

1

Thursday, 9 May 2019

1
2 (10.00 am)
3 **SIR BRIAN LANGSTAFF:** Our first witness wishes to be known
4 as Della, does she?
5 **MS RICHARDS:** That's right, sir. Della Ryness-Hirsch.
6 **SIR BRIAN LANGSTAFF:** May she come forward.
7 **DELLA RYNESS-HIRSCH, sworn**
8 **Questioned by MS RICHARDS**
9 Q. Della, you're here to talk today, with the support of
10 your husband, Dan, about your son Nick and what
11 happened to him and to your family.
12 **A. I am.**
13 Q. Now, Nick was a twin.
14 **A. He was.**
15 Q. Born in 1976 and there was no history of haemophilia
16 in either of your families.
17 **A. No.**
18 Q. But you found out when he was a baby that he had
19 haemophilia. How did that happen?
20 **A. We had the twins at Queen Charlotte's in Hammersmith**
21 **and we decided to have them circumcised at home when**
22 **they were six or seven weeks old, and later in that**
23 **day my mother-in-law, who, in fact, was a children's**
24 **nurse, had come from New York -- Dan is American) --**
25 **to be with us, went up to see how they were doing and**

3

1 mean in your lives bringing up the children.
2 **A. No. We had no idea. The first incident that we**
3 **recall -- shall I talk about that?**
4 Q. Yes, absolutely.
5 **A. -- with Nick was we had a very small paved back yard**
6 **where we were living and it was that very hot summer**
7 **of '76, so we were sitting outside with the boys and**
8 **Dan had Nick over his shoulder and we were sitting on**
9 **deck chairs, and the one he was sitting on collapsed**
10 **and the bar flew up and hit Nick in the forehead and**
11 **we were absolutely traumatised. We had no idea was**
12 **this what they meant and this, that and the other.**
13 **I mean, he got bruises but so did his twin brother**
14 **because they were -- they were very young. They were**
15 **only rolling around then.**
16 **Anyway we took him off to Great Ormond Street**
17 **and they gave him cryoprecipitate it was at the time**
18 **and it was all very traumatic and a friend from**
19 **San Francisco was staying with us at the time and she**
20 **was looking after [redacted], and when we got back**
21 **she'd laid out an old quilt we had in the sitting room**
22 **on the floor and [redacted] was laying there on his**
23 **stomach sort of looking up at us. Nick who had been**
24 **screaming hysterically quietened down we laid him**
25 **next to [redacted] on the quilt and the two boys**

2

found Nick laying in a pool of blood.

2 **So my sister Lynne Featherstone and Dan took him**
3 **immediately back to Queen Charlotte's where he was put**
4 **into an incubator and two days later or three days**
5 **later, they asked us if there was any haemophilia in**
6 **the family and I said -- we said no, not at all. The**
7 **only thing we knew about it was the connection with**
8 **the Russian Royal family.**

9 **So it turned out that this is what he had and we**
10 **were told at the time it was a one in a million chance**
11 **to happen spontaneously, although we found more**
12 **recently it seems to be more common than that**
13 **spontaneously. [redacted] was tested and he didn't**
14 **have anything.**

15 Q. Nick's care was transferred to Great Ormond Street
16 Hospital?

17 **A. It was.**

18 Q. And he came under the care of a Dr Sieff?

19 **A. Yes, Colin Sieff.**

20 Q. He gave you information about haemophilia. He told
21 you about the existence of the Haemophilia Society?

22 **A. Exactly.**

23 Q. But you have said in your statement although you were
24 given what you thought was sufficient information, you
25 didn't really have a sense of what haemophilia would

4

1 **looked at each other and they started laughing.**
2 **Really Dan, I thought, okay, all right, we can cope**
3 **with this. It was great. It was really**
4 **life-enhancing.**

5 Q. In about 1978 -- so when the twins would have been
6 about two years old --

7 **A. Yes.**

8 Q. -- you had a call from a very close friend of yours in
9 America and she wanted to discuss something with you,
10 share some information with you. What was that?

11 **A. She did. This was an English friend who I've known**
12 **since I was 17. We had travelled extensively**
13 **together, eventually ending up going to America, we**
14 **both got green cards and we worked our way across**
15 **America over a few months, and ended up in**
16 **San Francisco where [redacted] * was going to travel**
17 **to India and he said why don't you take the flat for**
18 **six months, and we remained friends all our lives.**

19 **So later during that time in San Francisco I met**
20 **Dan who was from New York originally but living in**
21 **San Francisco and at a point we came back to England**
22 **and she stayed there, got married and settled there**
23 **until she died. She died sadly just before Nick did.**

24 **She rang me and she said does Nick get any**
25 **American blood and I said not as far as I'm concerned.**

5

1 I think it always comes from Elstree Laboratories but
2 I don't think they use -- she said, "Well, listen,
3 there's something really weird going on here and
4 I think you ought to investigate". Now, I must add
5 here that both Irene and I had travelled since we were
6 17. We were pretty astute, let's put it like that.

7 So the next time I went -- we went to Great
8 Ormond Street, I asked Dr Sieff does Nick get the
9 American blood? He said, "Not yet, but we're working
10 on a new, whatever, product and -- which we don't
11 switch the children to until they're four", and
12 I said, "Well, you know, listen American blood's not
13 great", but he said, "No, no, we're not going to do
14 anything like that he's staying on cryo", so that was
15 it for then.

16 But in that two years until Nick became four
17 I brought him tonnes of articles that Irene sent.
18 I brought him articles. I brought him information
19 and, finally -- well, anyway that's the background.

20 Q. The particular concern that your friend had raised
21 with you and that you had, I think, some general
22 knowledge about about American blood or you gained
23 knowledge was about the paid donation --

24 A. Oh yes.

25 Q. Blood being collected from prisoners and those on skid

7

1 hospital and they said Nick has to go on to this new
2 treatment and I said, "The one from America?" They
3 said "Yes" and I said, "No, absolutely not. He cannot
4 have it and if you try and give it to him I'm going to
5 cause up", you know -- I went absolutely crazy. I had
6 a huge shouting match there and in the end they said,
7 "Okay, okay, we'll keep him on what he's on", so that
8 was when he turned four, yes.

9 Q. What you said in your statement, Della, is you kicked
10 up bloody murder.

11 A. I kicked up bloody murder.

12 Q. You told the medics to keep Nick on cryoprecipitate,
13 was told there was not enough available. You were
14 told that there was some cryoprecipitate in Elstree
15 but the supply was not sufficient but you were given
16 assurances that if Nick moved from cryoprecipitate to
17 factor products, they were safe and would come from UK
18 donors?

19 A. Absolutely, absolutely, that was what I was told,
20 I was promised, yes, so that's what happened.

21 But very quickly after that they said that they
22 weren't going to have enough and we went to the Royal
23 Free haemophilia department, which was more local to
24 where we were living then, and they said if we
25 transferred Nick they did have enough of the UK.

6

1 row?

2 A. Absolutely. I mean, over the years we spent in
3 America and our travels we absolutely knew. I mean,
4 we knew people who, you know, when they were short of
5 money they'd go and donate blood and it was --

6 DAN: Sell it.

7 A. Sell it, yes, not donate it, sell it. It was common
8 knowledge and ... yeah.

9 MS RICHARDS: You have said in your statement that when
10 you shared this information with the doctor at Great
11 Ormond Street you told him then and later that you did
12 not want Nick to receive American products.

13 A. I did.

14 Q. By which you meant you didn't want him to receive
15 anything derived from American blood?

16 A. I did, we did, absolutely.

17 Q. You've not kept copies of those articles but you
18 remember giving to the doctors over quite a prolonged
19 period of time information and articles about this
20 issue?

21 A. Yes, and as we'll talk about, it was later proved so.

22 Q. In around 1980, what were you told about changes to
23 Nick's treatment from cryoprecipitate to something
24 else?

25 A. Was it -- yes, okay, we arrived one day at the

8

1 Q. If we just stick with 1980 for the moment Della?

2 A. Okay, sorry.

3 Q. No, no, don't worry at all. It's important, some of
4 the details in your statement, it's important that
5 they come out.

6 What you've said is eventually you had no
7 choice -- this is still at Great Ormond Street in
8 1980.

9 A. Yes.

10 Q. You had to agree to Nick receiving Factor VIII
11 products instead of cryoprecipitate but it would be
12 Elstree only?

13 A. Elstree only.

14 Q. Which you understood at the time to have no
15 involvement whatsoever with any kind of American
16 imports?

17 A. That's right. Yes, sorry, yes.

18 Q. If we just get up on screen, please, Paul, document
19 282006.

20 It should come up on the screen in front of you,
21 Della. These are all documents you have exhibited to
22 your witness statement.

