of his HTLV-III antibody result,  
17          a position which would be untenable."

18          Dr Mitchell goes on to say what was being asked  
19          was you should not be told the result by a doctor who  
20          you had never met before and would never see again.

21                 Do you have any observations to make about that  
22          suggestion?

23     **A.** The doctor at Leicester was put in a difficult  
24          position. He was asked to keep something a secret.  
25          Morally and ethically maybe he had a duty to inform me



1 or at least inform the nurse at the training centre,  
2 but to my knowledge even she was unaware. They  
3 obviously had their reasons for keeping it a secret  
4 from me. I will probably never know what they are,  
5 but the fact that they wanted it secret, full stop, is  
6 a blatant disregard for other people's health.

7 **Q.** There is one further document we will look at, Martin.  
8 It is 0012006. So we can see this is a result. It is  
9 stamped 1 May 1986. Again, it records a positive test  
10 result for the antibody to HTLV-III. That's May 1986.

11 Were you aware that tests were being undertaken  
12 in May 1986?

13 **A.** No.

14 **Q.** And this test result was not communicated to you  
15 either?

16 **A.** No.

17 **Q.** Because the first you learned was 1 September?

18 **A.** The first I learned was September that year.

19 **Q.** Now in early December 1987, the following year, you  
20 were admitted to North Staffs Royal Infirmary with  
21 a knee bleed.

22 **A.** Yes.

23 **Q.** What can you recall about the circumstances of your  
24 treatment there?

25 **A.** Well, whenever I had been admitted into Birmingham

1 with a knee bleed, the normal procedure was I would be  
2 put on bed rest. I would be given factor. The  
3 bleeding would be under control and then they would  
4 resume physio to get my joint mobile again.

5 When I was admitted into North Staffs, the first  
6 thing they did was put my leg in plaster and then they  
7 put me in a side ward and effectively left me. When  
8 they brought my Factor VIII in to me, the staff were  
9 in full medical gear, masks, gloves, gowns, the whole  
10 lot, but the Factor VIII wasn't even made up. I had  
11 to make it all up myself and inject myself. They have  
12 even brought my dinner in in full gear.

13 The isolation was just so Draconian it was  
14 ridiculous, and I was -- I was scared. I had been  
15 told by this hospital that I had only got two years to  
16 live and then all of a sudden I am being treated like  
17 this leper.

18 Unfortunately, back then I was a very quiet  
19 person and I didn't really speak up. Thankfully for  
20 me, behind the scenes my mother was having a word with  
21 the doctor and basically begging him to let me out for  
22 Christmas that year, and he said to her -- he says,  
23 "Yes, he can go home for Christmas as long as you  
24 bring him back", and kind of discharged me on  
25 24 December, but I never went back there.

1 Q. And you have explained in your statement that was your  
2 first sign of any real stigma and isolation from  
3 medical practitioners --

4 A. Yes.

5 Q. -- in regard to your HIV status. Your mother was  
6 incensed and wrote to the Haemophilia Society about  
7 it.

8 A. Yes.

9 Q. And we can see the response at 0012009, and if we just  
10 have the second paragraph:

11 "I can only say that from our point of view, and  
12 the vast majority of haemophilia centres, the action  
13 taken by the hospital is absurd and ridiculous."

14 It goes on to talk about the irrational and over  
15 reactive way in which you were handled.

16 A. Yes.

17 Q. Now, you didn't return to the care to North  
18 Staffordshire Royal Infirmary for the reasons you have  
19 explained. You next came under the care of --

20 A. Derby Royal Infirmary --

21 Q. -- Derby Royal Infirmary.

22 A. -- in April 1988. I was effectively without  
23 a hospital for four months. In those four months  
24 I just basically went under the care of my local  
25 hospital, which doesn't deal with haemophiliacs, and

1 I can't remember which hospital I got my factor  
2 concentrate from for that four-month period. It might  
3 have been North Staffs. It might have been Derby.  
4 I can't honestly remember.

5 But in April 1988 I gave in and became a patient  
6 under Derby Royal Infirmary, which I had always been  
7 reluctant to do because it wasn't a proper  
8 comprehensive Haemophilia Centre and also growing up,  
9 I had seen my [redacted] and my cousin, who were all  
10 haemophiliacs, treated there and I had watched --  
11 grown up watching them in calipers and with bad legs  
12 and things and I thought it was the care of the  
13 hospital had made them that way. It turns out,  
14 obviously, it's just a progression thing with  
15 haemophilia, but that's how I was feeling at the time.

16 **Q.** And your diagnosis and the fact that you had been led  
17 to understand you only had a couple of years to live  
18 led to you making a will at that time at the age of  
19 17?

20 **A.** Yes, yes. It is still to date the only will I have  
21 ever made. I do mean to update it, but part of me  
22 thinks, well, if I do that, it is almost like  
23 an admission that I am getting on in life.

24 **Q.** In those early years after your diagnosis was finally  
25 communicated to you what was the impact on you of your

1 condition, both physically and mentally?

2 **A.** Sorry, could you repeat that.

3 **Q.** In the early years after you were told in

4 September 1986 of your diagnosis what was the impact  
5 physically and mentally?

6 **A.** Well, we started receiving some information. I can't  
7 remember who from. We got leaflets through the post  
8 of advice. I was advised to only eat tinned food.  
9 I was advised not to keep any pets and I had had dogs  
10 and cats my whole life.

11 I was toying with the idea of getting rid of my  
12 pets and I thought the psychological benefits of  
13 having pets far outweighs any potential risk in my  
14 book. Those pets had been with me throughout my  
15 childhood. Whenever I had had bleeds, whenever I was  
16 in pain, they always kept me -- they were always there  
17 as comfort. So they weren't going, but I found myself  
18 eating things that I wouldn't normally eat, you know,  
19 simply because of this advice, and I was told to only  
20 eat -- only drink bottled water and things like this,  
21 but Burton-on-Trent where I lived, we had some of the  
22 best water in the town because it was a brewing  
23 capital. I had been drinking tap water my whole life  
24 and I had never had any issues.

25 So it started affecting you mentally and how you

1       behave, and I was a very, very skinny person at that  
2       time, and people did actually say to me at times,  
3       "Have you got AIDS", and this kind of thing and  
4       I would say, "Why do you say that?" They would say,  
5       "Well, you're so thin". I'd say -- well, I was a very  
6       athletic person but, you know, when you live in  
7       a small town like that, it's difficult keeping those  
8       kind of things a secret.

9                You can go within yourself and hide away to try  
10       and keep these secrets or you can be open about it,  
11       which unfortunately can put you up to be shot at.  
12       I just tried to live my life day-by-day and just see  
13       where the future took me.

14   **Q.** In 1992 your haemophilia care transferred to the  
15       Oxford Haemophilia Centre, but for the time being your  
16       HIV care remained at Derby?

17   **A.** Yes. That basically happened because I was  
18       an in-patient at Derby with a bad knee, the same bad  
19       knee that I had had problems with for a number of  
20       years and they wanted to give me a knee replacement,  
21       but I was only 22 and I thought, "I am too young,  
22       surely", so we asked for a second opinion from Oxford,  
23       because one of my uncles who was a haemophiliac passed  
24       away in Oxford in '76 and they said to the family, "If  
25       any member of your family has a problem in the future,

1 you can always come to us for advice". So my mother  
2 wrote to Charles Rizza at Oxford explaining who she  
3 was and he said, "Well, we will see Martin. It is not  
4 a problem". So I went down there. I think it was  
5 about January 2, '92, something like that.

6 I met Paul Giagrande and Charles Rizza. They  
7 brought out my uncle's notes from 1976 with "deceased"  
8 written across them, which was quite freaky, but they  
9 said to me -- they said, "We keep all family's notes,  
10 because there may be some kind of genetic link further  
11 down the line", and he said straightaway, "Well, first  
12 of all, you are too young for a knee replacement". He  
13 said, "There is plenty each of other options. You  
14 could have a knee wash out. I see you are still under  
15 the care of Derby. We will ask Derby if they are  
16 prepared to pay for this. If they are not, we will go  
17 ahead and do it anyway". That's what they did and  
18 Derby did pay for it and I had the wash-out in June,  
19 I think, '92 and I became a haemophilia patient under  
20 Oxford, but I was still going back to Derby every  
21 quarter for blood tests for the HIV.

22 **Q.** A couple of years after that in 1994 at Derby it was  
23 suggested to you that you should start on AZT  
24 treatment?

25 **A.** Yes. It was early '94. It might have been about

1 March, something like that. I went to the HIV clinic  
2 as it was then. As I say, it was really just a case  
3 of routine bloods, and the two doctors, Mitchell and  
4 Maine, handed me a bottle of pills and I said "What is  
5 this". They said, "Well, it is AZT". I said, "Why  
6 are you giving me this?" They said, "We think you  
7 will benefit from them", and I thought, "I feel fine.  
8 I feel healthy". It just didn't feel right.

9           Anyway, I took the pills home with me and  
10 I mentioned them to my mother, because I had already  
11 got this link to Oxford, I thought, "Well, I'm going  
12 to ask for some advice", so I phoned the Haemophilia  
13 Centre at Oxford and they put me in touch with the HIV  
14 clinic there and Chris Conlon. He said, "Well,  
15 I notice that you are already come down here for your  
16 haemophilia. If you like, you can come down here and  
17 we will give you a review", so I did and he said,  
18 "Well, first of all, we don't give our patients  
19 anything unless they need it". He says, "And I notice  
20 here that you have been exposed to hepatitis C. Have  
21 you been vaccinated against hep A and B?"

22           This was the first I ever knew about any of the  
23 hepatitises. I said, "I haven't got a clue what you  
24 are talking about", and he said, "Right, we will ask  
25 Derby if they have vaccinated you against A and B".



1 He asked Derby and Derby said they wouldn't do it  
2 because it was too expensive, and he says, "I can see  
3 you have been exposed to hep C", which fortunately  
4 I spontaneously cleared it, and he gave me the  
5 opportunity to become a fully fledged Oxford patient,  
6 which I took.

7 **Q.** You didn't take AZT?

8 **A.** I didn't take AZT, no.

9 **Q.** You had a cousin --

10 **A.** Yes.

11 **Q.** -- who had also been infected in the same way as you,  
12 who had embarked upon AZT at that time --

13 **A.** Yes.

14 **Q.** -- and who died some months later?

15 **A.** Yes. He started taking AZT. I think it was the same  
16 day that I had been to the clinic and I refused it.  
17 He was offered it and he took it and he was dead in  
18 July that year.

19 **Q.** One of the observations you have made in your  
20 statement is at your cousin's funeral you recall  
21 family members looking at you and your sense is they  
22 were thinking, "How long has Martin got?"

