

Thursday, 25 July 2019

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(10.02 am)

SIR BRIAN LANGSTAFF: We start this morning, do we, with Tony and Monica?

MS RICHARDS: Yes, sir.

SIR BRIAN LANGSTAFF: Tony and Monica, please.

MONICA SUMMERS, sworn

MICHAEL ANTHONY SUMMERS, sworn

Questioned by MS RICHARDS

MS RICHARDS: Monica and Tony, you are here to talk about Paul. Paul was yours and your wife Patricia's son.

TONY: Yes.

MS RICHARDS: And your husband, Monica, and Paul's sister Bethan is here to provide you with support while you give evidence.

We're going to put up three photos of Paul during the course of the evidence and we're going to start with one particular photo and it will stay on screen for the first part of the evidence. Thank you.

Paul was born, Tony, in 1964.

TONY: Yes.

MS RICHARDS: And diagnosed with haemophilia A when he was about five years old.

TONY: Yes.

MS RICHARDS: There's no family history of haemophilia.

1 TONY: None whatsoever.

2 MS RICHARDS: So how did it come to be diagnosed?

3 TONY: He was frequently in hospital in Bridgend with
4 bumps and bruises and difficulty in walking on
5 occasions and that was over a period of about two/two
6 and a half years, and then a visiting doctor asked why
7 he was still on the same adult ward every time he went
8 there, sent for more blood tests and then about a few
9 days later we were asked to meet at the hospital and
10 go by ambulance with Paul to the Royal Infirmary in
11 Cardiff. We were told he had been diagnosed with
12 haemophilia.

13 We met Dr Bloom at the Royal Infirmary and he
14 told us what Paul's life would be like and how the
15 treatment would take place.

16 MS RICHARDS: Initially it would seem from the
17 documentation and from your statements that Paul's
18 haemophilia was categorised as being moderate.

19 TONY: Yes.

20 MS RICHARDS: Although he required treatment on a number
21 of occasions during his childhood and teenage years,
22 he led a very active sporty life.

23 TONY: Oh absolutely, yes. He played football, cricket,
24 he loved being active. He even went on a skiing
25 holiday and, of the four people in his room, he was

1 the only one who didn't need an ambulance at the
2 airport coming back.

3 MS RICHARDS: You have a memory of going to collect him,
4 seeing the ambulance --

5 TONY: Going to collect him, seeing the ambulance pulling
6 out of the plane at Cardiff Airport and thinking, "Oh
7 no, not to hospital" and finding it wasn't Paul at
8 all, it was the others.

9 MS RICHARDS: It was when Paul was about 14 or 15 years
10 old he began to receive home treatment.

11 TONY: Yes.

12 MS RICHARDS: In about the late 1970s.

13 TONY: Yes.

14 MS RICHARDS: Prior to that had he largely received
15 cryoprecipitate.

16 TONY: Yes, he had some, yes.

17 MS RICHARDS: Then he started to receive Factor VIII
18 products and he would inject himself or you and your
19 wife would at home.

20 TONY: That's correct.

21 MS RICHARDS: Can you recall what discussions there were
22 with you about the change from cryoprecipitate to
23 Factor VIII?

24 TONY: Yes. We were told that this was the way forward to
25 help people like Paul and he would not need to be

1 coming into hospital so often and, therefore, not miss
2 any schooling. It was a great step forward for young
3 boys and an odd statement at the time, it was cost
4 effective. I thought it was an odd statement at the
5 time. Being in business, I understood "cost
6 effective" but it was unusual to hear a doctor say it,
7 that this would be the way forward and to a degree it
8 was, it was good.

9 MS RICHARDS: Did Professor Bloom or anybody else at the
10 hospital give you and your wife or Paul himself any
11 warnings or advice or information about any risks of
12 infection associated with the use of the products?

13 TONY: Nothing.

14 MS RICHARDS: We're just going to have a look at some of
15 the documents to see what treatment Paul was receiving
16 and when.