23 If you could highlight the next entry please,
24 3 November 1980, that whole passage.

25 We can see here 3 November 1980:

1 "Injured right knee."
 2 There's a reference to slight swelling and then
 3 a small bleed into and around the right knee joint.
 4 Then there's a reference to Factor VIII being given,
 5 280 units, and you or Dan being shown how to give this
 6 for the first time. So that was the first time, as
 7 far as you've been able to understand from the medical
 8 records, that Nick was given Factor VIII products?
 9 **A. Yes, from Elstree.**
 10 Q. We can see the entry below that, 10 November 1980,
 11 there's another reference to a small bleed and
 12 swelling a week later and again a reference to
 13 Factor VIII products being given.
 14 In the period when Nick remained at Great Ormond
 15 Street before you transferred his care to the Royal
 16 Free, can you recall how often he'd be given factor
 17 products? Was it a regular occurrence?
 18 **A. It was, wasn't it? I mean, sometimes he'd go a week**
 19 **without something, he'd have bumps but not a bleed.**
 20 **DAN:** It was erratic.
 21 **A. It was erratic. It depends what he was doing really,**
 22 **what they were doing.**
 23 **MS RICHARDS:** Now if we come forward in time to
 24 January 1985, there came a point in time at which you
 25 read an article in the guardian, 21 January 1985, and

1 Nick, you wrote it in the name of your sister-in-law
 2 with her agreement and if we just have a look at that,
 3 Della.
 4 Paul, it's 282012, please. If we could
 5 highlight the top letter that's headed "Bad blood",
 6 that's right.
 7 So this is the letter that you wrote to the
 8 Guardian and it was published in the Guardian setting
 9 out your concerns in particular about the possibility
 10 of Nick having to be switched to American Factor VIII.
 11 What can you remember? What prompted your
 12 concerns and your decision to write this letter?
 13 **A. Well, the article prompted it. Everything that had**
 14 **gone before prompted it. I was absolutely beside**
 15 **myself, we were, and it happened that the letters**
 16 **editor of the Guardian was friend of ours because they**
 17 **don't normally let you publish letters not under your**
 18 **name and I talked to Patrick and he said it's okay and**
 19 **I published it. So there's nothing in there, the**
 20 **name, it's only what I said, but the person to whom it**
 21 **was directed, who read it, understood perfectly well**
 22 **it was me and --**
 23 Q. What then happened? That letter was published on
 24 23 January 1985 and then you got a phone call. Who
 25 was that from?

1 again we are going to put that up on the screen in
 2 front of you, Della.
 3 It is 282010 please, Paul.
 4 You'll see there the article, you have described
 5 reading it in your statement. It's called "AIDS and
 6 a caring society", and if we look at the second
 7 paragraph, a few lines in, it says:
 8 "AIDS is not exclusive to homosexuals at all.
 9 Not all those who contract the disease can be
 10 categorised as promiscuous but the problem is
 11 a serious one."
 12 Then a few lines later reference to the
 13 Department of Health having been too leisurely and too
 14 complacent:
 15 "It must ensure that all Factor VIII, the blood
 16 clotting agent for haemophiliacs, is heat-treated to
 17 destroy AIDS viruses and that all special clinics
 18 treating sexually transmitted diseases must be
 19 required to display notices warning the chief groups
 20 at risk from AIDS not to give blood. It is by blood
 21 that the virus is carried."
 22 So you read that article. That worried you?
 23 **A. Yes, it did worry me.**
 24 Q. So you wrote a letter to the Guardian. I think
 25 because you didn't want to disclose details about

1 **A. Well, first of all, Professor Hardisty published his**
 2 **own letter which I refuted and, yes, what happened was**
 3 **that he rang us at our business which was not far from**
 4 **Great Ormond Street.**
 5 **Now, there's no way in hell he would have known**
 6 **Julia Harrison. Dan's sister was a politician in**
 7 **New York but no-one -- he knew when he saw that letter**
 8 **there was no-one in the Great Ormond Street**
 9 **department, haemophilia department, who would have**
 10 **known those things, who would have done those things.**
 11 **So he just rang and he asked Dan and I to come and see**
 12 **him up at Great Ormond Street haemophilia unit.**
 13 Q. Can you recall anything about the conversation you had
 14 with him?
 15 **A. Oh, yes, I can recall everything. First of all, he**
 16 **told Dan and I that all the children in the unit had**
 17 **been tested for virus and Nick was the only one that**
 18 **didn't have it.**
 19 **DAN:** Didn't have AIDS.
 20 **A. AIDS, the HIV virus.**
 21 **DAN:** HIV.
 22 **MS RICHARDS:** Did you even know that Nick had been tested
 23 for HIV?
 24 **A. No, no. We had no idea he'd been tested.**
 25 Q. So he told you that whilst Nick did not have the

13

1 virus, all the other boys on the unit had been tested
 2 and were all HIV positive?
 3 **A. That's what he told us.**
 4 Q. Can you recall anything else about the conversation?
 5 **A. I can recall a lot of things because it was -- I mean,**
 6 **it was completely and utterly outrageous and by**
 7 **then -- what year did you say that was?**
 8 Q. 1985.
 9 **A. '85 and I had been talking about it since '78.**
 10 **I mean, if they -- anyway, that's beside the point.**
 11 **So he said there's going to be heat-treated**
 12 **factor going to be available, I think it was in the**
 13 **January or February. He said, "Do you want us to take**
 14 **Nick into hospital and keep him sort of immobile until**
 15 **then and that seemed a ridiculous idea, meaning that**
 16 **he shouldn't need any treatment, so -- especially if**
 17 **you knew Nick. I said to him, "We want to go away.**
 18 **We want to think about this and we'll be in touch with**
 19 **you tomorrow".**
 20 **So I don't know about other people but for me if**
 21 **there's something on my mind, quite often at night --**
 22 **and I also said to Dan, "Do you think if I'd have**
 23 **known anything about this we would have continued**
 24 **using it", which was complete bullshit, honestly, and**
 25 **so overnight I guess my mind was working and we went**

15

1 **of the same thing that Nick had had -- I can't**
 2 **remember all the details -- for Nick to go on to it.**
 3 **We let Hardisty know and said we were taking**
 4 **Nick away. They refused to give us Nick's medical**
 5 **file. The Royal Free said, "Don't worry". Maybe two**
 6 **weeks later -- I can't remember two or three weeks**
 7 **later, we got a phone call. It was someone, a nurse**
 8 **from Great Ormond Street saying, "Mr and Mrs Hirsch,**
 9 **if you'd like to meet me in the street, I've taken**
 10 **Nicholas' file and I would like to give it to you".**
 11 **We went, "Okay". Our business was near to Great**
 12 **Ormond Street. It was just off Tottenham Court Road.**
 13 **So we went over, we met the person, I don't remember**
 14 **her name, I don't remember what she looked like -- too**
 15 **long ago now even for me or my failing memory -- and**
 16 **we took it straight to the Royal Free.**
 17 **Now, my recall of this is that we took it in and**
 18 **the head nurse at the time, Chris Harrington, and**
 19 **I looked through it quickly.**
 20 Q. There was a particular note that leapt out at you.
 21 **A. There was.**
 22 Q. What was that?
 23 **A. On the day when I had kicked up such a fuss at Great**
 24 **Ormond Street about them -- not allowing them to give**
 25 **him American treatment, right across that note in tram**

14

1 **back the next day and I said, "I've been thinking**
 2 **about it. When they gave you the vials from Elstree,**
 3 **depending on the weight of the person taking it, it**
 4 **changed the quantities maybe every six months. As**
 5 **they got bigger they needed more". So I said to him**
 6 **there was -- and you always had to return all the ends**
 7 **of bottles and things. So I said to him, "If they --**
 8 **do they retain those ends of bottles?" He said,**
 9 **"Yes". So I said, "Well, normally, you're not allowed**
 10 **to mix batches but since we know that Nick doesn't**
 11 **have HIV, if you could put all those ends of bottles**
 12 **together that you say you retained where Nick did have**
 13 **treatment from it, maybe there will be enough there to**
 14 **see him through to heat treatment", and that's what**
 15 **happened. We got them, all the ends, and that's what**
 16 **Nick used and he never did get HIV.**
 17 **At that point we didn't know anything about**
 18 **hepatitis C. It wasn't even non-A non-B.**
 19 **So -- okay, so Dan and I were extremely**
 20 **dissatisfied by that time with what had gone on and**
 21 **since the Royal Free was nearer to us, by then we'd**
 22 **moved from Shepherd's Bush, we went to the Royal Free**
 23 **haemophilia department, we had a discussion there.**
 24 **I think Dr Kernoff, wonderful doctor, unfortunately**
 25 **not alive anymore, and he said they would have enough**

16

1 **lines was written "neurotic mother", and that about**
 2 **summed up the way we were considered by the medical**
 3 **profession -- ugh.**
 4 Q. You subsequently many years later obtained such
 5 records as you can --
 6 **A. Yes.**
 7 Q. -- but you haven't been able to find a copy of that
 8 record?
 9 **A. No, and Chris Harrington says she has no recall of it.**
 10 Q. Just before the transfer to Great Ormond Street --
 11 from Great Ormond Street to the Royal Free, you
 12 referred to Professor Hardisty having sent his own
 13 letter to the Guardian and then you wrote a response
 14 to him.
 15 **A. Well, all the letters there. I remember it, later on**
 16 **when all the inquiry started, I went to the Guardian**
 17 **archives, which were in the East End and, together**
 18 **with someone there was helping me, looked on**
 19 **microfiche and I found my letter and I found Hardisty.**
 20 **The way I remember it is that article was**
 21 **published. Hardisty sent a letter saying, "No, not**
 22 **so. We did not know". I sent a letter under Julia's**
 23 **name and then he responded again but the dates don't**
 24 **quite correlate. I'm not quite sure which way round**
 25 **it was.**