23 **A.** I remember going to see him in the hospital about two  
24 hours before he passed away and I was there with his  
25 brother. We walked out and he said to me, "Is that

1 normal?" And I said, "I have got to be honest", he  
2 was the first person I had seen die from it. I have  
3 seen people die in front of me. I have had a couple  
4 of friends die of heart attacks right in front of my  
5 eyes, one 29, one 55, die just like that, but I have  
6 never seen anybody suffering like that and that scared  
7 me.

8 Then at his funeral I thought, "My God, is that  
9 what's going to happen to me", and I felt all these  
10 eyes looking at me, you know. They probably weren't,  
11 but that's how paranoid I was.

12 **Q.** Now, by 1997 you were starting to be physically unwell  
13 in consequence of the HIV infection?

14 **A.** Yes.

15 **Q.** You put it in this way in your statement:

16 "HIV was starting to get a grip on me."  
17

18 **A.** Yes. I had been in a relationship and I always knew  
19 that the person I was with would want her own children  
20 one day, because she was adopted. Children -- having  
21 children has never been a massive issue for me and,  
22 even before HIV came along, it was a moral dilemma  
23 whether I wanted to carry on the haemophilia gene or  
24 not. So I took the decision for us to end, for us to  
25 split, at the end of 1996 so that she could go off and

1 have children and thankfully she did and she is happy,  
2 but I went downhill to the point where I effectively  
3 wanted to die.

4 I was as low as you could get, and then in  
5 January '97 I started getting all kinds of internal  
6 infections, and whether it was self preservation  
7 kicked in I don't know, but I drove myself down to  
8 Oxford and I checked myself into the John Warin  
9 Infectious Diseases Clinic at Oxford, and Chris Conlon  
10 came to see me and he started treating me for the  
11 various infections, and he said to me, "Your CD4 count  
12 is down to 70 at the moment and I think it is time we  
13 started thinking about putting you on some kind of  
14 a drug regime", which for me taking pills is something  
15 I have always been against, but needs must. He put me  
16 on a double therapy of didanosine and AZT.

17 When he said to me he was putting me on to AZT  
18 I had a rye smile on my face, because I thought the  
19 difference is I trust this guy. I didn't trust the  
20 ones at Derby.

21 **Q.** And you were on that combination of drugs for two  
22 years --

23 **A.** Yes.

24 **Q.** -- until early 1999, during which you regained some of  
25 the weight --

1   **A.** Yes.

2   **Q.** -- that you had lost and your CD count did go up?

3   **A.** Yes.

4   **Q.** Then since that time you have gone through a range of  
5       different drugs?

6   **A.** Yes.

7   **Q.** In 1998 the medication that you started Crixivan had  
8       a lot of side effects.

9   **A.** Yes, indinavir.

10  **Q.** What were they?

11  **A.** The main side effect of indinavir, or Crixivan as it  
12       is known, is a condition called lipodystrophy.  
13       Basically, what it does is it takes the fat off your  
14       arms and legs and backside and it moves it and your  
15       body and it puts it in places where you don't really  
16       want it, round your stomach, round your internal  
17       organs and in my case on the back of my neck. You end  
18       up with what is known as a buffalo hump.

19               I have also had ingrowing toenails and I also --  
20       one of the biggest problems with indinavir was you  
21       were supposed to drink plenty of fluid and during the  
22       summer of '98 I went travelling in America and,  
23       basically, I didn't drink enough while I was out there  
24       and I came back and I started with kidney crystals, so  
25       I had to be flushed out for them as well.

1 Q. And that was a very painful condition whilst it  
2 lasted?

3 A. It was, yes.

4 Q. You then changed to Viracept?

5 A. Yes. I think I went on to probably nelfinavir before  
6 that.

7 Q. You went through a trial. You describe it as --

8 A. Yes, in 2001.

9 Q. -- ESPRIT trial.

10 A. It was a trial called the ESPRIT trial, interleukin.  
11 This basically came about in 1982 when I was in having  
12 my ingrown toenail sorted. A professor came to see me  
13 at the Churchill Hospital in Oxford. He said, "We are  
14 doing this trial called the interleukin trial for  
15 people with a CD4 count of 300 or more". At the time  
16 mine was 450.

17 I said, "Okay. What does it involve". He said,  
18 "It involves two subcutaneous injections a day for  
19 five days and it is to basically stimulate your immune  
20 system. We don't know what your base CD4 count is  
21 because we don't know what it was at the point of  
22 transmission, but if we can get it up as high as  
23 possible, the better".

24 He says, "There is quite a few side effects with  
25 this interleukin". I thought, "Well, I am prepared to

1 try it. I am already infected. I have got nothing to  
2 lose", so I took this interleukin home and after three  
3 days I was practically bed bound. I had put on  
4 9 pounds in weight. I was aching, feverish, all kind  
5 of symptoms, diarrhoea.

6 Then on the final day I tried to have a bowl of  
7 soup and I was just projectile vomiting everywhere and  
8 I lost all 9 pounds in one go. The doctor phoned me  
9 up to see how I was doing at the end of the week and  
10 I told him about the side effects. He said, "Right.  
11 Give yourself a week to recover. Then come down and  
12 we will take some bloods".

13 I went down and he took some bloods and my CD4  
14 count had gone up to about 1,300 and I felt like  
15 superman at that time. Bugs were just bouncing off  
16 me, but over the next six months my CD4 count dropped  
17 and I think they estimated my base level was probably  
18 around 700.

19 **Q.** After the conclusion of that trial you went on to  
20 Viracept and then in 2014 to Truvada?

21 **A.** Yes.

22 **Q.** Then in 2017 you switched into your current regime --

23 **A.** Triumeq.

24 **Q.** -- which is three pills in one. That has not had any  
25 particularly bad side effects?

1   **A.** No, I was at the hospital yesterday and they were  
2       asking me how I was doing with that. Triumeq, I don't  
3       seem to have any issues with that. One of the main  
4       reasons they put me on to Triumeq because of all the  
5       other protease inhibitors before that had caused this  
6       lipodystrophy and basically they were hoping -- they  
7       said it is irreversible, but they can probably stop it  
8       getting worse and it does seem to have worked because  
9       quite a few people look at me and said, "You look like  
10      you have lost weight", which I don't think I have, but  
11      if they think so, then fine.

12   **Q.** You have told us already about the experience you had  
13      being treated late '87 at the North Staffs Royal  
14      Infirmary. What impact, if any, has your HIV status  
15      had on your dental care?

16   **A.** I did have one bad episode with a local dentist some  
17      years ago. I had got bad toothache and I went to see  
18      him and he took x-rays and said, "Yes, there is no  
19      problem with your teeth". I went home and it got that  
20      bad that I contacted Oxford and they put me in touch  
21      with their haemophilia dentist.

22           I went down there and they examined me. He  
23      said, "How has this been missed. You've got four  
24      wisdom teeth coming through". I was admitted into the  
25      John Radcliffe where under general they had to break

1 my jaw and get the wisdom teeth out. I do believe  
2 that dentist was just scared. He didn't want to treat  
3 me. Thankfully, he's the only dentist I have  
4 witnessed that from, but I have heard that it is quite  
5 a lot more commonplace.

6 **Q.** Martin, can I ask you about how your infection -- the  
7 treatment you have received for it over the years have  
8 impacted on your family and your private life.

9 **A.** My brothers thankfully they have got no health  
10 problems. I am probably built to withstand these kind  
11 of things. I can deal with them. I wouldn't wish it  
12 on anybody, but I've seen the look of anguish on their  
13 faces at times.

14 I remember one incident. I was being taken to  
15 hospital some years ago and I remember seeing out the  
16 back doors of the ambulance my eldest brother running  
17 down the street after the ambulance. They don't talk  
18 about it to me. I think they can't even use the word  
19 HIV, you know. My eldest brother refers to it as the  
20 lurgy. Whether they talk to their friends I don't  
21 know, but they do struggle.

22 I learned from a very young age to use a bit of  
23 reverse psychology on people, because I was born blind  
24 in one eye and I had a very bad squint in my left eye,  
25 so I used to get the Micky taken out of me from a very



1 young age. I used to turn this around and take the  
2 Micky out of myself and give these people no room for  
3 manoeuvre.

4 I have always been able to deal with it. I have  
5 got a bit of a wicked sense of humour in that fact,  
6 but the years between '87 and 2000 really were dark  
7 years for me and I started playing pool. This was --  
8 it was almost -- it was an emotional crutch as well,  
9 but it also helped me build myself confidence because  
10 I was good. I was good at it, but that didn't always  
11 go that smoothly. I had problems with prejudice from  
12 people in that area, but I also gathered a lot of good  
13 friends.

14 **Q.** We have got a newspaper article you shared with the  
15 Inquiry. 0012008. "AIDS scare youth ban".

16 Can you tell us what happen?

17 **A.** Yes. I had been playing pool for that pub in South  
18 Derbyshire for a number of months. This wasn't  
19 a local pub. This wasn't a five minute walk round the  
20 corner. This was a 7-mile trip. I wasn't driving at  
21 the time so I had to get a lift there. I had been  
22 playing there for a number of months and I went there  
23 one Thursday night to play my match and I walked in  
24 the door and the pool team and the [redacted] were all  
25 stood in a circle by the bar and as soon as I opened

1 the door he just looked at me and pointed at the door  
2 and said, "You, get out", and I just felt numb, empty,  
3 worthless.

4 This wasn't a spur of the moment thing. This  
5 was done to humiliate me, because these people had my  
6 phone number. As I say, it wasn't a five minute walk  
7 round the corner. These people could have -- one of  
8 them could have phoned me up and warned me, but they  
9 didn't. They wanted to publicly humiliate me, but the  
10 crazy thing is about human beings is that bunch of  
11 people were there to put me down, but I got home.  
12 I can't remember whether I was in tears or not.  
13 I certainly felt low. I know that, but within half  
14 an hour of me being back at home, there was another  
15 public house, which was 100, 200 yards down the road  
16 from that one, phoned me up. They had heard about  
17 what happened and they asked me to go and play pool  
18 for them. Somebody is there to kick you down and  
19 somebody is there to pick you up.

20 **Q.** You have travelled to the States on and off. What's  
21 your experience been of trying to get visas to travel  
22 there?

23 **A.** Well, my eldest brother went to America in the early  
24 '90s and when he came back, he had a picture of  
25 himself sat on the edge of the Grand Canyon and I used

1 to look at it and think, "I want to go there". I had  
2 asked my 16 year old cousin at the time, I said, "Do  
3 you fancy going to America?" He was big into going to  
4 airshows and things. We talked about going to San  
5 Diego and various places, so 1998 I thought, "Let's  
6 go".