17 Paul, could we have up on screen, please,
18 2406002.

19 We can see there it's -- we see there a list of
20 treatments and the reason for them. Picking it up in
21 1979 onwards we have, first of all, 16 May 1979 bed
22 rest and cryoprecipitate but then we see Paul
23 receiving on a prophylactic basis three times a week
24 Factor VIII.

25 TONY: Yes.

1 MS RICHARDS: And that continuing in the course of 1979
2 and then in 1980 twice weekly prophylactically through
3 to the end of 1980.

4 TONY: Right.

5 MS RICHARDS: Then if we have up on screen, please,
6 2406003, we've got a letter here from Professor Bloom
7 dated 13 June 1979 and we can see here the reference
8 to, it's a letter to the GP, but to Paul being on
9 prophylactic injections of anti-haemophilic factor
10 500 units three times a week for the past couple of
11 weeks. Then we see in the second paragraph
12 Professor Bloom informing the GP of the home treatment
13 regime and Paul now keeping a supply of the factor in
14 his fridge at home.

15 If we look halfway down that paragraph, we can
16 see Professor Bloom telling the GP that the
17 concentrate is a highly purified preparation of
18 Factor VIII from normal human plasma and very rarely
19 gives rise to reaction and then it talks about what
20 you might do in the case of allergic reaction.

21 No reference there to any more significant risks
22 of infection.

23 TONY: No.

24 MS RICHARDS: At the time that Paul changed from having
25 his treatment in hospital to home treatment, was there

1 at that stage any discussion with you about any risks?

2 TONY: No.

3 MS RICHARDS: Then if we could have up on screen please,
4 Paul, 2560007 -- I'm sorry, that's a wrong one. We
5 will come back to that document.

6 If we have up on screen, please, 2406004, we can
7 see there a further letter from the hospital, not this
8 time authored by Professor Bloom, referring again to,
9 if we can have the first main paragraph of the letter,
10 please, referring in the last part of that paragraph
11 in 1982 to Paul's haemophilia being well controlled:

12 "He last required Factor VIII injection for
13 a cut on his hand and he has not bled into the joints
14 for three or more years."

15 In the early 1980s, the time with which this
16 letter is concerned, what can you recall about the
17 extent to which Paul needed to have treatment?

18 TONY: Things had improved as far as having the treatment
19 and helping him to get about and pursue his education
20 but Paul was finding it more and more difficult at
21 times to cope with it and the -- I just felt we had
22 very little communication with the hospital to tell
23 us -- yet already we were seeing letters in the media
24 about the possibility that blood was a problem. But
25 whenever I asked at the hospital, they said, "No,

1 there's nothing. It's fine".

2 MS RICHARDS: Then if we can have up on screen, please,
3 2406005. This is a letter May 1983, so we're one year
4 further on, and we can see here in the second
5 paragraph and it says Paul's had quite a good year.
6 No admissions to hospital over this time. He's only
7 had three bleeds in the last year receiving 2,000
8 units of Factor VIII on each occasion at the Bristol
9 Royal Infirmary.

10 Paul was being treated at this time partly at
11 Bristol because he was studying there.

12 TONY: Yes, he was in Bristol College studying civil
13 engineering --

14 MS RICHARDS: He was obviously by that time a young man.

15 TONY: Yes.

16 MS RICHARDS: -- and attending appointments without you.

17 TONY: Yes.

18 MS RICHARDS: But as far as you can recall from any of the
19 subsequent discussions you had with him, was he given
20 at that hospital any information or advice or warnings
21 about the risk of --

22 TONY: No, it was regarded as routine. If he had a bleed
23 he went to the hospital. As it states here, he had
24 a fairly good period at that time, that first year in
25 Bristol, and we didn't have the same -- well, we had

1 concerns but not as deeply. Everything seemed to be
2 under control.

3 MS RICHARDS: Now, Paul didn't complete his studies at
4 Bristol. He decided civil engineering was not for
5 him.

6 TONY: Yes.

7 MS RICHARDS: If we have up on screen, please, 2406006, we
8 can see that Paul here in September 1984 he's back in
9 Cardiff under the care of Professor Bloom. We can see
10 in the first paragraph reference to being given a dose
11 of Factor VIII concentrate and this being the only
12 dose of Factor VIII that he's had in the last
13 20 months. There's no reference in this letter
14 addressed to the GP to any issues about risks of
15 infection in September of 1984.