17

1 Q. Don't worry. I am just going to ask you just to look
2 at one passage from Professor Hardisty's letter and
3 then your response to Professor Hardisty, just because
4 it helps illustrate some of the points you are making.
5 282013, please. It is:
6 "Over-heated about blood."
7 So this we can see at the very bottom is
8 a letter from Professor Hardisty, the director of the
9 Haemophilia Centre, Hospitals for Sick Children and
10 the first paragraph of the letter expresses sympathy
11 with Mrs Harrison, that being the pseudonym you had
12 used, and then sets out he must correct some
13 misstatements in the letter to allay possible distress
14 which the letter may have caused, and then the facts
15 set out in the second paragraph are as follows:
16 "AIDS was first described early in 1981. The
17 first case in a haemophiliac was reported to the
18 Centre for Disease Control in the United States later
19 that year. Medical intelligence travels fast and
20 these facts were well known to this, as to all British
21 haemophilia centres at that time."
22 Then it goes on to talk about not until 1984
23 that the precise causative virus had been identified
24 and heat treatment.
25 You responded directly to Professor Hardisty,

19

1 We've got the whole response so I'm only going to ask
2 you just to look at the first paragraph, the second
3 sentence, where you said this:
4 "My only purpose in writing the letter was to
5 stir the complacency of the Government into producing
6 the heat-treated Lister factor by April as per the
7 information they have been handing out to the press."
8 So you were trying to bring your concerns to
9 public and national attention.
10 Do you recall whether you had any further
11 dialogue with Professor Hardisty after you sent him
12 this letter?
13 **A. No, I don't think we did, did we, Dan? I don't**
14 **remember. I mean, I never met him or maybe he passed**
15 **once --**
16 Q. Until you had that meeting with him after the first
17 letter?
18 **A. Yeah, we dealt with Colin Sieff almost exclusively.**
19 Q. Again, just before we move on to Nick's care at the
20 Royal Free you have explained in your statement that
21 after this exchange of correspondence, after the
22 meeting with Professor Hardisty, there was a regular
23 appointment that Nick had on 9 July 1985 at Great
24 Ormond Street and you were told at that appointment
25 that Nick was going to be switched to American

18

1 didn't you?
2 **A. No, I responded in the Guardian to it.**
3 Q. You certainly wrote a letter to Professor Hardisty
4 because you have given us a copy of that.
5 **A. Right.**
6 Q. That's 282014. It is a letter dated 4 February 1985.
7 **SIR BRIAN LANGSTAFF:** Just before we leave -- we just have
8 left the last --
9 **MS RICHARDS:** We can put it back, sir.
10 **SIR BRIAN LANGSTAFF:** The bit in the middle, the sentence
11 written by Professor Hardisty begins:
12 "Although the occurrence in haemophiliacs
13 provided strong evidence that the disease could be
14 transmitted by blood products, it was not until
15 1984 ..."
16 So he must have been talking then about, in his
17 view and it follows from what he was saying earlier,
18 in the views of all the haemophilia centres, there was
19 strong evidence in 1983 and before May 1984 that it
20 was transmitted by blood products.
21 Would that be a proper interpretation of that?
22 **MS RICHARDS:** That certainly seems to be the natural
23 interpretation of his words, sir.
24 **SIR BRIAN LANGSTAFF:** Thank you very much.
25 **MS RICHARDS:** Then we have your response, Della, 282014.

20

1 Factor VIII because haemophilia centres were running
2 out and you describe yourself as being livid and
3 that's the point at which the decision was finally
4 made that you would move to the Royal Free?
5 **A. Mmm. God.**
6 Q. Nick's regular routine haemophilia care transferred to
7 the Royal Free in 1985, 10 July, and he came under the
8 care of Dr Goldman, who you liked?
9 **A. We did.**
10 Q. And Professor Lee with whom you have said in your
11 statement your relationship over the years
12 deteriorated?
13 **A. Yes. She wasn't there at the beginning, Kernoff was**
14 **there.**
15 Q. After Nick had been at the Royal Free for about five
16 years, you and Dan and Nick attended a review with
17 Dr Goldman on 5 June 1990.
18 I'm going to ask for that document to be put up
19 on screen or such notes as there are of it. It is
20 282016. We can see the date there, 5 June 1990,
21 review, and if you could just scroll down a bit,
22 please, Paul, towards the bottom of the entry for that
23 date.
24 **A. I can't read that.**
25 Q. Thanks. So two lines up from the next entry there's

21

- 1 a reference to "discussed anti-HCV with" --
- 2 **A. That's hep C.**
- 3 Q. Yes, "with Mr and Mrs Hirsch and Nicholas" and then
- 4 "review in six months' time".
- 5 It subsequently became apparent to you, and we
- 6 will look at the later documents over the following
- 7 weeks, that blood samples were taken and Nick was
- 8 tested for hepatitis C.
- 9 What, if anything, can you recall about that
- 10 review?
- 11 **A. I don't recall much. We knew that there was what they**
- 12 **call non-A non-B hepatitis virus potentially, possibly**
- 13 **in the blood. The thing was that [redacted] * whose**
- 14 **flat in San Francisco we had gone out originally to**
- 15 **take while he went to India, he'd had hep c and I had**
- 16 **sort of nursed him through it.**
- 17 Q. Was it hep c he had had or hep A?
- 18 **A. No, no, sorry, he had had hep A and that's curable.**
- 19 **So when I think Christine Lee talked about hep c**
- 20 **possibilities or Dr Goldman, whoever it was,**
- 21 **I actually didn't take it very seriously. I thought,**
- 22 **well, if that's the worst he gets, that's dealable**
- 23 **with. But they called it non-A non-B. I didn't**
- 24 **really go into it. It was all already had been so**
- 25 **traumatic the whole thing and the fights and the**

23

- 1 for the virus has now been identified and there's
- 2 a new test available. Then it says this:
- 3 "Nicholas' anti-HCV was positive on
- 4 5 June 1990."
- 5 And then the letter continued by telling you
- 6 that some people who have been exposed to non-A non-B
- 7 HCV in the past may after many years go on to develop
- 8 chronic hepatitis but we cannot determine who will
- 9 progress in this way."
- 10 You were told that although there were some
- 11 trials of treatment for such liver disease no-one was
- 12 using treatment on a regular basis in haemophiliacs at
- 13 the present time, and then there was a reference to
- 14 the limited information about sexual transmission of
- 15 HCV and then it says:
- 16 "We can discuss this with you at your next
- 17 review or sooner if you would like."
- 18 What, if anything, can you recall about
- 19 receiving that letter or the impact on you?
- 20 **A. Well, I mean, it was very distressing but again at**
- 21 **that time I did not know that hepatitis C was such**
- 22 **a serious disease. The only, as I said, experience**
- 23 **I had was with hepatitis A and they'd got better.**
- 24 **I did not -- I didn't take it to be really**
- 25 **serious in that way and, if I recall, Christine Lee**

22

- 1 **difficulties and we didn't have that fight at the Free**
- 2 **but we had other things there.**
- 3 Q. So what you've said in your statement about this
- 4 review on 5 June 1990 is you have very little memory
- 5 of the actual visit, you've seen the notes referred to
- 6 a discussion about HCV, hepatitis C, you have said
- 7 that you had no knowledge what that was at the time
- 8 and it wasn't explained to you, blood examples were
- 9 taken but that was the routine and you don't believe
- 10 that you were informed specifically that there was
- 11 going to be a test of the blood for hepatitis C.
- 12 **A. No, we weren't. Well, I'm sure you'll bring it up.**
- 13 Q. Then on 9 July you received a letter from the Royal
- 14 Free and we're going to have that up on screen,
- 15 please.
- 16 It is 282017, Paul.
- 17 So this is the letter sent to you from Dr Lee:
- 18 "I'm writing to tell you about the new anti-HCV
- 19 test. Many haemophiliacs who have been treated in the
- 20 past with unheated clotting factor concentrates or
- 21 other blood products have been exposed to the non-A
- 22 non-B hepatitis virus, so-called because it is
- 23 unrelated to hepatitis A and unrelated to hepatitis
- 24 B."
- 25 It goes on to explain that an agent responsible