7 I asked at Oxford about going and I said, "How  
8 easy is it to go there?" They said, "Well, if you  
9 want our advice, we suggest you are open about it and  
10 contact the American Embassy and tell them  
11 everything", so I filled in an application form for  
12 a visa and I put that I had got a communicable disease  
13 and they refused me point blank.

14 I was deflated but I thought, okay, let's  
15 persevere with this", you know, because I have been  
16 open. I have been honest and I kept asking, asking  
17 and asking. Eventually they gave me a two month visa,  
18 so me and my cousin, we went. We had a week in San  
19 Diego and a week in Florida. I drove from San Diego  
20 to the Grand Canyon, had my picture taken, great time.  
21 No issues at all over there.

22 I came back and then a friend of mine asked me  
23 to be best man at his wedding. I thought, yes,  
24 brilliant. Where is it? Florida. I had to apply for  
25 another visa and, again, they refused me and I said,

1 "You have already given me one. What are your grounds  
2 for refusing me?" Eventually they gave me another  
3 visa so I went over there for the wedding. I came  
4 back and then I went again in 2001, did a five-week  
5 trip. That's when I had the -- came back and had the  
6 kidney problems, because I wasn't drinking enough.

7 Then I went again in 2002, 2003 and the final  
8 time I went was 2004, but in 2003 I landed at Boston  
9 Logan Airport and I was at immigration. I handed my  
10 passport over and my visa was in the passport. The  
11 guy in the booth he says, "Why, have you got this  
12 visa", and I said, "Well, I have got a communicable  
13 disease", and I went "and", and before I could say  
14 anything else, he says, "Right. Come with me". He  
15 closed his booth up and put me in a holding cell for  
16 an hour. So I just sat there and I thought, "Okay.  
17 Well, you know, there is no point in getting angry.  
18 It's not going to get you anywhere. Just let things  
19 settle down".

20 Eventually, this guy comes and gets me out. He  
21 says, "Can we have a chat?" I said, "Yes". He says,  
22 "Why have you been pulled in?" I says, "Good  
23 question". I said, "Well, I am HIV positive and  
24 I have put that on the document", and he says -- well,  
25 he was all apologetic. He said, "Look, all I can do

1 is apologise. I can't guarantee this won't happen  
2 again but you have got my sincere apologies. I will  
3 sign you in for six months. Go off and have a good  
4 holiday".

5 **Q.** Martin, in terms of your employment you did a Youth  
6 Training Scheme?

7 **A.** Yes.

8 **Q.** 1987/1988. What happened there?

9 **A.** Well, after I had finished at the training centre in  
10 Leicester, when I came back to Burton, I started on  
11 a Youth Training Scheme. I think it was Friday,  
12 December 6, 1985. This was basically a two-year  
13 course doing electronics.

14 During that period we were trained in all  
15 various aspects of electronics. I remember --  
16 obviously it was during this two-year period that  
17 I was told of my diagnosis, and I think this happened  
18 probably some time in '87. I was talking to a lad who  
19 I was working with and I mentioned that I was HIV  
20 positive and one of the bosses overheard me and he  
21 pulled me to one side and he says, "I think it would  
22 be a good idea if we informed everybody".

23 I don't know why, but -- so he took everybody  
24 into a conference room. There was a couple of hundred  
25 people in there and he just stood up and he basically

1 told everybody.

2 **Q.** Sorry.

3 **A.** He basically stood up in front of everybody and told  
4 them about my HIV status and I am thinking --  
5 afterwards I was thinking, "This guy probably knows  
6 less about it than I do", you know, and there he is  
7 telling everybody. I mean, thankfully, I didn't  
8 receive any prejudice from the other colleagues, you  
9 know, whether they didn't have any full understanding  
10 of it, I don't know.

11 **Q.** You then went to work at a local electronics company.

12 **A.** Mm-hm.

13 **Q.** You had an experience there again with one of the  
14 members of the management.

15 **A.** Yes. I finished the Youth Training Scheme in January  
16 '88. It was a month or two after that I started on  
17 a three-month placement at a company called [redacted]  
18 doing electronics. Basically, everybody sat at a desk  
19 and you have got to assemble circuit boards. The work  
20 crew were predominantly women. There was one man next  
21 to me, a gay man next to me, and there was another man  
22 in the stores and the rest were all women.

23 The days went by and there never seemed to be  
24 any issues. We all got on with our work, you know,  
25 and that was it.

1           Then after about two months the bosses called me  
2           in and they said, "The work force isn't happy and they  
3           have basically said 'either he goes or we go'", and  
4           I was forced out.

5   **Q.** You have since that time spent a significant portion  
6           of your time doing public speaking --

7   **A.** Yes.

8   **Q.** -- at various places across the country. What can you  
9           tell us about that?

10 **A.** That started in 1997 after I came out of the John  
11       Warin Ward, started on the regime of pills and I was  
12       on the road to recovery, as I call it. Some time that  
13       year there was a clinical nurse specialist who phoned  
14       me up. She had got my details I think from Derby  
15       Royal Infirmary. I think she was doing a dissertation  
16       or something and she asked me if she could come and  
17       have a chat. So she came over and we talked about my  
18       experiences and things. She said to me, "Would you be  
19       interested or would you talk to some medical  
20       students?"

21           She worked for Staffordshire Health Authority.  
22       I said, "Yeah, okay", so she arranged these meetings  
23       three or four times a year at various places around  
24       the country and I would go. I would tell them my  
25       experiences and then I would do a Q&A session at the

1 end. This was all voluntary.

2 Then there was other people got to hear of it,  
3 word of mouth, and I also did talks at a prison to the  
4 prisoners and the prison staff, and then a few of the  
5 doctors at Oxford heard about it, so I got invited to  
6 do talks at Oxford University and the John Radcliffe  
7 Hospital and Cardiff University. Basically, my  
8 attitude has been it has happened to me. It shouldn't  
9 have done, but if people can learn from me, then fine,  
10 and I did that for the next 22 years.

11 **Q.** You are now involved or you were at the time you  
12 prepared your statement for the Inquiry with a review  
13 of quality standards --

14 **A.** Yes.

15 **Q.** -- in hospitals.

16 **A.** Yes. I got invited to join the West Midlands quality  
17 review group last year and this, basically, involves  
18 going round haemophilia centres seeing where they can  
19 be improved and seeing what things they need to be  
20 pulled up on.

21 The first one I did was at Derby Royal  
22 Infirmary, which was an eye opener, because it is good  
23 to see how well the place is run. The staff there are  
24 superb I have to say, but they are under a lot of  
25 pressure.



1 Q. Martin, you have made applications to the MacFarlane  
2 Trust over the years?

3 A. Yes.

4 Q. You have said you didn't find the form filling  
5 problematic but having to trace your medical record  
6 and provide the required documentation to the  
7 MacFarlane Trust is where you had some difficulties?

8 A. Yes. I mean, when I got my medical records from  
9 Birmingham, considering they had 17 years' worth of my  
10 notes, they were the most helpful out of everybody.  
11 They sent me 17 years' worth of notes and they never  
12 charged me a penny for them or anything. It was easy,  
13 but other places I have struggled to get hold of  
14 records.

15 Q. Although you have, as you have said, a number of  
16 records, you haven't been able to locate in those  
17 records a copy of whatever letter it was that  
18 Birmingham Children's Hospital sent to Leicester --

19 A. Yes.

20 Q. -- which elicited that October 1985 letter? Yes. That we  
21 looked at earlier.

22 A. Well, when I got hold of those records in 2006, when  
23 they call came in the post -- through the post, big  
24 boxes, curiosity, I started looking through them, and  
25 I found that letter from '85 where it was being

1 withheld from me and I thought, "Well, I am going to  
2 make a copy of that", and I made a copy of a few  
3 others and then I put them all in the box. I thought,  
4 "I don't want to read anymore".

5 I sent them away to the solicitors in Preston.  
6 This was all to do with the US litigation. One of the  
7 forms I actually ticked that I would like a copy of  
8 these notes back. I think I got them -- got the  
9 copies back a couple of years later or something like  
10 that, lo and behold the original of that 1985 letter  
11 is missing and those notes have been through three  
12 different solicitors.

13 **Q.** We have the copy because you had made a copy of it?

14 **A.** Yes.

15 **Q.** But you don't have very much else from the 1980s --

16 **A.** No.

17 **Q.** -- in terms of records?

18 **A.** No.

19 **Q.** Martin, those are the questions I have for you.

20 Is there anything else that you would like to  
21 add?

22 **A.** There's many -- there's many sad things about this  
23 entire scandal. It's not just the loss of life and  
24 the destruction of communities that this has caused  
25 and the pain on people. People are accountable.

1           I am not going to sit here and bash doctors,  
2           because I don't believe that all doctors go into the  
3           profession to hurt people. They make mistakes along  
4           the way. They are human beings. They lose track  
5           sometimes of what they are there for, but this goes  
6           higher up than that. There are MPs that are  
7           accountable and they should be made to answer and  
8           I believe now is the time for justice.

9   **Q.** Thank you, Martin?

10 **A.** Thank you.

11 **MS RICHARDS:** Sir?

12 **SIR BRIAN LANGSTAFF:** There's just one thing that I want  
13           to ask you about. When after 1997 for the next 20-odd  
14           years you went around talking to medical students, the  
15           doctors of tomorrow, you gave them your presentation  
16           and then you say there were question and answer  
17           sessions.

18           I just wonder if there was any general theme  
19           that you picked up of interest from the questions that  
20           these future doctors were asking you.

21 **A.** One of the main questions was do I believe that  
22           attitudes have changed and on the whole they have.

23           There is still stigma out there, especially in  
24           the small communities. I have met haemophiliacs over  
25           the years that live in small communities that are too

1       afraid or too scared to speak out about what's  
2       happened to them because of the possible  
3       repercussions.

4               The town I live in is not a massive town, but it  
5       is bigger than most, and I have always tried to  
6       encourage people to ask me questions and be open and,  
7       you know, I don't want people walking away from me  
8       thinking, "I wished I had asked him that. I wish  
9       I had asked him this". You know, take the  
10      opportunity.

11             One thing that does sadden me, and I had this  
12      conversation with my HIV consultant yesterday. I said  
13      to him, "How long have you been in the medical  
14      profession?" He said to me, "Oh, I long time".  
15      I said, "No, how long". He said, "Since 1993".  
16      I said, "So really you are still a newcomer. You  
17      weren't around when all this kicked off". He says,  
18      "No". I says, "I tell you what saddens me. When  
19      I get doctors that have only been in the game 10,  
20      20 years, apologising to me and a lot of them do and  
21      they are red faced and they apologise, and it saddens  
22      me that they feel they have to apologise for the  
23      mistakes that their predecessors have made".