16 Again, was anything said to Paul when he came
17 back under the care of Professor Bloom in 1984 about
18 risks?

19 TONY: No.

20 MS RICHARDS: Then could we have up on screen, please,
21 2406007. This is an extract from the clinical notes
22 relating to Paul and there's an entry dated
23 14 April 1983. It starts with quite a good year.
24 Then if we can just go down a little further with the
25 document, we can see something has been redacted

1 halfway down the page. If we could just have that
2 line highlighted.

3 "Patient has had same batch number as ..." and
4 then something's redacted.

5 Tony, could you tell us how you came to receive
6 this document.

7 TONY: For many years I had been asking the University
8 Hospital could we have sight of Paul's records and
9 they were either -- we were told they were not
10 available, they had been destroyed or they were in
11 a warehouse somewhere in Treforest, and just not
12 available. It was a brush off each time.

13 Then last September our chair of the Haemophilia
14 Society phoned me and said, "Paul's records are
15 available and if you go to the University Hospital
16 this week you can pick them up". That's the first
17 sight we had of any of his records for all the years
18 he was back and forward to hospital was last
19 September.

20 MS RICHARDS: The page you were given of which this is
21 a copy had a Post-It on which a nurse had written
22 something on. What was that?

23 TONY: The nurse had highlighted all the pages that we
24 needed to consider and look and read and this one in
25 particular because, you know, in that time it was

1 obviously known by then that Paul was HIV. But we
2 didn't know and he didn't know and he was receiving
3 blood, the same batch as somebody who possibly had
4 died. We don't know who that person was because, as
5 you can see, it has been blanked out completely.

6 That makes you more angry that the information
7 was hidden from us for all those years. Reaction: not
8 surprised, not totally shocked, what we expected to
9 see, but the fact they kept these records from us for
10 such a long time it wouldn't have made any difference
11 but it would have helped us to understand what he was
12 going through at that time.

13 Had we known as far back as 1980 they were
14 testing him for AIDS at 16 years of age and he was
15 a minor, but nobody consulted us on that. We never
16 knew that he was being tested. That's only been
17 discovered recently as well.

18 MS RICHARDS: In relation to this particular document, the
19 copy that was given to you has this redaction but the
20 nurse who gave it to you has put on a Post-It note
21 informing you that what has been redacted is the name
22 of a patient.

23 TONY: Yes.

24 MS RICHARDS: The inference that you have drawn from this
25 document seeing the date, 14 April 1983, and knowing

1 as you now know that there is evidence, indeed
2 evidence the Inquiry has heard this week about
3 a report in May 1983 being made public of
4 a haemophiliac dying of AIDS in Cardiff, reported
5 in May 1983, your concern and belief is that this is
6 a record made in 1983 that Paul had had the same batch
7 as the patient who died.

8 TONY: Absolutely. Apart from blanking the name out, it's
9 quite clear that that's what happened.

10 MS RICHARDS: You are concerned that someone has thought
11 it sufficiently significant to record in April 1983
12 that Paul had had the same batch as another named
13 person but no-one told you or your wife or Paul of the
14 significance of that fact.

15 TONY: No.

16 SIR BRIAN LANGSTAFF: Can we go back to 006, please. The
17 last big paragraph describing the examination of the
18 blood reveals a low platelet count.

19 MS RICHARDS: Yes.

20 SIR BRIAN LANGSTAFF: And a low white cell count.

21 MS RICHARDS: And an intention from Professor Bloom to
22 keep on eye on it.

23 SIR BRIAN LANGSTAFF: If you go back to the paragraph
24 above that, it looks as though -- this is
25 Professor Bloom, is it?

1 MS RICHARDS: In September 1984 this is Professor Bloom,
2 sir.

3 SIR BRIAN LANGSTAFF: -- was examining him for symptoms
4 which might be indicative of AIDS.

5 MS RICHARDS: Yes. Without that, as I understand the
6 evidence, having been communicated in any sense to
7 Paul or his family.