24

- 1 **didn't -- I mean, it didn't seem particularly serious.**
- 2 **It was as the years went on that everybody's attitude**
- 3 **changed and maybe at that time they didn't know; so in**
- 4 **that case I wouldn't say anybody was to blame but all**
- 5 **I know is that after that I think it was six months**
- 6 **before they saw Nick again.**
- 7 Q. If we take it in stages, Della.
- 8 **A. Okay.**
- 9 Q. You subsequently on looking at Nick's records found
- 10 out that between 5 June 1990 when the blood was taken
- 11 for testing and 9 July when the letter was written to
- 12 you as Nick's parents telling you the result, a letter
- 13 had been sent by the Royal Free to your GP on 22 June.
- 14 That's 282022, please, Paul.
- 15 So we can see the date at the top of the page
- 16 and although the text isn't very clear -- we only need
- 17 the last paragraph of this page, Paul, which is
- 18 clear -- so your GP was being told on 22 June this:
- 19 "We discussed the tests for antibody to
- 20 hepatitis C. Mr and Mrs Hirsch and Nicholas are aware
- 21 that the anti-HCV test has been performed."
- 22 Just pausing there, you don't recall any such
- 23 discussions having taken place, do you?
- 24 **A. No, but that I wouldn't, you know -- I don't recall**
- 25 **it.**

- 1 Q. Then it says this:
 2 "The result was positive but they have not yet
 3 been told the result. Since this is the virus thought
 4 to cause non-A non-B hepatitis and since most
 5 haemophiliacs treated with Factor VIII concentrate
 6 before screening and heat treatment have been infected
 7 with non-A non-B hepatitis, the result was not
 8 unexpected."
 9 **A. Right. So in terms of this, I didn't recall it but**
 10 **when Mike and Sarah were going through all the papers**
 11 **and they came up with this, I took it to -- we're**
 12 **still with the same centre, health, GP unit, but the**
 13 **doctor who I had at the time who retired recently who**
 14 **knew everything about everything all the way through,**
 15 **when he retired he asked me to come and see him and he**
 16 **said -- I don't think I said this, "If there is**
 17 **anything I can ever do to confirm all we've discussed,**
 18 **you only have to call on me".**
 19 The thing is that I took it to the doctor we see
 20 now in the practice and she was horrified because it's
 21 illegal to basically indicate we haven't told the
 22 parents, you shouldn't either, which is what it's
 23 basically saying and she said she was going to give
 24 the letter to the practice lawyer. I've not heard
 25 more about it but it was shocking.

- 1 this contains the sentence:
 2 "I note he has chronic hepatitis C genotype 1
 3 and he was probably infected in 1980 with first
 4 clotting factor concentrates."
 5 So that's the information you've subsequently
 6 been given, that Nick's infection probably derived
 7 from the first factor concentrates given in late 1980?
 8 **A. Yes.**
 9 Q. Thanks, Paul. You can take that down.
 10 Now, through the 1990s, you observed that Nick
 11 was getting increasingly unwell, always tired, didn't
 12 look well I think is how you've described it in your
 13 statement, and there was a suggestion at one point by
 14 your GP I think of glandular fever.
 15 You saw Dr Goldman in November 1990 and a query
 16 was raised whether it could be attributed to
 17 depression and the question you've raised in your
 18 statement is the obvious cause must be the
 19 hepatitis C?
 20 **A. (The witness nodded)**
 21 Q. In 1992, Nick embarked upon his first course of
 22 treatment for the HCV, a course of interferon. Was
 23 that as part of a trial? What can you recall about
 24 that process of treatment and Nick's response to it?
 25 **A. It was absolutely ghastly, terrible.**

- 1 Q. You've explained in your statement you cannot
 2 understand why the first people who were informed were
 3 not you as Nick's parents and instead that letter
 4 comes some weeks later from Dr Lee. This letter goes
 5 to your GP without your knowledge.
 6 **A. Quite.**
 7 Q. The passage that we read concludes with saying:
 8 "Since most haemophiliacs have been infected
 9 with non-A non-B hepatitis, the result was not
 10 unexpected."
 11 Was that ever explained to you, that this, in
 12 fact, was something that the medical profession
 13 expected by this time to find out?
 14 **A. I can't say -- what I know is that Dan and I, and**
 15 **particularly me, I never left anything to chance.**
 16 **I never stopped asking questions, but in this case**
 17 **I had no idea from what I remember that it was**
 18 **a serious thing. I thought -- I didn't think that it**
 19 **was -- it was certainly not explained that it was**
 20 **serious at all.**
 21 Q. You've drawn attention in your statement and in the
 22 documents you've produced to some subsequent notes.
 23 If we could have up on screen please, Paul,
 24 282018 and it's the first entry, please.
 25 The details of the review we can leave aside but

- 1 **Was that when he was doing his GCSEs? I can't**
 2 **remember.**
 3 Q. 1992, Della. He would have been about 16?
 4 **A. I think he was doing his O levels then, sort of, and**
 5 **oh it was just terrible. It was ... it made him ill**
 6 **in every way that he wasn't ill already. It made him**
 7 **sick -- ugh. It was ghastly. I don't want to talk**
 8 **about it. It was --**
 9 **DAN:** Is this not the one where he was clear for a while
 10 and then fell ill --
 11 **MS RICHARDS:** I think that was later.
 12 **A. I think was the next -- I think he had it two or three**
 13 **times, he had -- three times.**
 14 Q. If we just stick with 1992, Della, and I can take it
 15 from your statement so you don't need to talk about it
 16 through the detail. You described it as being
 17 extremely toxic and unpleasant for him, a difficult
 18 year for him, debilitating as if he had the flu for
 19 12 months, and it didn't clear the virus and his view
 20 was he didn't want to go through anything like that
 21 again.
 22 **A. That's right.**
 23 Q. A few years later, 1996-1997, he was offered a second
 24 course of treatment, combination therapy, of
 25 interferon alfa and ribavirin but he didn't want to go

- 1 through it at that stage?
- 2 **A. I can't remember. I mean --**
- 3 Q. That's what you put in your statement.
- 4 **A. I probably had documents in front of me that said**
- 5 **that, yes.**
- 6 Q. It was around this time you've described in your
- 7 statement that you were becoming increasingly
- 8 concerned about what you described as the purity of
- 9 the treatment and whether there might be other
- 10 infections or other viruses to which Nick and indeed
- 11 others might be being exposed and you repeatedly
- 12 requested for him to be switched from the factor
- 13 product he was using to recombinant factor because you
- 14 thought that was much safer.
- 15 Now we will go into the detail of some of the
- 16 documents in a few minutes, but what was the general
- 17 concern that you had at that time about the way in
- 18 which recombinant was or wasn't being made available?
- 19 **A. You'll have to remind me. I'm just finding this too**
- 20 **much.**
- 21 Q. Don't worry, Della, I can imagine and if I you want
- 22 a break at any time ...
- 23 **A. No, no, just ...**
- 24 Q. What you have said in your statement is:
- 25 "It became obvious that there were two different

- 1 **I begged him in this letter to let him have it.**
- 2 **I mean, he was so frightened of giving himself an**
- 3 **injection and he refused, and in those few months he**
- 4 **got exposed to --**
- 5 Q. VCJD?
- 6 **A. Yes, CJD.**
- 7 Q. Della, I am going to come on and ask you now about the
- 8 issues relating to the risk of exposure from vCJD.
- 9 I can take it reasonably quickly, if that would help.
- 10 **A. No, no, it's all right. I just feel so passionately,**
- 11 **not only because it was my son. There were tonnes of**
- 12 **people that this was happening to, so there were**
- 13 **families all over who were suffering like we were and**
- 14 **like Nick was.**
- 15 Q. So you had some discussions with the Royal Free
- 16 because they were going to be sending out a letter.
- 17 You'd read in the news coverage about the risks of
- 18 vCJD and you were worried about the impact upon Nick
- 19 of receiving a letter telling him about it. But
- 20 you've recalled in your statement that in early
- 21 December 1997 Nick went to his usual clinic
- 22 appointment, was called into an interview room and
- 23 told the news very bluntly by one of the doctors.
- 24 **A. Can I say more on this?**
- 25 Q. Of course you can, yes.