24      **MS RICHARDS:** Thank you.

25      **A.** Thank you.

1 **SIR BRIAN LANGSTAFF:** Martin, thank you very much indeed  
2 for that. Thank you for being here and sharing your  
3 experiences with us.

4 **A.** No problem. Thank you.

5 **SIR BRIAN LANGSTAFF:** We will take a break now until  
6 12.05. At 12.05 who do we have?

7 **MS RICHARDS:** We will be hearing from David Gort.

8 **SIR BRIAN LANGSTAFF:** Thank you. 12.05.

9 (11.35 am)

10 **(Short break)**

11 (12.08 pm)

12 **SIR BRIAN LANGSTAFF:** Now our next witness wishes to be  
13 known as Dave, does he?

14 **MS RICHARDS:** That's right, sir.

15 **DAVE ANTHONY GORT, sworn**

16 **Questioned by MS RICHARDS**

17 **Q.** Dave, you have haemophilia A classified as severe.

18 **A.** Yes. That's right.

19 **Q.** And that was diagnosed when you were a baby?

20 **A.** That's right.

21 **Q.** You would receive during your early childhood  
22 cryoprecipitate administered by the GP?

23 **A.** Yes.

24 **Q.** You also then started to receive Factor VIII, but that  
25 was reserved for very severe bleeds in your case. Why

1           was that?

2   **A.** Because I developed antibodies to the treatment Factor  
3       VIII, so I developed inhibitors, so I would always  
4       have to be admitted into hospital. So the first  
5       treatment would work to some degree before my immune  
6       system would recognise that the clotting factor was  
7       not its own and suddenly put up the barriers to that  
8       treatment, so it was always administered in the  
9       hospital.

10 **Q.** The care that you received at the time was Royal  
11       Manchester Children's Hospital in Pendlebury.

12 **A.** That's right.

13 **Q.** For reasons you have explained when you received  
14       Factor VIII, you received it there.

15 **A.** Yes.

16 **Q.** You think it was around 1983 there that you first  
17       received Factor VIII?

18 **A.** Yes. My mum kept a diary and there is a note of me  
19       having a knee bleed in 1983 where I was administered  
20       Factor VIII. That's the kind of earliest record we  
21       could find.

22 **Q.** You would have been about 6 years old at the time. Is  
23       that right?

24 **A.** Yes.

25 **Q.** Now, as far as you are aware, were your parents given

1 any information or warnings or advice about any risks  
2 to you of infection from receiving the factor  
3 products?

4 **A.** No, they weren't.

5 **Q.** They weren't?

6 **A.** No.

7 **Q.** There is one letter that I am going to ask to be put  
8 up on screen. It should come up on the screen in  
9 front of you, Dave. It is 1244003. We can see it's a  
10 letter of 24 August 1985 addressed to your parents  
11 from the Royal Manchester Children's Hospital and it  
12 says this:

13 "We have been sending blood samples away from  
14 the children with haemophilia and similar disease to  
15 see if they are at risk of AIDS. None of our patients  
16 has developed AIDS or has shown any signs of doing so,  
17 but all of us, both parents and staff, are anxious  
18 about the problem. The results are now coming  
19 through. The blood tests on your child", then we have  
20 inserted, "[David] show he is negative for HTLV-III  
21 (ie the AIDS virus). This is good news. We hope to  
22 be able to repeat the test every year or so to see if  
23 there is any change."

24 Do you know whether your parents were aware  
25 before receiving this that you were being tested for

1 HIV?

2 **A.** No. As far as I am aware they were not told I was  
3 being tested for HIV.

4 **Q.** Now, that was 1985 and you were given or your parents  
5 were given the news you were negative in terms of HIV.  
6 Your care then transferred in 1992 to the Royal  
7 Hallamshire Hospital?

8 **A.** Yes, that's right.

9 **Q.** You received a letter in June 1992 asking that you  
10 come in for an appointment?

11 **A.** Yes, to register with the Haemophilia Centre there in  
12 Sheffield.

13 **Q.** I think you said in your statement that the letter  
14 specifically referred to coming in for testing for HIV  
15 or hepatitis C, but you have now found the letter and,  
16 in fact, it simply invites you in for an appointment?

17 **A.** That's right.

18 **Q.** But when you attended that appointment, were tests  
19 undertaken in relation to hepatitis?

20 **A.** Yes. When I registered at the Haemophilia Centre in  
21 Sheffield, they just said all new patients, they are  
22 routinely tested for hepatitis C and HIV.

23 **Q.** What can you recall about being told of the results of  
24 those tests?

25 **A.** I seem to remember it was a couple of weeks later and



1 the tests came back and I was called in, I think with  
2 my parents present, to say that they'd found that  
3 I was hep C positive, and that was the first I'd ever  
4 been told of that.

5 There'd never been any mention at Royal  
6 Manchester Children's Hospital. In fact, I think  
7 there is a letter somewhere in my records from Royal  
8 Manchester Children's Hospital denying that. My  
9 parents actually wrote to them to ask, because I think  
10 it was referred to as non-A non-B or something --

11 **Q.** That's right.

12 **A.** -- before they called it hepatitis C. My parents had  
13 obviously heard something, I think in the press, had  
14 written to Dr Evans at the Royal Manchester Children's  
15 Hospital and there was a flat denial that, you know,  
16 I had received that, so ...

17 **Q.** So you were told in around the middle of 1992 at the  
18 Royal Hallamshire that you had contracted hepatitis C.

19 Were you given information about the condition?

20 **A.** The sort of key message to me I think was that not to  
21 pass it on to anyone else. I think that was one of  
22 the main things is kind of to be careful of sexual  
23 contact, that I wasn't to pass it on. From memory  
24 they gave me a booklet about sort of healthy eating  
25 and foods to avoid. I have tried to find that but

1 I've unfortunately not been able to locate it.

2 **Q.** You have said in your statement you were told that you  
3 shouldn't be too worried, but you were also told that  
4 there'd be regular scans to check for liver lesions  
5 and liver cancer?

6 **A.** That's right. So they did say, you know, not to be  
7 too concerned, that the treatments that were available  
8 at the time they thought were ineffective for  
9 hepatitis C and the side effects were worse than kind  
10 of the outcomes I suppose, that they would monitor it  
11 through quarterly blood tests and I had I think it was  
12 yearly ultrasounds.

13 **Q.** You said if your statement also you think you were  
14 provided with the information that the doctors had at  
15 the time.

16 **A.** Yes.

17 **Q.** The one message that you say wasn't spelt out to you  
18 was advice about not drinking alcohol.

19 **A.** Yes. I don't think that was communicated strongly  
20 enough really considering my age and the fact, you  
21 know, I would be drinking fairly soon, that I don't  
22 think they spelt out the possible consequences really  
23 of that strongly enough.

24 **Q.** Now, you don't know precisely when you were infected  
25 with hepatitis C, but you have seen something in

1 a more recent letter, which we will look at. It is  
2 1244004. If we just look at the first part of that  
3 letter under the heading "Diagnosis", we have got some  
4 numbered paragraphs and (2) says:

5 "Chronic hepatitis C genotype 4 -- infected  
6 before 1985 ..."

7 That's the first time you have been given any  
8 kind of date range?

9 **A.** Yes. That's the first time I have ever seen that in  
10 writing, that I was infected with hepatitis C.

11 **Q.** Can I just ask you about what information you received  
12 about the risk of vCJD?

13 Now, you have said in your statement that you  
14 learned about that, first of all, from communications  
15 from the Haemophilia Society. We will just look  
16 briefly that.

17 It is 1244005, please, Paul.

18 We can see that you received this communication  
19 from the Haemophilia Society dated September 2004,  
20 which talks about:

21 "You should have received notification from your  
22 Haemophilia Centre about steps that some people will  
23 need to take to prevent any possible transmission of  
24 vCJD to other patients."

25 **A.** Yes.

1 Q. Then that I think triggered you contacting your  
2 Haemophilia Centre and having a conversation with the  
3 doctors there?

4 A. Yes. During a review clinic, you know, I was  
5 obviously concerned about the possibility of  
6 developing vCJD -- contracting vCJD, and sort of gave  
7 me some reassurance about that but then I had  
8 subsequent letters that said I had not received  
9 implicated batches, but then I think the Department of  
10 Health changed their mind and decided that for public  
11 health purposes all haemophiliacs were considered to  
12 be at risk for public health.

13 Q. We can just look at a couple more documents. In the  
14 same -- with the same reference number, please, Paul,  
15 but the seventh page.

16 We can see here in late 2004 this is a letter  
17 from Sheffield Teaching Hospitals to you and it refers  
18 to:

19 "The recent information we have sent you  
20 regarding the vCJD and our subsequent conversation.

21 "I am writing to confirm that we have checked  
22 our records and these show that you have received UK  
23 NHS clotting factor concentrate at Manchester  
24 Children's Hospital but not at the Royal Hallamshire.  
25 In view of this you are at risk for public health

1 purposes."

2 Then if we go to the second paragraph of the  
3 letter, please, Paul:

4 "As discussed, I can also confirm that you have  
5 not received any of the implicated batches of clotting  
6 factor that have been prepared from plasma of donors  
7 who subsequently developed variant CJD."

8 Then you produced a letter you received some  
9 five years later.

10 That's at 1244002, please, Paul. Next page.

11 This is a letter, February 2009, and it is:

12 "... writing it all our patients who have  
13 received clotting factors made from UK plasma during  
14 1980 to 2001 to tell them about a person with  
15 haemophilia who has been found to have evidence of the  
16 infection that causes vCJD in his spleen at post  
17 mortem. All haemophilia centres are contacting their  
18 patients throughout the UK to give them this  
19 information."

20 What you have said in your statement is that  
21 although you have been told that you hadn't received  
22 implicated batches in 2004, you still worry about the  
23 possible implications --

24 **A.** Yes.

25 **Q.** -- of these risks?

1 **A.** Absolutely.

2 **Q.** Do you have a clear understanding from the  
3 communications you have received about the extent of  
4 any risk to you?