8 SIR BRIAN LANGSTAFF: So this document would tend to
9 support the inference which Tony draws from the letter
10 of 007.

11 MS RICHARDS: The record at 007, yes. The letter, sir, is
12 1984 so it is a year further on but absolutely yes.

13 SIR BRIAN LANGSTAFF: But it shows who was examining Paul
14 at the time had in mind that he might well be
15 suffering from AIDS.

16 MS RICHARDS: Sir, that is indeed a legitimate inference.
17 Tony, we're just going to look a couple of other
18 documents from around the mid-1980s which I know you
19 are familiar with now. 2406010 extract from the
20 clinical notes. We can see the date there
21 12 September 1985 and if we go down to the bottom of
22 the page, we can see there the last line, "check
23 HTLV-III", and then on the right-hand side we've got
24 LFTs, liver function tests, HTLV-III, HB platelets.
25 So that's September 1985 and a note is being

1 made in Paul's records that there's going to be
2 a check of HTLV-III, a test for that.

3 Was that communicated to Paul at the time?

4 TONY: No, it wasn't and it's only when I saw these
5 documents in September that I understand that HTLV-III
6 was the code for HIV at the time. It's not used now
7 as HIV is used but that I would have been totally
8 confused about, if I'd read it then think what is it?
9 What's it all about? I now realise it was HIV they
10 were talking about.

11 MS RICHARDS: But the fact that that test was being
12 arranged in September 1985 was not shared with Paul?

13 TONY: No.

14 MS RICHARDS: We then see a series of letters starting at
15 2406008, please. This is a letter of
16 23 September 1985. It's from Professor Bloom to the
17 GP. It refers to reviewing Paul at the clinic this
18 week and then in the last paragraph it says this:

19 "I am pleased to say that the liver function
20 test which were grossly abnormal last year have now
21 reverted to normal so presumably his attack of
22 hepatitis has cleared up."

23 Just pausing there, as far as you're aware was
24 Paul informed that his liver function tests were
25 grossly abnormal and that he had had an attack of

1 hepatitis.

2 TONY: Didn't know anything about liver function tests at
3 all for him. My disappointment when I read that
4 I realised there's a professional Code of Conduct but
5 our GP had been our GP ever since they were small and
6 I would have thought he could have possibly talked to
7 us about it at that time and told us what the worry
8 and concern was but there was still nothing coming
9 through from either side.

10 MS RICHARDS: We then have reference to various
11 haematological findings and then this sentence:

12 "Unfortunately, his tests for HTLV-III antibody
13 came out as positive and I will clearly have to keep
14 a close eye on him. There is no current evidence that
15 he has the immune deficiency syndrome and I do not
16 think that there is the slightest need to label him as
17 such but nevertheless I shall keep a close eye on him
18 and review him from time to time. I will also counsel
19 him regarding his mode of life, et cetera. Can
20 I suggest that this information be maintained in the
21 strictest confidence."

22 So Professor Bloom September '85 wrote to the
23 family GP, Paul's GP, informing him that Paul's tests
24 for HTLV-III were positive.

25 TONY: Yes.

1 MS RICHARDS: Was that information shared with Paul?

2 TONY: No. Paul knew nothing about it. In fact, I have
3 no recollection of Paul having any conversations with
4 Dr Thomas about this situation or any counselling.

5 MS RICHARDS: Just in relation to the reference to
6 counselling him regarding his mode of life, Monica,
7 you've got a recollection of something Paul said to
8 you, you hadn't met Paul at this stage, we will talk
9 about that in a little while, but Paul told you about
10 questions he was being asked at the Haemophilia
11 Centre.

12 MONICA: Yes, when he would go for his monthly check-ups
13 to have his blood drawn and his weight, then they
14 started asking if he wanted condoms and I remember him
15 saying to me, "I have no idea why they would be asking
16 me that out of the blue". That wasn't the norm.