- 1 classes of haemophiliacs developing, those who were
- 2 already infected with HCV who were kept on their
- 3 existing treatment and newly diagnosed who might be
- 4 given recombinant."
- 5 **A. Yes, that was true, that was true, and I remember**
- 6 **getting sort of phone calls and emails from people**
- 7 **saying do you want -- how old was Nick then?**
- 8 Q. So we're talking I think about 1996?
- 9 **A. 18. Yes, that was then that I got messages saying**
- 10 **from people who were on the -- saying they could spare**
- 11 **an injection. I mean, they were trying to help, they**
- 12 **were trying to share safe treatment in the UK, in**
- 13 **a civilised country, they were offering us -- ugh,**
- 14 **yeah.**
- 15 Q. Amongst other things you wrote to the Secretary of
- 16 State for Health?
- 17 **A. Alan Milburn, yeah, I certainly did.**
- 18 Q. And as you described you were contacted by
- 19 haemophiliacs who were receiving recombinant and
- 20 offering to share it.
- 21 Then a particular --
- 22 **A. Can I stop you because I want to say specifically,**
- 23 **Alan Milburn, when the safe treatment was introduced,**
- 24 **said it had to be -- you had to be 18 -- under 18 and**
- 25 **Nick was about two months past his 18th birthday and**

- 1 **A. Nicholas, as you will hear later, was a musician and**
- 2 **he often went on tour. He was so frightened of going**
- 3 **to the Royal Free, they pulled him out sometimes he'd**
- 4 **be going off and he'd go in for treatment, at that**
- 5 **time it wasn't home delivered. They'd pull him into**
- 6 **a side office and some totally disinterested doctor**
- 7 **would say, "Oh, by the way, you've been exposed to**
- 8 **this", or, "Oh, by the way, that batch you had ..." He**
- 9 **was frightened to go there anymore, and every time --**
- 10 **being us, I wrote to them, I complained and then Dan**
- 11 **and I would find ourselves sitting in a room with some**
- 12 **doctor going, "I'm so sorry that I distressed**
- 13 **Nicholas". It was so terrible what they did, so**
- 14 **terrible, particularly to the young ones and the**
- 15 **teenagers, well, to everyone. It was so without care**
- 16 **and thought that these were real human beings with**
- 17 **lives and feelings. It was disgusting and I mean I'm**
- 18 **not just saying it here, I expressed it forcefully in**
- 19 **letter and in person many times.**
- 20 Q. There was a particular letter that Nick did receive
- 21 and we're going to put it up on screen, Della, if
- 22 that's all right. It's exhibited to your statement.
- 23 It's 282027. This is a letter, 2 December 1997, from
- 24 Professor Lee to Nick and it says this:
- 25 "It's our practice to keep you informed of

1 issues that relate to haemophilia care. You may have
2 heard or read about CJD and the concerns that the
3 agent causing this may be transmitted by blood
4 transfusion and blood products. At the present time
5 there is no evidence for this. The basis for
6 scientific speculation is that the new form of CJD
7 infects the lymphocytes, a type of white cells found
8 in the blood. Blood products used for the treatment
9 of inherited bleeding disorders do not contain white
10 cells."

11 But then reference is made to:

12 "As a precautionary measure, there have been two
13 recent recalls of BPL Factor VIII batches because it
14 was found a donor had not met the current health
15 requirements for CJD", and then Nick was informed:

16 "According to our records you received some of
17 the 8Y batch in 1995."

18 I don't think I need to take you to it but we've
19 got -- in fact, I will ask you to look at one
20 document, Della. It is 282028.

21 **A. Is that what -- oh.**

22 Q. You will see that's 31 October 1997, probably,
23 confirming that Nick had received that particular
24 batch.

25 The next page please of that, Paul.

1 Q. Now, you renewed your efforts both on behalf of Nick
2 and more generally to lobby for recombinant to be made
3 available more widely?

4 **A. I did.**

5 Q. I don't propose to take you through all the documents
6 because you describe them in detail in your statement
7 and provided them to the Inquiry and they will be
8 publicly available, but you and your MP (who was your
9 sister who was MP by that time) and others were
10 lobbying for recombinant to be made available more
11 generally to haemophiliacs who had been infected with
12 HCV or HIV; is that right?

13 **A. I think -- yes, I'm sure I did.**

14 Q. You wrote to Dr Ludlam at one point in his capacity as
15 chair of the UKHCDO about it?

16 **A. I wrote to everybody.**

17 Q. You wrote to the Government, you wrote to your local
18 health authorities?

19 **A. Oh.**

20 Q. You investigated the possibility of legal action,
21 judicial review --

22 **A. I did.**

23 Q. -- to try and get Nick given with recombinant on an
24 individual patient basis if you couldn't change the
25 national policy but, in fact, it was not until

1 We'll see here there's a fax from BPL,
2 30 November 1997, to the Royal Free and if we just
3 look at the first paragraph please, last sentence,
4 having explained the recall, it says this:

5 "The advice from the Ethical Committee is that
6 the recipients/patients should not be informed that
7 product that they have received has been recalled for
8 this reason."

9 **A. Yeah, right.**

10 Q. Professor Lee did, in fact, inform Nick. We have seen
11 the letter.

12 What can you recall about Nick's response or his
13 reaction?

14 **A. What year was that?**

15 Q. So it's 1997. I think that's right. You have
16 described it in your statement, Della?

17 **A. Yes, I mean.**

18 Q. He was devastated you said.

19 **A. I mean he was devastated. What else could they do?**

20 Q. What you have said in your statement Della is:

21 "He phoned Dan and I at work and I remember him
22 saying, 'You will never believe what they have given
23 me now'", and you went home and when he turned up he
24 was very angry and kicking furniture around the house.

25 **A. Yes, this is true.**

1 August 2003 that Nick moved on to recombinant.

2 **A. Yes.**

3 Q. You've explained in your statement that Nick was so
4 fearful he didn't want to use the products and so he'd
5 avoid injecting himself as much as he could and even
6 though that was having -- causing damage to his
7 joints.

8 **A. Yes, I think that by that time he was living with his
9 partner, yes, and I'm sure -- all of that and more is
10 true.**

11 Q. There's a document that Nick wrote at the time in
12 2001, Nick's perspective on being refused recombinant,
13 and I'm going to put that up on screen. Again, it's
14 one of the documents you have exhibited to your
15 statement.

16 It is 282040 please, Paul.

17 I think you are happy that with this particular
18 document that you've seen I will read Nick's words?

19 **A. Please.**

20 Q. "I will start" -- so it starts, Nick's perspective on
21 being refused recombinant and what this means for him,
22 how does he view plasma derived Factor VIII products,
23 and he was writing this in September 2001:

24 "I will start with my personal experience of
25 being aware that the treatment I receive is something

1 to be equally fearful of as the disease. When I was
 2 13 I was made aware of what had gone on in the early
 3 '80s regarding the HIV infection of a generation of
 4 haemophiliacs. Through what I could only call
 5 educated luck I managed not to be affected. However,
 6 on being mildly taunted about my haemophilia on day at
 7 school I broke down crying. It was a realisation of
 8 how vulnerable I was. Until then I had a disease that
 9 the outside world gave me sympathy for but I could
 10 handle it myself now. I was seeing why adults gave me
 11 respect and sympathy. Not long after I was diagnosed
 12 with hepatitis C, well, I was kind of sort of told
 13 something was up. Clarity is not rife in the Health
 14 Service. At the time I felt grateful it could have
 15 been worse but now that I'm older my opinion is that
 16 every profession is a business even the ones that come
 17 at you differently, just as financial decisions made
 18 in the '80s by governments of the world killed many,
 19 many people, what has changed."

20 Then Nick talks about being told about vCJD,
 21 Della, and he says this:

22 "A couple of years ago I was pulled into an
 23 office in my hospital as I was on my way to just pick
 24 up my supplies and told that one blood donor had
 25 contributed to a batch along with hundreds of other

1 **A. Was that at the Free or had he left the Free?**
 2 Q. I think that was at the Free, Della.
 3 **DAN:** That was the Free.
 4 **A. It was all -- how old would he have been then?**
 5 **DAN:** His age doesn't matter.
 6 **A. It helps me place it in my head.**
 7 **MS RICHARDS:** Mid-20s I think Della 2002.
 8 **DAN:** 25 then, 26.
 9 **A. He would have been with Olga by then. By then he and**
 10 **[redacted] had gone to do music at Brunel and then he**
 11 **wasn't living at home. It was a different -- I don't**
 12 **remember.**
 13 **DAN:** That's off the point.
 14 **A. Sorry, I'm just trying to remember.**
 15 **MS RICHARDS:** I can prompt you from your statement because
 16 you told us about it in your witness statement, Della.
 17 So this was his second course of treatment. It was
 18 again very gruelling. It had side effects. He had to
 19 inject himself twice a week in the stomach to keep his
 20 immune system strong.
 21 **A. Oh, right, right.**
 22 Q. After three months he'd cleared the virus it seemed
 23 but then he was tested again and, in fact, the virus
 24 had returned or he hadn't cleared it?
 25 **A. Right.**

1 donors that I had used. This donor had subsequently
 2 died of CJD. To all intents and purposes, end of
 3 story, good day. At that moment I felt like history
 4 was repeating itself. Later I was reliably informed
 5 that this bombshell was nothing more than the health
 6 service legally covering its own arse due to what had
 7 and was happening to them from the fallout of the HIV
 8 scandal. So where does this leave me? I'm treated
 9 with blood, a risky thing at the best of times. I'm
 10 surrounded by doctors who have the weight of the world
 11 on them, only a fraction of which is concern for my
 12 health, the health authority that wants a fresh start
 13 with all kids born after 1985, a Government that has
 14 infinite pillars and posts. I want this treatment.
 15 It is owed to me. It won't give me back a life of
 16 ignorant bliss but it will give me a chance at it."

17 That was what Nick wrote in 2001. Would you
 18 like us to take a break, Della?

19 **A. No, it's okay.**

20 Q. Are you sure? Okay.

21 The following year Nick started on a second
 22 course of treatment so we're talking now, Della, about
 23 2002 and it was PEGylated interferon and ribavirin.