5 **A.** Not really, no. I think it's mixed and that is sort  
6 of evidenced to me through the treatment I have had  
7 since then. So in 2014 I was diagnosed with cirrhosis  
8 of the liver and I was sent for tests, endoscopy to  
9 check for oesophageal varices. Because of the severe  
10 nature of my bleeding disorder I had to take  
11 an injection of my clotting factor before and the  
12 clotting factor only has a half life of two hours. It  
13 is a recombinant product but only lasts for two hours  
14 in the system. I think it is radiographers. They  
15 spent an hour and a half of that time deciding what  
16 they would do with the scopes afterwards because on my  
17 records it said that I was at risk of vCJD. So I got  
18 quite panicky in that last half an hour. I knew  
19 clotting factor was running out but they were going to  
20 push this scope down my throat and possibly cause, you  
21 know, bleeding during that procedure.

22 **Q.** What physical impact has the hepatitis C had on you in  
23 those first few years?

24 **A.** I don't think I realised it at the time, because  
25 I suppose I didn't know what life was like without

1 hepatitis C so I had nothing really to compare to, but  
2 I just felt extremely tired. I just thought everybody  
3 felt like that. I can remember driving home from  
4 a job and almost falling asleep at the wheel and  
5 thinking "This is dangerous. Maybe I am working too  
6 hard". I was thinking, "No, everybody works the same  
7 hours I do", so I was inexplicably tired. Sometimes  
8 I would be okay but I would hit a wall of tiredness  
9 and I just couldn't explain that.

10 **Q.** You said you tried to remain positive, but when you  
11 were having the blood tests or scans, you would worry  
12 about the results and their consequences.

13 **A.** Yes, absolutely. I think my coping strategy was --  
14 I hate to say it -- but was to stick my head in the  
15 sand and hope that everything would be okay and, you  
16 know, that was just my way of coping really.

17 **Q.** In 2011 you embarked upon a course of treatment for  
18 the hepatitis C, Interferon and ribavirin?

19 **A.** Yes.

20 **Q.** What was that like?

21 **A.** Horrendous, absolutely the worse thing in my life  
22 I think. I wonder to some degree whether that brought  
23 on some of the cirrhosis -- it is hard to say -- or  
24 just if hepatitis C progressed anyway.

25 I was working full-time then for the Civil

1 Service at the time and I had no social life at all.  
2 It was just work. Work were very good with me. I had  
3 to go to hospital every Friday in Sheffield because  
4 the treatment was so severe it was knocking my  
5 platelet count and I would have to have a blood test  
6 every week to check my level and then they would  
7 adjust the dose of the Interferon and ribavirin, but  
8 my sort of viral load was decreasing so, you know, the  
9 advice was to carry on.

10 I did this for a year, but the treatment made  
11 me -- I had dry skin, very itchy. I couldn't sleep.  
12 I'd get very hot. I was incredibly moody. The  
13 hospital did say that that was a known sort of side  
14 effect of the treatment and they offered me  
15 anti-depressants, which at first I declined, but after  
16 I think only a week I said, "Okay, yes, I will have  
17 the antidepressants please". So throughout the course  
18 of treatment I was on antidepressants as well because  
19 I would just have complete mood swings. I would be  
20 low and depressed or high as a kite, and kind of --  
21 but just so fatigued all the way. That was probably  
22 worse than the hepatitis C itself really.

23 I was very irritable with people around me.  
24 I would get very angry and I think that has caused me  
25 some sort of brain fug. I lose my thread, I lose my



1 track. I was very sharp and I feel that mentally that  
2 has affected me.

3 **Q.** You have also described in your statement that during  
4 the course of the treatment you suffered from memory  
5 loss.

6 **A.** Yes.

7 **Q.** You found it difficult to concentrate and you would  
8 read stuff at work and not be able to take any of it  
9 in.

10 **A.** I think I just read a sentence and I have no idea what  
11 it says in that sentence and have to start again. You  
12 know, I work in communications. So, you know, I would  
13 be proof reading document and, you know, it was so  
14 frustrating that I couldn't keep my concentration.

15 **Q.** You ended up accepting voluntary redundancy because of  
16 it?

17 **A.** Yes.

18 **Q.** What was the outcome of that treatment? Did it clear  
19 the virus?

20 **A.** So by month 12 I had cleared hepatitis C and there was  
21 no detectable virus and then in month 13 it came back,  
22 because obviously I had sort of gone six weeks without  
23 treatment and so the virus just came back.

24 **Q.** How did that make you feel, that news?

25 **A.** I was completely gutted really because of all that

1 I had been through, you know, and I would have done  
2 anything to sort of get rid of the virus. I really  
3 would. To have been through what I have been through,  
4 it just seemed, you know, futile really.

5 **Q.** You have mentioned that in 2014 you discovered that  
6 you had developed cirrhosis of the liver and  
7 an enlarged spleen?

8 **A.** Yes.

9 **Q.** And you were becoming prone to infections and so you  
10 had a fibroscan. What did that show?

11 **A.** So the hospital obviously sort of said to me that they  
12 would monitor with regular blood tests and they had  
13 said -- they had always said to me from 1992 that my  
14 liver function test was normal, within a range for  
15 somebody who had hepatitis C.

16 Obviously, because of the bleeding disorder of  
17 haemophilia I couldn't have a liver biopsy, because it  
18 would cause bleeding and obviously, you know, risk of  
19 dying. So a new test became available called  
20 fibroscan, which sort of flicks the body in the side  
21 and measures the elasticity of the liver and the scan  
22 came back with a really high score of 21.4 showing  
23 that I had got cirrhosis. The consultant at the  
24 Hallamshire said to me that, you know, he was really  
25 surprised that. It didn't correlate really with my

1 blood results and it did show that I had got cirrhosis  
2 of the liver.

3 They then referred me to a hepatologist in the  
4 infectious diseases team. I was very worried about  
5 the prospect of developing cancer of the liver.

6 I discussed that with the hepatologist and he just  
7 didn't seem to have any empathy with haemophilia and  
8 he just said "Well, if you get a bit of cancer, we  
9 will just cut it out", so I said to the Haemophilia  
10 Centre, "I'll cut him out and I won't be seeing him  
11 again. Thank you", so ...

12 **Q.** You were desperate to rid yourself of the hepatitis C  
13 by this stage.

14 **A.** Yes.

15 **Q.** And there was a particular drug, Harvoni, that you  
16 wanted to take.

17 **A.** That's right.

18 **Q.** But you couldn't get that drug. Why was that?

19 **A.** Because the strain of hepatitis C I had contracted was  
20 genotype 4, which is an Egyptian strain of the virus.  
21 It seemed that the drug companies were not really  
22 investing in that because not many people contracted  
23 that strain of the virus. My partner, Lee, he had --  
24 I didn't realise this at the time, but he had --  
25 sorry ...

1 Q. It is all right, Dave. Would you like me to read that  
2 bit of the your statement for you?

3 A. Please.

4 Q. So your partner Lee, now your husband, became very  
5 concerned and he was obsessively trying to find some  
6 kind of trial that you could get on because you and he  
7 both feared that because of the fibroscan result you  
8 would develop cancer?

9 A. Yes.

10 Q. And he would stay up at night researching hepatitis C,  
11 researching possible trials and possible treatments  
12 for you?

13 A. That's right. He had been going into work and  
14 breaking down and he didn't tell me any of that. He  
15 was just desperate to find something, as you would be  
16 for the person that you love.

17 Q. You went to see a doctor in London at Bart's,  
18 Professor Graham Foster in February 2015 to discuss  
19 the possibility of a course of treatment of Harvoni.  
20 What happened?

21 A. So at that time he said that NHS England sort of were  
22 discussing, you know, the availability of Harvoni and  
23 whether they would fund the treatment and to come back  
24 and see him in a couple of months' time. We went back  
25 in the April and he said, "I am really sorry to say

1 this. I thought NHS England would have got their act  
2 together by now". He basically suggested that if we  
3 had the means to pay for it, to do it. He more or  
4 less said that.

5 I had been given an ex gratia payment of £50,000  
6 after the diagnosis of cirrhosis of the liver and we  
7 used £45,000 of that to fund a 12-week course of  
8 Harvoni. After that 12-week course, touch wood,  
9 I have been clear of the virus ever since.

10 At the time NICE were saying that for somebody  
11 with genotype 4 rather than taking 12 weeks to clear  
12 the virus. It would take 24 weeks. Therefore it  
13 would cost nearly £100,000, so it wasn't therefore  
14 clinically effective for me.

15 What I found really perverse was that they were  
16 funding treatment for people whose liver had  
17 already -- was already decompensated, but they had  
18 just kind of written me off really in the process.

19 **Q.** Just taking you back to the discussions you had with  
20 Professor Foster, he told you your liver was currently  
21 holding up, but without treatment there was  
22 a possibility it might degenerate to a stage where you  
23 would need a liver transplant.

24 **A.** Yes.

25 **Q.** You wanted to make it clear you are not critical of

1 Professor Foster at all?

2 **A.** No, not at all.

3 **Q.** Your criticism is reserved for the lack of funding?

4 **A.** Yes.

5 **Q.** Which meant you used the money which the Skipton Fund  
6 had given you because of you being infected?

7 **A.** You know, I would have -- like I said before, I would  
8 have done anything to clear myself of the virus.  
9 I had always kept very private about having contracted  
10 hepatitis C, but I really felt that point I was  
11 fighting for my life.

12 **Q.** So you spent the £45,000 from the Skipton Fund on the  
13 12 weeks of treatment?

14 **A.** Yes.

15 **Q.** Were there any side effects during the course of that  
16 treatment?

17 **A.** To begin with it made me a little bit drowsy, so  
18 I just learned to take it just before bedtime. I kind  
19 of got a better night's sleep but compared to  
20 interferon and ribavirin it was a walk in the park.

21 **Q.** And the treatment was successful in clearing the  
22 virus?

23 **A.** Yes.

24 **Q.** You have had a fibroscan the following year. What did  
25 that show?

1 **A.** That showed a score of 11.4 I think it was that, you  
2 know, my liver had become much more elastic again and  
3 kind of showed signs of improvement.

4 **Q.** You put it this way in your statement, your liver was  
5 still cirrhotic but there had been a dramatic  
6 improvement.

7 **A.** Yes.

8 **Q.** Since then you have continued to have regular liver  
9 function tests?

10 **A.** Yes, yes, and I still have -- Professor Foster, when  
11 he kind of discharged me from his care said to have  
12 quarterly ultrasound scans just to check for any  
13 lesions or cancer of the liver.

14 **Q.** Now, one of the observations you have made in your  
15 witness statement is that you think it should be  
16 a matter of priority for the NHS that treatment is  
17 funded for those who were infected through the NHS?

18 **A.** Absolutely, yes.

19 **Q.** Can I just ask you about a couple of trials you have  
20 been involved with?

21 First of all, if we go back to document 1244004,  
22 please, Paul.

23 We looked at this letter earlier. If we go to  
24 the second page, in the penultimate paragraph it says:

25 "There are a number of trials being undertaken

1 in individuals with severe haemophilia and  
2 inhibitors", and you might well be eligible for one of  
3 those.