24 Can you recall anything about how that second
 25 course in 2002 --

1 Q. That you have said in your statement had quite
 2 a devastating impact upon Nick's mental well-being.
 3 **A. Yes, yes, because we were so hopeful and ... yeah.**
 4 Q. So there came a point in 2009 when Nick's care
 5 transferred to the Royal London Hospital and he was
 6 under the care of Professor Foster.
 7 **A. Right.**
 8 Q. So can you recall, first of all, just generally by
 9 about 2009 can you recall how Nick was physically or
 10 mentally?
 11 **A. Well, I recall very clearly he wasn't going to go back**
 12 **to the Free. He was so frightened, he was so**
 13 **exhausted by everything that had gone on there and**
 14 **I had heard Professor Foster speak at a lecture and he**
 15 **seemed to have slightly different take, a slightly**
 16 **different view, and I think I went up and chatted to**
 17 **him afterwards and Nick wouldn't go back to the Free.**
 18 **He just couldn't. He was ... yeah.**
 19 So Dan and I and Nick went to see, at the time
 20 he was working at Queen Mary's, we went to see
 21 Professor Foster and what I do remember of that first
 22 meeting is he was extremely kind and attentive to what
 23 Nick had to say, which often didn't happen, and he
 24 really felt to take it all in and to say, "I think we
 25 can do something here". I think at that point there

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1 was yet another possible trial of something or other
2 and he said, "I don't think that's good, we've got to
3 get Nick strong", or something like -- and Nick came
4 away and he said, "Yes, I think -- you know, I'm not
5 going back to the Free and I would like to transfer to
6 his care", so I mean, he was an adult by then so,
7 obviously, we asked for him to do so and he
8 transferred his care to Graham Foster at the Royal
9 London.

10 But just prior to him doing that, he had had
11 a fibroscan at the Free and that -- I'm saying that
12 now because that figures later on.

13 Q. So Nick was looked after, came under the care of the
14 Royal London Hospital from about the autumn of 2009
15 and there came a point, I don't think we've got the
16 precise date but perhaps some time in 2011, when Nick
17 was put on another trial of treatment for HCV.
18 I think this was, by this time, it was a triple
19 therapy, interferon, ribavirin and telaprevir.

20 A. Okay, so over the earlier period Professor Foster
21 had -- there's what we always thought was a state of
22 the art scan you could have called, a fibroscan, which
23 told you the state of the liver and, as I say, this is
24 relevant, if I may --

25 Q. Yes, of course.

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1 that time -- but this thing of not believing in
2 fibroscans and not giving Nick fibroscans came to be
3 very important, although at that time that wasn't what
4 we were thinking about and he wouldn't -- he didn't
5 want Nick to go on any unnecessary trials, et cetera,
6 et cetera.

7 Q. But a point came when Nick did start this third
8 treatment regime.

9 A. Yes, okay. Right.

10 Q. What can you recall about the effects of that?

11 A. It was unbelievably terrible. It had been -- I want
12 to make a point: this may have been a trial but it had
13 been approved by NICE before Nicholas started on it.
14 That's what -- well, everybody knows what they did,
15 which was reassuring.

16 It was beyond terrible. I mean, he was so ill.
17 He developed these most terrible sores all over his
18 legs which his partner looked after. He was so
19 frightened. They would send him up to the --
20 Professor Foster would send him up to the dermatology
21 department. He was in pain, he was sick, and we would
22 sit with him for hours until they would see him.

23 On one occasion a doctor was looking at these
24 sores and she said, "I think I'll take a biopsy", and
25 she went to get the knife and I said, "You can't give

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1 A. -- that just before Nick left the Free he had one and
2 it wasn't good. I mean, he didn't have cirrhosis but
3 it wasn't good really as what we understood from
4 Professor Foster or I can't even remember which of
5 them.

6 Okay, so when we went to him, he was very
7 reassuring and very positive and we all liked him and
8 we all had a lot of confidence in him and he said that
9 there weren't any new treatments at that moment but
10 they would be -- generally he would be looking after
11 his health and doing his best and he wouldn't let Nick
12 start a treatment that he didn't absolutely feel would
13 be the answer, so I think at that point that's where
14 we were with him.

15 Q. One of the concerns you have, however, about the
16 treatment that Nick received during this period was
17 that Professor Foster did not undertake or arrange for
18 any further fibroscans; is that right?

19 A. No, he absolutely did not believe in them. He didn't
20 believe in them. I had written to my friend in
21 America, the same one who had alerted me, and she had
22 a lot of sort of people she knew and influence there
23 and she said that there was a professor there who she
24 knew who had worked with Professor Foster and thought
25 it would be a good place for Nick. So, you know, at

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1 him a biopsy. He's a haemophiliac." She looked at
2 his notes and she says, "It doesn't say he's
3 a haemophiliac here". I mean, it was unbelievably
4 terrible.

5 Q. Just in relation to the sores and lesions on Nick's
6 body and legs, you've shared some photographs of that
7 with the Inquiry but we are not going to share
8 those --

9 A. No, don't, please.

10 Q. -- or put them up because you don't want those to be
11 seen.

12 A. No.

13 Q. But you wanted the Inquiry to see them.

14 A. Yes, we did.

15 Q. Throughout this period when Nick was on this treatment
16 and in very considerable pain, discomfort, the sores
17 you have described, is it right, you then pressed
18 Professor Foster to undertake a fibroscan; is that
19 your recollection?

20 A. I pressed him, we both pressed him. I said, "What
21 about a transplant". I said, "I'll give half my
22 liver", or something. "No, no, no", he said, "He's
23 nowhere near that point yet".

24 Q. But he'd also -- you said in your statement you
25 thought that Professor Foster had made a comment at

1 a conference about Nick's condition.

2 **A. Oh, yes, yes.**

3 Q. What was that?

4 **A. He'd gone away to Japan or somewhere out there to**

5 **a big liver conference and when he came back the next**

6 **time we saw him, he said to us blithely, "Oh, yes**

7 **I talked about Nicholas. I said he was having the**

8 **worst reaction of anybody I had ever seen on this**

9 **treatment", like he was a specimen and Nicholas**

10 **started to get, I felt, really frightened, scared. We**

11 **both felt it.**

12 Q. There's an email that Nick wrote at the time that

13 Dan's looked at, you don't want to look at, but you

14 want me to say a little bit about, I think, just so

15 that Nick's perspective is heard.

16 I don't need to, Della, if you would like me not

17 to?

18 **A. No, no, if it helps, if it shows.**

19 Q. I think you wanted Nick's voice to be heard. He

20 talked in January 2012 in an email to --

21 **SIR BRIAN LANGSTAFF:** Just a moment. Let's just stop the

22 broadcast for a moment. *(Pause)*

23 Are you all right?

24 **A. Yes.**

25 **No, no, go -- I mean, anything, anything.**

1 **and were staying. For three bloody hours we tried to**

2 **get an ambulance to take Nick from the house to the**

3 **Royal London. They said everything under the world**

4 **and in the end we paid for a terrible private**

5 **ambulance to take him. Dan went in the ambulance.**

6 **Olga, the baby, me, and the parents followed.**

7 **We got there. They put him in the special care**

8 **unit downstairs for very sick people.**

9 **Professor Foster's locum was flapping around and**

10 **ringing him and saying this, that and the other. They**

11 **gave him morphine for the pain and they said to us,**

12 **"You go and have a cup of coffee. We're getting him**

13 **ready. We're taking him up into intensive care. Have**

14 **a cup of coffee. He'll be up there ready by the time**

15 **you've had your coffee".**

16 **We were probably not more than 15 or 20 minutes**

17 **and we all went up there. They'd locked us out of**

18 **intensive care. They locked us out. Meanwhile my**

19 **sister, who's an MP, had got permission to leave**

20 **Parliament and come. We slept on the bloody floor**

21 **outside the doors of intensive care that night and in**

22 **the morning this complete shit of a nurse comes out**

23 **and says to me, "Nicholas was so distressed last night**

24 **that we've had to sedate him".**

25 **I said, "How could you bloody well sedate him**

1 **MS RICHARDS:** He talked in it about not feeling well,

2 about being sore, about the pains in his legs, about

3 the lack of energy and large periods of the day when

4 he couldn't do anything and feeling struggling and

5 scared.

6 **SIR BRIAN LANGSTAFF:** Can we please have the camera on

7 Ms Richards. *(Pause)*

8 **MS RICHARDS:** A few weeks after that, Della, as you set

9 out in your statement, Nick was admitted to hospital

10 mid-March 2012 into the Intensive Care Unit.

11 **A. May I speak on this?**

12 Q. Of course you can, Della. This is your evidence.

13 **A. Very sadly, three weeks, four weeks before then, my**

14 **best friend in America died. Dan and I flew out there**

15 **to go to the memorial.**

16 **When we came back, Nick had worsened and but he**

17 **would come up to our flat, he and his partner lived**

18 **near us, and he would come round and he would lay on**

19 **our settee. We live high up with a wonderful view and**

20 **the sun would shine in and he would lay there and we**

21 **would talk for hours.**

22 **Then one day we got this call from his partner**

23 **to say Nick was really bad. We rushed round there.**

24 **By this time they had had a baby ten months before**

25 **and, luckily, Olga's parents were over from Ireland**

1 **when his parents and everyone he loved is laying on**

2 **the floor outside". We never saw him alive again. We**

3 **never saw him. We couldn't comfort him. We couldn't**

4 **talk -- that evil shit. I reported him and they sent**

5 **someone over. Nothing was ever done. The ambulance**

6 **never apologised. I mean, it was so terrible and only**

7 **when Lynne turned up, my sister, they let us -- they**

8 **found us a room because she was an MP and they were**

9 **more concerned, they found us a room inside so we**

10 **could at least comfortably all night.**

11 **And I know this same sadistic bastard was**

12 **really, really cruel to Olga as well. I'm telling**

13 **you ... just one long, long history of deceit and**

14 **unkindness. What for? For money. That's what it was**

15 **all about. Like I said, in my earlier speech, it was**

16 **only about money in the end. Sorry.**

17 Q. Della, there's no need to apologise. This is your

18 evidence and your opportunity to say what you need to.

19 **A. That's it.**

20 Q. Nick died on 18 March 2012. He died of multiple organ

21 failure. He had sepsis associated with his

22 hepatitis C and he was 35 years old.

23 You have put it this way in your statement,

24 Della:

25 "Nick died on 18 March and the medical system

1 had screwed us from beginning to the end."
 2 That's the point you wanted to make your
 3 statement.
 4 Della, I've only a few more questions.
 5 **A. Yes, sure.**
 6 Q. We can take a break, if you would like?
 7 **A. No, no, go ahead.**
 8 Q. One of the particular concerns that you have had since
 9 Nick's death is in relation to the combination of
 10 drugs.
 11 **SIR BRIAN LANGSTAFF:** Just take a moment. *(Pause)*
 12 **MS RICHARDS:** I don't think there's any more documents
 13 I need to ask you to look at, Della, anyway.
 14 **A. Good.**
 15 Q. One of the concerns you have had was about the
 16 combination of drugs and the one particular drug, the
 17 telaprevir?
 18 **A. Of course, yes.**
 19 Q. And after Nick's death you did some brief research of
 20 your own and what did you understand from what you
 21 found?
 22 **A. Okay, I only heard yesterday that Nick's twin also did**
 23 **some brief research and I mean, I didn't, I wasn't on**
 24 **the net for more than five minutes when I found there**
 25 **had been all sorts of deaths from this trial of**

1 **A. Yes, that's what they said. They said, "Oh you want**
 2 **charity", and I said, "What? Are you crazy?" I said,**
 3 **"How dare you say that to me".**
 4 Listen, Dan and I ran a successful business for
 5 many years. I have never encountered -- organised
 6 several of the Skipton and the other one, whatever
 7 they were called, they were just terrible. They
 8 didn't know what they could do. They didn't -- their
 9 website was appalling. I wrote numerous letters
 10 showing how it could be organised better. They
 11 described it as charity. They were staffed by retired
 12 members of the National Health Service whod probably
 13 been cognisant of what was going on anyway. They were
 14 I think over a number of years they got themselves
 15 together a bit but if I can add to this, when it all
 16 transferred to the so-called national health business
 17 unit, which now exists -- may I add something that's
 18 not in my statement?
 19 Q. Yes, of course.
 20 **A. For many, many years after Nick died, I went together**
 21 **with my friend, Lynn Kelly, who is head of Haemophilia**
 22 **Wales. I met Lynn at a meeting of the Department of**
 23 **Health. We're both on a committee. They had asked**
 24 **her to give an exposition on fibroscan which the Welsh**
 25 **people, the haemophiliacs, had managed to buy but they**

1 **telaprevir and NICE had approved it.**
 2 What were they thinking? It had happened before
 3 it approved, all over the world. So what was that
 4 about? You know, we have to wait for NICE, we have to
 5 wait for NICE. It didn't take me five minutes and it
 6 didn't take [redacted] five minutes to find all these
 7 examples. So I just ... well, I just wanted to kill
 8 him really but it was done, you know. It was done.
 9 They lied, they cheated him, hundreds of others
 10 and now his daughter doesn't have a Dad, we don't have
 11 a son, Olga doesn't have a partner. He was -- well,
 12 I've got to read you something in a minute. Yeah, we
 13 were lied and, ugh, it was disgusting. I mean what
 14 was the point of taking an oath as a doctor to protect
 15 and -- the Hippocratic oath? Just a load of bullshit.
 16 And they were cruel to us, cruel, anyway.
 17 Q. One last topic, Della, which is just -- and a brief
 18 one because you have addressed it in your statement
 19 but I think there was a little more you wanted to add.
 20 You made contact with the Skipton and Caxton funds
 21 after Nick's death on Olga's behalf and you have
 22 described in your statement some of the dealings you
 23 had, but one of the particular concerns you have had
 24 was what you were asking for for Nick's partner and
 25 daughter was being regarded as charity; is that right?

1 didn't have enough money for a technician to work it,
 2 and they had asked Lynn to come and give a talk on
 3 that subject.
 4 It was so clear, so precise, so short and the
 5 minute she stopped, the woman who in the Department of
 6 Health was chairing the meeting -- somebody
 7 I personally hold to blame for some of this
 8 disaster -- didn't thank her, didn't say anything, and
 9 all the haemophilia heads from all the units who were
 10 there just started arguing about funding. And
 11 I thought to myself, "Fuck this, who wants to be on
 12 here", and I resigned.
 13 But I found out who Lynn was and Lynn and I have
 14 become really good friends still and she's done
 15 fantastic work my sister, Lynne Featherstone, who is
 16 unwell today and not here and who is now in the House
 17 of Lords and has done brilliant work to further this
 18 and ... it's just, yes, it's just unbelievable.
 19 That's it.
 20 Q. Della.
 21 **A. I'm done.**
 22 Q. It's all right. So am I. I've been asking you about
 23 Nick's illness and treatment but you wanted to say
 24 something about Nick himself.
 25 **A. I do, I do. Hang on, guys. This is really important**

1 for Dan and I and [redacted], his twin, and Olga his
2 partner.
3 Nick and his twin brother [redacted] showed an
4 early interest in music. They wrote their first song
5 entitled hearts on fire at the age of 8. God knows
6 what that was about, and when he was 12 he had his
7 first guitar lesson. Arrogant little sod that he was
8 the following week he booked a recording studio.
9 He handled his haemophilia well despite the
10 periodic body blows he received courtesy of the poison
11 pumped into his veins as a child hep c, close brushes
12 with HIV and CJD exposure.
13 He was good at sports but truth to tell not so
14 good at sportsmanship. He liked to win too much and
15 yes, he did go on to become a fine blues and rock
16 guitarist gigging all round the UK, Europe and
17 America. He and his brother simultaneously ran
18 a rehearsal and recording studio at the Chocolate
19 Factory in Wood Green.
20 Nick and his partner had a baby girl in 2011 and
21 when she was a couple of months old he started taking
22 her out to the various venues in which he played,
23 plopping her down on the bar and introducing her to
24 one and all as the fruit of his loins. The following
25 year, just shy of his 36th birthday, hep c finally did

1 for him. He was funny, irreverent, talented, loving,
2 maddening and wonderful son, brother, partner and
3 father too, if only for ten months. We miss the hell
4 out of him.
5 Q. Della, you know that in relation to some of the points
6 made in your statement that responses have been
7 obtained by some of the doctors involved?
8 A. I do.
9 Q. You have been able to look at some of them but not all
10 of them and I think you know they will in due course
11 be published by the Inquiry but so too will any
12 response you want to make once you have been able to
13 bring yourself to look at them.
14 A. Okay.
15 MS RICHARDS: I have no further questions for Della.
16 A. Thank you, everyone.
17 SIR BRIAN LANGSTAFF: Thank you, Della. As you say,
18 you're done. Thank you very much.
19 A. Thank you.
20 SIR BRIAN LANGSTAFF: We will take a break until
21 12 o'clock.
22 MS RICHARDS: Yes, sir.
23 SIR BRIAN LANGSTAFF: 12 o'clock.
24 (11.22 am)
25