4 Was that a trial you participated in?

5 **A.** Yes. So I took part in the trial of Emicizumab. It  
6 is a recombinant product, that rather than it being an  
7 intravenous injection, it is an injection into  
8 my stomach once a week that gives me a low level of  
9 background clotting factor.

10 **Q.** That's a treatment you participated in a trial that  
11 relates to your haemophilia.

12 **A.** Yes.

13 **Q.** Then you participated in another trial. You said in  
14 your statement you have been told you were exposed to  
15 HIV but didn't contract it. Is that right?

16 **A.** That I think is the implication of the trial, yes,  
17 that -- for people with inhibitors who had been -- it  
18 seems had been exposed to HIV but not gone on to  
19 contract it.

20 **Q.** If we just have up on the screen 1244006, we have got  
21 a collection of documents that relate to this trial.

22 If we just go to page 4, please, Paul, it should  
23 be a letter of 20 November 2009. Thank you.

24 So this is an invitation you received, Dave,  
25 from Sheffield Teaching Hospitals enclosing



1 information about a research study which might be of  
2 interest to you. It is headed:

3 "Genetic basis of resistance to HIV in  
4 haemophilia A."

5 Do you know how it was you were identified as  
6 a possible candidate for this?

7 **A.** No, I don't know how I have been identified other  
8 than, you know, somebody somewhere thought that I had  
9 been exposed to HIV through contaminated blood  
10 products.

11 **Q.** If we go back to the first couple of pages of this set  
12 of documents, please, Paul, we can see that in  
13 relation to this trial you were asked to confirm your  
14 understanding about the information you were given.  
15 You were given a detailed patient information leaflet  
16 that you have given to us.

17 **A.** Yes.

18 **Q.** The ramifications and implications of the trial were  
19 explained to you.

20 **A.** Yes.

21 **Q.** And recorded in writing.

22 **A.** Yes.

23 **Q.** Can I ask you then, Dave, about the stigma generally  
24 that you have felt or experienced in relation to the  
25 hepatitis C infection. You have described what

1           happened with the treatment in 2014.

2                   Have you kept your infection private generally  
3           or have you shared the information with others?

4   **A.** I did, so obviously when we learned that I have been  
5           infected with hepatitis C in 1992, I kept it  
6           completely private even sort of from best friends and  
7           so on. I just really felt the stigma. You know,  
8           I had seen how people with HIV were treated and,  
9           I mean, even during my sort of working career --  
10          I worked for the Disability Rights Commission and  
11          I worked for the Equality and Human Rights Commission  
12          and it still didn't feel at work that I could tell  
13          people.

14                   It was more the people I worked with I thought  
15          might treat me differently if they knew that. For  
16          example, when I was undergoing the treatment, you  
17          know, I didn't make it clear what exactly I was going  
18          for. They just knew it was related to my haemophilia  
19          and I left it at that.

20   **Q.** And you said in your statement that you had horrible  
21          experiences when treated by medical professionals.  
22          You would have nurses always putting on gloves and  
23          being particularly cautious around you. Then there  
24          was an incident where a doctor stuck himself with  
25          a needle. What happened?

1 **A.** I think it was a female doctor. It was a junior  
2 doctor. I was in hospital with an active bleed and  
3 I think she had been taking some blood from me or  
4 giving me clotting factor, one or the other. She  
5 didn't have gloves on, I don't think. She stuck  
6 herself with the needle, the butterfly needle, as she  
7 was taking it out, and I didn't really think any more  
8 of it, went to sleep and I was woken during the night,  
9 actually taken out of bed, taken to a side room and  
10 asked about what sexual partners I had had, was there  
11 a possibility I had HIV.

12 They knew I had hepatitis C and how I had  
13 contracted that, but had I -- you know, they asked  
14 about sexual partners and so on. It was just  
15 humiliating, yes.

16 **Q.** And you have also described how whenever you have had  
17 blood tests you see a label on your file that says  
18 "Category C risk".

19 **A.** Yes.

20 **Q.** In terms of friends and family who you have shared  
21 this with, your husband, your close family, what has  
22 the impact been on them?

23 **A.** I mean, I felt guilty for keeping the secret from them  
24 for so long and I only went public about it when for  
25 me it became life-threatening, so when I got the

1 diagnosis of cirrhosis I felt, "I have nothing to lose  
2 really. I need to be open and honest about it".  
3 I feel guilty about it because I know a lot of people  
4 have campaigned on the issue.

5 In terms of impact on others, you know, my  
6 parents -- having haemophilia is difficult enough, but  
7 thinking I had then got an infection on top of that  
8 I think there's a burden of guilt for my parents.

9 You know, I have already spoken about my partner  
10 and kind of it's only come out after the fact that he  
11 was -- he was getting no sleep really. He was staying  
12 up, researching every clinical trial and so on and,  
13 you know, he has a really professional job. It must  
14 have impacted on him, and for him going into his work  
15 place and kind of breaking down, I feel guilty about  
16 that as well. There is a lot of guilt really for me.

17 I just think it's really difficult all round,  
18 but people have been very sort of understanding really  
19 and friends and family because I have got fantastic  
20 friends and family.

21 **Q.** Have you ever been offered any counselling or  
22 psychological support?

23 **A.** No.

24 **Q.** Do you think it would have been helpful?

25 **A.** Yes, I think it would. I mean, the whole thing has

1       been so traumatic, yes, I think it would help.

2   **Q.** Have there been impacts in terms of your ability to  
3       obtain insurance?

4   **A.** Yes. So trying to get travel insurance or life  
5       insurance is, you know -- well, it's sort of  
6       impossible to get life insurance. Travel insurance is  
7       just prohibitively expensive, you know. I thought  
8       once I had cleared the virus, that would make  
9       a difference, but the series of questions that  
10      underwriters seem to ask, you know, first of all, you  
11      say you have got haemophilia. Then I think it asks  
12      about any joint replacements. There is a path and it  
13      asks about, you know, have you ever kind of contracted  
14      hepatitis C. So, of course, you must answer honestly  
15      and yes, I have. Have you cleared the virus? Yes.  
16      Have you had oesophageal varices? No. And some  
17      insurers just decline you completely, you know. You  
18      only get so far and that's it. It's declined, so ...

19   **Q.** In terms of other financial impacts, you took  
20      voluntary redundancy during that first course of  
21      treatment for the reasons you have described. Did  
22      your infection or the treatment and the symptoms you  
23      experienced impact upon the development of your  
24      career?

25   **A.** Yes. I think I would have gone on to progress my

1 career within probably the Civil Service and, you  
2 know, somebody who was one of my trainees is now  
3 an assistant director of communications and policy at  
4 a local authority. Hopefully I would have achieved  
5 that level, but I was just kind of so tired and, you  
6 know, just -- at one point I was really sort of sharp  
7 and I had to be. I worked in public relations. I was  
8 dealing with journalists. I had to be ready for  
9 questions and kind of -- yes, I'd just kind of lose my  
10 thread.

11 The concentration aspect, like I say, of just  
12 proof reading and reading the same paragraph over and  
13 over until I have actually taken it in, I am sure is  
14 an impact of either hepatitis C or the interferon  
15 treatment.

16 **Q.** You have told us obviously how, again, in terms of  
17 financial impact, you spent the money from the Skipton  
18 Fund on funding the treatment that you couldn't get  
19 funded by the NHS. In terms of applications to the  
20 Caxton Fund you have said in your statement that that  
21 had implications in terms of life decisions you were  
22 making, because they would take into account partner's  
23 income?

24 **A.** Yes. So we sort of delayed moving in together and  
25 I think because my partner has a decent career and so

1 on, I think it is unfair that he is kind of expected  
2 to pick up the bill. When we looked at total  
3 household income, you know, why should he have to  
4 foot, you know, that bill really.

5 **Q.** So Dave, those are the questions I have for you. Is  
6 there anything you'd like to add?

7 **A.** Just going back to the point about treatment, I think  
8 if ever there was a cure for HIV, just as with  
9 hepatitis C, I do think that those of us who  
10 contracted contaminated blood through contaminated  
11 blood products should be put to the front of the queue  
12 and I wouldn't want anybody to go through what I have  
13 gone through in terms of, you know, having to fight to  
14 get the treatment. I just think that's disgusting, so  
15 ...

16 **MS RICHARDS:** Dave, I am just going to ask Mr Snowden, who  
17 represents you, if there are any other further  
18 questions he would like to add. No, there aren't.  
19 Thank you.

20 **SIR BRIAN LANGSTAFF:** I have no further questions. Just  
21 let me thank you very much for coming and coming at  
22 such short notice to give the evidence which you have  
23 to us. So thank you, Dave.

24 **A.** Thank you.

25 **SIR BRIAN LANGSTAFF:** Well, we will take a break now until





1 **A.** I was rushed to the hospital and then obviously I was  
2 given a blood transfusion. I was rushed on to the --  
3 into theatre and that's when they gave me the blood.

4 **Q.** So you were taken back to hospital for a further  
5 operation to sort it out and during that operation you  
6 were given a transfusion?

7 **A.** That's right, yes.

8 **Q.** You think it was about two pints of blood?

9 **A.** About two pints.

10 **Q.** Before the operation was your mum, as far as you are  
11 aware, was your mum told about any risks associated  
12 with having a transfusion?

13 **A.** No, she weren't, no.

14 **Q.** In 2004 you started to have severe nosebleeds. Can  
15 you describe what happened?

16 **A.** Yes. I was walking home from the town centre and my  
17 nose just burst. I lost quite a bit of blood. This  
18 was going on for about a week or so and I just went  
19 for a check up at my GP and, at this point, I had  
20 found out then that I had hepatitis C.

21 **Q.** So you had one huge nosebleed and then a few days  
22 later another huge nosebleed and it went on for about  
23 a week.

24 **A.** Yes.

25 **Q.** You went to your GP and he did a series of blood

1 tests?

2 **A.** That's right, yes.

3 **Q.** When you were told by your GP that you had hepatitis  
4 C, can you remember anything else you were told? What  
5 did the GP tell you about hepatitis C?

6 **A.** Nothing. He was just going to refer me to  
7 a specialist and that was the last I heard from him  
8 really.

9 **Q.** Were you told anything at that point about the risks  
10 of transmitting hepatitis C?

11 **A.** No.

12 **Q.** You were referred to a specialist and seen about six  
13 months later. What can you tell us about that first  
14 appointment?

15 **A.** Well, they just said basically that I got the  
16 hepatitis C. They'd do a bit of monitoring and that  
17 was really it really. That's the last I heard until  
18 probably about a year later.