<p>DAN: [9] 6/6 9/20 12/19 12/21 28/9 39/3 39/5 39/8 39/13 MS RICHARDS: [15] 1/5 6/9 9/23 12/22 18/9 18/22 18/25 28/11 39/7 39/15 46/1 46/8 49/12 54/15 54/22 SIR BRIAN LANGSTAFF: [11] 1/3 1/6 18/7 18/10 18/24 45/21 46/6 49/11 54/17 54/20 54/23</p> <hr/> <p>'76 [1] 3/7 '78 [1] 13/9 '80s [2] 37/3 37/18 '85 [1] 13/9 'You [1] 34/22</p> <hr/> <p>... [6] 28/5 40/3 40/18 48/13 50/7 52/18</p> <hr/> <p>1 10 [1] 20/7 10 November 1980 [1] 9/10 10.00 [1] 1/2 11.22 [1] 54/24 12 [1] 53/6 12 months [1] 28/19 12 o'clock [2] 54/21 54/23 13 [1] 37/2 15 [1] 47/16 16 [1] 28/3 17 [2] 4/12 5/6 18 [3] 30/9 30/24 30/24 18 March [1] 48/25 18 March 2012 [1] 48/20 18th [1] 30/25 1976 [1] 1/15 1978 -- so [1] 4/5 1980 [8] 6/22 8/1 8/8 8/24 8/25 9/10 27/3 27/7 1981 [1] 17/16 1983 [1] 18/19 1984 [3] 17/22 18/15 18/19 1985 [8] 9/24 9/25 11/24 13/8 18/6 19/23 20/7 38/13 1990 [6] 20/17 20/20 22/4 23/4 24/10 27/15 1990s [1] 27/10</p>	<p>1992 [3] 27/21 28/3 28/14 1995 [1] 33/17 1996 [1] 30/8 1996-1997 [1] 28/23 1997 [6] 28/23 31/21 32/23 33/22 34/2 34/15</p> <hr/> <p>2 2 December 1997 [1] 32/23 20 [1] 47/16 2001 [3] 36/12 36/23 38/17 2002 [3] 38/23 38/25 39/7 2003 [1] 36/1 2009 [3] 40/4 40/9 41/14 2011 [2] 41/16 53/20 2012 [3] 45/20 46/10 48/20 2019 [1] 1/1 20s [1] 39/7 21 January 1985 [1] 9/25 22 June [2] 24/13 24/18 23 January 1985 [1] 11/24 25 [1] 39/8 26 [1] 39/8 280 [1] 9/5 282006 [1] 8/19 282010 [1] 10/3 282012 [1] 11/4 282013 [1] 17/5 282014 [2] 18/6 18/25 282016 [1] 20/20 282017 [1] 22/16 282018 [1] 26/24 282022 [1] 24/14 282027 [1] 32/23 282028 [1] 33/20 282040 [1] 36/16</p> <hr/> <p>3 3 November 1980 [2] 8/24 8/25 30 November [1] 34/2 31 October 1997 [1] 33/22 35 years [1] 48/22 36th [1] 53/25</p> <hr/> <p>4 4 February [1] 18/6</p> <hr/> <p>5 5 June 1990 [5] 20/17 20/20 22/4 23/4 24/10</p>	<p>8 8Y [1] 33/17</p> <hr/> <p>9 9 July [2] 22/13 24/11 9 July 1985 [1] 19/23 9 May 2019 [1] 1/1</p> <hr/> <p>A able [4] 9/7 16/7 54/9 54/12 about [80] absolutely [13] 3/4 3/11 6/2 6/3 6/16 7/3 7/5 7/19 7/19 11/14 27/25 42/12 42/19 According [1] 33/16 across [2] 4/14 15/25 action [1] 35/20 actual [1] 22/5 actually [1] 21/21 add [4] 5/4 50/19 51/15 51/17 addressed [1] 50/18 admitted [1] 46/9 adult [1] 41/6 adults [1] 37/10 advice [1] 34/5 affected [1] 37/5 after [19] afterwards [1] 40/17 again [11] 9/12 10/1 16/23 19/19 23/20 24/6 28/21 36/13 39/18 39/23 48/2 age [2] 39/5 53/5 agent [3] 10/16 22/25 33/3 ago [2] 15/15 37/22 agree [1] 8/10 agreement [1] 11/2 ahead [1] 49/7 AIDS [7] 10/5 10/8 10/17 10/20 12/19 12/20 17/16 Alan [2] 30/17 30/23 alerted [1] 42/21 alfa [1] 28/25 alive [2] 14/25 48/2 all [56] allay [1] 17/13 allowed [1] 14/9 allowing [1] 15/24 almost [1] 19/18 along [1] 37/25 already [3] 21/24 28/6 30/2 also [3] 13/22 44/24 49/22 although [6] 2/11 2/23 18/12 23/10 24/16 43/3 always [4] 5/1 14/6</p>	<p>27/11 41/21 am [6] 1/2 1/12 17/1 31/7 52/22 54/24 ambulance [4] 47/2 47/5 47/5 48/5 America [8] 4/9 4/13 4/15 6/3 7/2 42/21 46/14 53/17 American [11] 1/24 4/25 5/9 5/12 5/22 6/12 6/15 8/15 11/10 15/25 19/25 Amongst [1] 30/15 an [19] angry [1] 34/24 another [3] 9/11 41/1 41/17 answer [1] 42/13 anti [4] 21/1 22/18 23/3 24/21 anti-HCV [4] 21/1 22/18 23/3 24/21 antibody [1] 24/19 any [12] 2/5 4/24 8/15 13/16 19/10 24/22 29/22 42/9 42/18 43/5 49/12 54/11 anybody [2] 24/4 45/8 anymore [2] 14/25 32/9 anything [17] 2/14 5/14 6/15 12/13 13/4 13/23 14/17 21/9 23/18 25/17 26/15 28/20 38/24 45/25 45/25 46/4 52/8 anyway [6] 3/16 5/19 13/10 49/13 50/16 51/13 apologise [1] 48/17 apologised [1] 48/6 appalling [1] 51/9 apparent [1] 21/5 appointment [3] 19/23 19/24 31/22 approved [3] 43/13 50/1 50/3 April [1] 19/6 archives [1] 16/17 are [11] 8/21 10/1 17/4 17/15 20/19 24/20 36/17 38/20 44/7 45/23 51/2 arguing [1] 52/10 around [6] 3/15 6/22 9/3 29/6 34/24 47/9 arrange [1] 42/17 arrived [1] 6/25 Arrogant [1] 53/7 arse [1] 38/6 art [1] 41/22 article [5] 9/25 10/4 10/22 11/13 16/20</p>	<p>articles [4] 5/17 5/18 6/17 6/19 as [41] aside [1] 26/25 ask [6] 17/1 19/1 20/18 31/7 33/19 49/13 asked [7] 2/5 5/8 12/11 25/15 41/7 51/23 52/2 asking [3] 26/16 50/24 52/22 associated [1] 48/21 assurances [1] 7/16 astute [1] 5/6 attended [1] 20/16 attention [2] 19/9 26/21 attentive [1] 40/22 attitude [1] 24/2 attributed [1] 27/16 August [1] 36/1 August 2003 [1] 36/1 authorities [1] 35/18 authority [1] 38/12 autumn [1] 41/14 available [7] 7/13 13/12 23/2 29/18 35/3 35/8 35/10 avoid [1] 36/5 aware [3] 24/20 36/25 37/2 away [4] 13/17 15/4 41/4 45/4</p> <hr/> <p>B baby [4] 1/18 46/24 47/6 53/20 back [12] 2/3 3/5 3/20 4/21 14/1 18/9 38/15 40/11 40/17 41/5 45/5 46/16 background [1] 5/19 bad [2] 11/5 46/23 bar [2] 3/10 53/23 basically [2] 25/21 25/23 basis [3] 23/12 33/5 35/24 bastard [1] 48/11 batch [4] 32/8 33/17 33/24 37/25 batches [2] 14/10 33/13 be [47] became [3] 5/16 21/5 29/25 because [21] become [2] 52/14 53/15 becoming [1] 29/7 been [43] before [14] 4/23 9/15</p>
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<p>B</p> <p>before... [12] 11/14 16/10 18/7 18/19 19/19 24/6 25/6 42/1 43/13 46/13 46/24 50/2</p> <p>before May 1984 [1] 18/19</p> <p>begged [1] 31/1</p> <p>beginning [2] 20/13 49/1</p> <p>begins [1] 18/11</p> <p>behalf [2] 35/1 50/21</p> <p>being [19]</p> <p>beings [1] 32/16</p> <p>believe [4] 22/9 34/22 42/19 42/20</p> <p>believing [1] 43/1</p> <p>below [1] 9/10</p> <p>beside [2] 11/14 13/10</p> <p>best [3] 38/9 42/11 46/14</p> <p>better [2] 23/23 51/10</p> <p>between [1] 24/10</p> <p>beyond [1] 43/16</p> <p>big [1] 45/5</p> <p>bigger [1] 14/5</p> <p>biopsy [2] 43/24 44/1</p> <p>birthday [2] 30/25 53/25</p> <p>bit [4] 18/10 20/21 45/14 51/15</p> <p>blame [2] 24/4 52/7</p> <p>bleed [3] 9/3 9/11 9/19</p> <p>bleeding [1] 33/9</p> <p>bliss [1] 38/16</p> <p>blithely [1] 45/6</p> <p>blood [26]</p> <p>blood's [1] 5/12</p> <p>bloody [5] 7/10 7/11 47/1 47/20 47/25</p> <p>blows [1] 53/10</p> <p>blues [1] 53/15</p> <p>bluntly [1] 31/23</p> <p>body [2] 44/6 53/10</p> <p>bombshell [1] 38/5</p> <p>booked [1] 53/8</p> 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