19 **Q.** At that first appointment you said in your statement  
20 that the doctor asked you a series of questions that  
21 made you really quite angry. Can you tell us about  
22 those.

23 **A.** Say that again, sorry.

24 **Q.** At that first appointment in your statement you have  
25 said the doctor asked you a series of questions that

1       made you really quite angry. Can you tell us about  
2       those.

3       **A.** Yes. Basically, he asked me how I could have got  
4       this. He asked if I was using drugs. Obviously  
5       I wasn't. I never touched drugs in my life other than  
6       prescribed and that's how it come to light and I got  
7       a bit angry at that.

8       **Q.** The doctor asked if you were a drug user and you  
9       responded by showing her your arms and saying, "No,  
10      absolutely not"?

11      **A.** That's right.

12      **Q.** You were asked whether you had a sexual partner.  
13      There was a series of questions about tattoos as well?

14      **A.** That's right, yes.

15      **Q.** At that stage did you understand that you might have  
16      been infected through a transfusion?

17      **A.** I didn't have a clue. It was later on that I found  
18      out in the local newspaper by a local chap and,  
19      obviously, my mum said, basically, "Well, you had  
20      a transfusion in '88", and this is where it all come  
21      to light.

22      **Q.** Because we have looked at your -- at the medical notes  
23      of that first appointment and there is a note that  
24      says "blood transfusion" with a star next to it but,  
25      as far as you were concerned, that wasn't discussed

1 with you?

2 **A.** That wasn't discussed, no.

3 **Q.** At that appointment what were you told about hepatitis

4 C? Were you told anything?

5 **A.** Not a thing, no.

6 **Q.** Again, we have looked at the note of the appointment

7 and it does refer to telling you about how hepatitis C

8 is transmitted, but you are clear you weren't told

9 that?

10 **A.** That's right, yes.

11 **Q.** Why are you so clear about that in your mind?

12 **A.** Just -- because I just know it weren't true, what they

13 said.

14 **Q.** You said that you had to go away and look it up.

15 **A.** Yes, I had to go away and look it up myself to find

16 out how you could catch it and stuff and what impact

17 it would have.

18 **Q.** Can you tell us what the effect on you was of that

19 appointment, on your mental health?

20 **A.** Yes. I just -- I tried ending my life.

21 **Q.** That was a little bit later on in the time, wasn't it?

22 That was 2011, but the very first time when you had

23 that appointment I think you said your head just blew?

24 **A.** Yes. My head just blew. I felt dirty. I was getting

25 in the bath every hour or so and I felt disgusted in

1           myself.

2   **Q.** Because at that stage you didn't understand how you'd  
3       come to be infected?

4   **A.** That's right, yes.

5   **Q.** And you've described that as the time when your  
6       depression started to set in.

7   **A.** When it started setting in, yes.

8   **Q.** You had a couple of further appointments with  
9       specialists at the hospital, but then you didn't  
10      attend appointments until about 2011.

11                Can you recall what was happening for you in  
12      terms of your mental health during that time?

13   **A.** I just couldn't face up to knowing it and I just  
14      wanted to get it all clear out of my mind that I never  
15      had hepatitis and I just didn't feel right going to  
16      the hospital and finding if there was anything else  
17      the matter with me and that's it.

18   **Q.** If we can have document 1963008, please, this is  
19      a letter from the specialist actually in 2011, but if  
20      we look at the very first few sentences of the letter,  
21      we can see that it says:

22                "This gentleman came to the clinic today  
23      together with his mother and his girlfriend. He was  
24      first tested positive for hepatitis C back in 2005.  
25      However due to his anxiety and other problems he

1 didn't turn up for any further follow ups and has now  
2 been re-referred as he now feels more able to face his  
3 diagnosis."

4 Is that what was going on?

5 **A.** Yes.

6 **Q.** Periodically from 2005 through to 2011 you were  
7 drinking very heavily?

8 **A.** I weren't drinking heavily. It were just not as much  
9 as --

10 **Q.** More than recommended?

11 **A.** More than recommended, yes. I just had to try to get  
12 it out of my mind and that, you know.

13 **Q.** If we can keep the letter up, Paul, we can see on the  
14 letter there is reference in the middle of that first  
15 paragraph to you drinking 310 units of alcohol a week.  
16 In fact, you think that's a typographical error and it  
17 was about 31 units of alcohol a week.

18 **A.** Yes.

19 **Q.** By 2011 you had cut it down to 12 units a week?

20 **A.** Yes.

21 **Q.** You have said -- you referred to it just a moment  
22 ago -- in 2009/2010 your mum read an article in the  
23 paper?

24 **A.** That's right.

25 **Q.** What did she tell you about that or from that article?

1 **A.** Obviously, they knew about the hepatitis C and it  
2 started to spring to the mind that this is where the  
3 hepatitis could have come from. So we sat down, had  
4 a chat and started looking into it a little bit more  
5 and that's obviously where it's all come out that it  
6 was from the blood transfusion.

7 **Q.** How did that realisation make you feel?

8 **A.** I was angry. I was really angry about it, because  
9 obviously what they had put into me.

10 **Q.** You referred earlier to an attempted suicide?

11 **A.** Mm-hm.

12 **Q.** In 2011. That you have said was really the lowest  
13 time for you?

14 **A.** Yes.

15 **Q.** Can you tell us a little bit about that time in your  
16 life?

17 **A.** Yes. Everything just got on top of me and I just  
18 thought it was time for me to go. I got a bottle,  
19 a small bottle of vodka, drunk it and tried hanging  
20 myself.

21 **Q.** You were rescued by a neighbour who heard a thud.

22 **A.** Yes, that's right, yeah, because I was living in  
23 a flat at the time and she heard the thud. Luckily my  
24 door was open and she come in and she rung the police  
25 and ambulance.

1 Q. And you were admitted --

2 A. And I was admitted to the hospital.

3 Q. To the hospital. But you have also said that

4 that moment was something of a wake-up call for you

5 and you realised that you needed to deal with the

6 hepatitis C.

7 A. That's right, yes.

8 Q. And that's why we saw that letter a moment ago from

9 2011 where you had been re-referred --

10 A. Yes.

11 Q. -- for treatment.

12 So in 2011 you then underwent some tests to see

13 what state your liver was in and 2012 you were offered

14 some treatment?

15 A. That's right, yes.

16 Q. You didn't have the treatment at that stage?

17 A. No, because --

18 Q. Can you tell us why not?

19 A. I had a child on the way, so I delayed the treatment

20 and that's the reason why I delayed it, because

21 obviously there was too much going on. I didn't want

22 to be poorly, you know, when the baby come out.

23 I didn't want to be poorly.

24 Q. 2013, your second child --

25 A. Second child.



1 Q. -- was arriving. So again you didn't feel able to  
2 undergo treatment then?

3 A. That's right.

4 Q. Then there was a further short delay while you waited  
5 for Harvoni treatment to become available --

6 A. Yes.

7 Q. -- instead of having to have the interferon.

8 A. That's right, yes.

9 Q. So you had Harvoni treatment in 2016 and you cleared  
10 the virus?

11 A. Cleared the virus, yes.

12 Q. Can you tell us a little bit about what the side  
13 effects were when you underwent the Harvoni treatment.

14 A. There was no real side effects to it, to be honest.  
15 It is more after where my health has sort of like  
16 deteriorated a bit.

17 Q. Can you tell us about that. What are the ongoing  
18 difficulties that you're facing?

19 A. I have had pneumonia. Just my mental health has got  
20 a little bit worse, not as much, but it's creeping  
21 back up. I feel more tired. My memory seems to be  
22 going quite a bit to what it was before.

23 Q. You have described in your statement of having extreme  
24 tiredness, deep fatigue. Your sleep pattern is  
25 totally unpredictable and you are tired most of the

1 time. You had pains in your joints, itchiness and you  
2 feel like your immune system is weakened, because you  
3 constantly get coughs and colds --

4 **A.** Coughs and colds.

5 **Q.** -- and pneumonia.

6 **A.** Yes.

7 **Q.** You have also said you suffer from brain fog?

8 **A.** Brain fog, yes.

9 **Q.** In terms of your mental health, what that has been  
10 like since you had the treatment?

11 **A.** It's been on and off. I can have my good days, I can  
12 have my bad days. It is unpredicted. Going back  
13 a couple of weeks ago, I just went on a downer.  
14 I wanted to drive my car off a cliff.

15 **Q.** And you found it very difficult as well to interact  
16 with the health service, with any doctors?

17 **A.** Yes.

18 **Q.** Can you tell us why that is.

19 **A.** Because they just don't seem to give me the support  
20 that I need. My doctors took me off all my medication  
21 because obviously he said he don't want to affect my  
22 liver, didn't want to give it any more damage, so now  
23 I'm just seeing a mental health nurse.

24 **Q.** So you've been taken off your anti-depressants because  
25 of concerns about the liver but for you you said to me

1 earlier that that was causing -- obviously causing  
2 difficulties with your depression?

3 **A.** That's right, yes.

4 **Q.** You have also said in your statement you were angry at  
5 the system, that the public health system you had been  
6 brought up to respect, had let you down?

7 **A.** Yes.

8 **Q.** You said in your statement:

9 "I have trusted that the system, including the  
10 medical professionals, would take care of me for  
11 years. My mum did too. That trust has gone and  
12 I have been left feeling totally vulnerable as  
13 a person and completely let down. I feel particularly  
14 vulnerable, because I now have to seek help from the  
15 system that has hurt me so badly. I simply can't  
16 trust it now."

17 **A.** That's right.

18 **Q.** You struggled to receive counselling and psychological  
19 therapy during this time. Can you tell us what  
20 provision has been given to you.

21 **A.** Obviously, I have had my tablets, depression tablets,  
22 I have seen a hypnotist, hypnotherapist.

23 **Q.** You did that privately.

24 **A.** Privately, yes, yes.

25 **Q.** But in terms of NHS provision what counselling and

1           psychological support have you been given?

2   **A.** They just referred me to a Let's Talk service, which

3           I had a few sessions with them, and it just weren't

4           right for me really.

5   **Q.** You had just three sessions.

6   **A.** Three sessions, yes.

7   **Q.** With a counsellor.

8   **A.** I just didn't seem to be getting anywhere.

9   **Q.** Now you are being seen by a mental health nurse, but

10          that's relatively recent.

11   **A.** That's right, Yes.

12   **Q.** So until very recently all you had had was three

13          sessions of counselling.

14   **A.** Yes.

15   **Q.** In terms of the on going monitoring of your liver,

16          have you had a fibroscan since you cleared the virus?

17   **A.** No.

18   **Q.** You have said you feel you should be monitored more

19          regularly?

20   **A.** More regularly, yes.

21   **Q.** What do you feel should be done?

22   **A.** I think they should just keep -- you know, just keep

23          a regular check on me. It seems to be every year that

24          I'm having these checks and I think it should be more

25          like every six months. I think a year is far too

1           much. You don't know what's going to happen in that  
2           year. Could get worse, you know.

3   **Q.** Each year since you have cleared your virus you have  
4           just gone to your GP for some blood tests, not for  
5           a fibroscan?

6   **A.** Not for a fibroscan, no.

7   **Q.** That's something you have had to initiate, you have  
8           had to sort out?

9   **A.** I have had to sort out, yes.

10 **Q.** What you feel is you should be monitored by the  
11          hospital every six months?

12 **A.** That's right, yes.

13 **Q.** Until about 2016 you didn't tell anyone about your  
14          infection. Why was that?

15 **A.** I just felt dirty. My wife knew. My parents, but  
16          like my friends and stuff, they didn't know.

17 **Q.** You were worried about what would happen on social  
18          media as well, I think.

19 **A.** Yes, that's right, yes.

20 **Q.** Can you tell us what you were worried about.

21 **A.** Just about all the backlash and, you know, probably  
22          losing friends, but since I have come out with it,  
23          it's been fine, especially meeting people in like the  
24          groups, you guys that are here today. It's been --  
25          you know, it's helped me a lot actually but, yes,

1 I just didn't want to -- just kept it secret.

2 **Q.** You said in your statement you were worried about  
3 being trolled on Facebook?

4 **A.** Yes.

5 **Q.** Or being bullied or harassed about it?

6 **A.** That's right.

7 **Q.** You are now married with children. What was the  
8 impact of your infection on them, on your children?

9 **A.** They are fine. [Redacted]. [Redacted].

10 **Q.** In terms of your relationship with your partner and  
11 your children.

12 **A.** Yes, they are all fine. [Redacted].

13 **Q.** You have said that it was hard for you to be a partner  
14 and father that you wanted to be. Can you tell us  
15 a little bit about that.

16 **A.** Yes, because obviously it is like I can't really do  
17 much with my children, because I just get too tired.  
18 My motivation, I have got just no motivation. I want  
19 to do more with my children, but it just doesn't  
20 happen.

21 **Q.** You said that your mum and grandparents have worried  
22 about you a lot and that's caused difficulties in your  
23 relationship with them as well?

24 **A.** Yes.

25 **Q.** In 2015 you wrote to the hospital trust raising

1 concerns about the original transfusion?

2 **A.** That's right.

3 **Q.** Could we have document 1963006, please. This is the  
4 response you received, and if we can look at  
5 paragraphs 3 and 4, there was a -- the Chief Executive  
6 was asked to convey to you the following information  
7 from your treating consultant:

8 "Transmission of viruses via blood transfusion  
9 was a worldwide problem until the mid 1980s when it  
10 was known as non-A non-B hepatitis. Hepatitis C was  
11 not identified until 1989. In England and Wales blood  
12 began to be heat treated to destroy any viruses during  
13 1985 and slightly later than this in Scotland.

14 "According to our records you were given blood  
15 in 1988 and this was done in the belief that the blood  
16 from the Transfusion Service was safe and heat  
17 treated. We have formally requested if the blood  
18 transfusion service could trace the blood given to you  
19 but they do not keep records this far back. As our  
20 investigations stand we acknowledge that it may have  
21 been the blood transfusion that caused your hepatitis  
22 C infection and if this is the case we sincerely  
23 apologise. However, we are unable to confirm this."

24 **Q.** How did you feel when you received this letter?

25 **A.** I was angry, especially, like with, the Blood

1 Transfusion Service. How come they can't trace it?  
2 There's got to be something there and it -- yeah,  
3 I was just angry.

4 **Q.** Because you have the blood numbers.

5 **A.** I've got the blood numbers, yes. So why can't it be  
6 traced. This is what I need to know. It's  
7 ridiculous.

8 **Q.** Because you are clear that there's no other risk  
9 factors. There's no other way in your mind that you  
10 could have contracted the hepatitis C.

11 **A.** That's right.

12 **Q.** But you would like more definitive confirmation that  
13 it was the transfusion?

14 **A.** Yes.

15 **Q.** You have received some financial assistance from the  
16 Skipton Fund and from Caxton and, more recently, you  
17 applied for special category mechanism payments  
18 because of your mental health condition. That was  
19 refused. Can you tell us why?

20 **A.** They didn't have enough evidence.

21 **Q.** Of what?

22 **A.** On the forms that my specialist put in.

23 **Q.** So your specialist had filled in the forms for you and  
24 put in information about your mental health condition?

25 **A.** That's right, yes.



1 Q. But the form was rejected because -- and you appealed.  
2 So it was there was not enough evidence that on the  
3 balance of probabilities your mental health condition  
4 was caused by the hepatitis C?  
5 A. Yes.  
6 Q. And that's why they rejected it?  
7 A. And that's why they rejected it.  
8 Q. When that was rejected, you had a phone conversation  
9 with them?  
10 A. That's right.  
11 Q. What did they say to you?  
12 A. They told me to apply for the stage 2 application.  
13 Q. So they had rejected the special category mechanism.  
14 A. Yes.  
15 Q. But on the phone they said you should be applying for  
16 stage 2?  
17 A. Yes.  
18 Q. They sent you the application form.  
19 A. Sent me the application form. Sent it off to my  
20 specialist. She filled it out and it took about  
21 a month to get it back from the specialist. Sent it  
22 off to -- and they rejected it.  
23 Q. Do you know why they rejected it?  
24 A. They didn't say.  
25 Q. And you have now applied again for the special

1 category payment?

2 **A.** Yes.

3 **Q.** Again, on the basis of your mental health condition?

4 **A.** That is with my specialist at the minute.

5 **Q.** You are just waiting to send it off again?

6 **A.** Yes.

7 **Q.** How have you found the process of dealing with EIBSS  
8 through this?

9 **A.** A nightmare.

10 **Q.** Can you tell us a bit more about why?

11 **A.** Yes. They just seem to be wanting too much, because  
12 it is always -- every time you apply for things off  
13 them, it is always "go see your GP" or "go see your  
14 specialist".

15 Now when you go see them, it could take months  
16 to get a letter off them or any form of anything. It  
17 is just like a waiting game. It is just ...

18 **Q.** You said to me earlier that you had found it very  
19 difficult to understand what was required of you as  
20 well?

21 **A.** That's right, yes. Because every time -- obviously,  
22 when you fill these forms out, it always says "Is this  
23 caused by your hepatitis?", you know, and then  
24 obviously when you send it into your specialist, they  
25 are going, "Oh, well, we don't know". It's -- so it's

1           just like a fighting battle with them and I don't  
2           think it's right.

3   **Q.**   Because you are clear that your mental health  
4           difficulties started with the diagnosis of hepatitis C  
5           but the clinicians can't say for sure what caused your  
6           depression?

7   **A.**   That's right, yes.

8   **Q.**   Those are all the questions I have for you.  Is there  
9           anything you want to add?

10 **A.**   No.  I think that's it.

11 **Q.**   I am just going to talk to Ms Gibbs, who, as you know,  
12           represents you, to see if she has any points she wants  
13           me to raise.

14                 Just two points that Ms Gibbs would like me to  
15           raise with you.  Can you tell us how the infection has  
16           impacted on your education and work?

17 **A.**   Yes.  Obviously I haven't worked for a long time.  The  
18           first job was being a Red Coat at Butlins and I was  
19           only there six months.

20 **Q.**   What made you stop work there?

21 **A.**   I just couldn't cope.  I was too -- I was too  
22           distressed, but I was just more tired than anything,  
23           because obviously it was long hours, but this was  
24           before I found out like I had the hepatitis C.  This  
25           was 2002.  Obviously, I didn't know nothing about

1           that, that I had the hepatitis C then, so that's ...

2   **Q.** Because of that lack of regular income you have

3           struggled to have any form of credit scoring and

4           mortgages and things?

5   **A.** That's right, yes.

6   **Q.** Secondly, even though you have now cleared the virus,

7           what fears do you still have for your family and your

8           children?

9   **A.** I think it's -- it is like if I have a bleed or

10          anything, I still think I've got it to be honest and

11          it is just -- I don't like to be too close near them

12          when things like that happen. That's my biggest fear,

13          you know, still having to -- yes. That's my biggest

14          fear.

15   **Q.** You are still fearful that you will infect them?

16   **A.** Yes.

17   **Q.** Because you're worried that although it's cleared --

18   **A.** It's cleared.

19   **Q.** -- it hasn't gone away?

20   **A.** Yes.

21   **Q.** I think you said earlier to Ms Gibbs that you were

22          scared of even kissing and cuddling your children?

23   **A.** That's right, yes.

24   **MS FRASER BUTLIN:** Sir, do you have any further questions?

25   **SIR BRIAN LANGSTAFF:** Yes, I do. You said in your

1 evidence that you'd lost trust in the system,  
2 including medical professionals.

3 What in particular do you think they did that  
4 caused you to lose trust.

5 **A.** Obviously, they never told me that about the blood  
6 transfusion. It is just that it's been going on and  
7 they've sort of like lied about it sort of type thing  
8 and that's -- when they put that blood into me, never  
9 told me, that's my trust just ... it's -- I just --  
10 I don't know.

11 **SIR BRIAN LANGSTAFF:** Thank you very much. Well, thank  
12 you, Darren, for telling us your story. It can't have  
13 been easy for you, so thank you very much for coming  
14 and doing that.

15 **A.** Not a problem. Thank you.

16 **SIR BRIAN LANGSTAFF:** Now, Ms Fraser Butlin, that's the  
17 last witness I think for today.

18 **MS FRASER BUTLIN:** It is, sir.

19 **SIR BRIAN LANGSTAFF:** Who do we have tomorrow.

20 **MS FRASER BUTLIN:** Tomorrow we'll be hearing from Lesley  
21 McEvoy, Leroy Scarlett, and Sean and Eleanor Nevin.

22 **MS RICHARDS:** Tomorrow we start at 10.30. 10.30 tomorrow.  
23 (2.31 pm)

24 (Adjourned until 10.30 am the following day)

25 **I N D E X**

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MARTIN BEARD, affirmed .....1  
Questioned by MS RICHARDS .....1  
DAVE ANTHONY GORT, sworn .....45  
Questioned by MS RICHARDS .....45  
DARREN RAWSON, affirmed .....72  
Questioned by MS FRASER BUTLIN .....72