17 MS RICHARDS: If we then have up on screen, please,
18 2406009, this is another entry from the medical
19 records. The purpose of this entry is just to help us
20 date another document but we can see here it's an
21 entry for 24 September 1985 and about eight or nine
22 lines down it refers to Paul going away to Corfu on
23 holiday on Monday, so September '85 Paul is about to
24 go off to Corfu.

25 If we then have please 246011, this is undated

1 in the records but it's referring to an injury that
2 Paul sustained I think it was paragliding in Corfu.

3 TONY: He went paragliding. There was no point in telling
4 him not to do it. Paul had to try everything, but
5 when he came back he really was in absolute agony and
6 had to be taken straight to hospital.

7 MS RICHARDS: We can see it says -- refers to bleeding
8 into the right thigh:

9 "Parachute harness whilst paragliding in Corfu",
10 and then these words:

11 "HTLV-III positive."

12 That reference to Corfu tells us that this is
13 probably October 1985. It's just after he's come back
14 from holiday and he's gone to seek treatment. Again,
15 in October 1985 when he is seeking treatment for this,
16 was Paul told then that he was HTLV-III positive?

17 TONY: No.

18 MS RICHARDS: Can we then have up on screen, please,
19 2406013. This is a letter dated 18 September 1986.
20 It is from Professor Bloom's clinical assistant
21 Dr Greedharry and it's addressed to Plymouth. Paul
22 was about to move to Plymouth, wasn't he?

23 TONY: Yes, he was starting a degree course in Plymouth.

24 MS RICHARDS: In architecture?

25 TONY: Yes.

1 MS RICHARDS: So his haemophilia care was going to need to
2 be transferred in part at least to Plymouth at least
3 for --

4 TONY: All his documentation went to Plymouth.

5 MS RICHARDS: We can see it is addressed to a doctor in
6 the haematology department at Plymouth General
7 Hospital:

8 "I am writing to introduce the above named
9 haemophiliac who will shortly be coming to reside in
10 Plymouth."

11 Then there is set out some history in relation
12 to bleeds and Factor VIII treatment.

13 If we go to the top of the second page of the
14 letter, please, we see it says this:

15 "Paul has always responded reasonably well to
16 conventional treatment. He has no inhibitors to
17 Factor VIII. He is hepatitis BS antigen negative,
18 hepatitis BC antibody positive. He is HTLV-III
19 antibody positive but he has not so far suffered from
20 any symptoms of AIDS-related complex", and then there
21 are references to clinical examination and to a low
22 platelet count from 1982 and going up and down since.

23 So we have here Professor Bloom's assistant
24 writing to Plymouth telling Plymouth that Paul was
25 HTLV-III positive.

1 TONY: Yes.

2 MS RICHARDS: Was Paul told at this stage by
3 Professor Bloom or his team?

4 TONY: He went to hospital in Plymouth to have a check up
5 and met the doctor and the doctor asked him how he was
6 handling his HIV and that was the first Paul had heard
7 of it.

8 MS RICHARDS: That's how Paul discovered --

9 TONY: That's how Paul discovered --

10 MS RICHARDS: He was HTLV-III/HIV positive.

11 TONY: Yes.

12 MS RICHARDS: We can see that when we look at 2406014.
13 This is a letter dated 26 November 1986 from
14 Dr Prentice, the haematologist in Plymouth and he says
15 this:
16 "This young man came to my clinic this morning
17 having presented at the weekend with a necrotic
18 bleeding tip of his right middle finger. We stopped
19 the bleeding and cleared up the infection. He was
20 apparently unaware that he was HTLV-III antibody
21 positive so I've told him this morning and given him
22 some basic counselling."
23 Then the doctor says this:
24 "I wonder if he is correct in this statement."
25 So that was how Paul learnt --

1 TONY: That's the first any of us knew that this -- and
2 Paul knew and we knew. Paul, phoned me and he said,
3 "I've got a problem", and from that point onwards life
4 changed.

5 MS RICHARDS: We'll just look at two more letters, Tony.

6 TONY: Right.

7 MS RICHARDS: 2406015. This is Professor Bloom's response
8 to Dr Prentice. It is dated 1 December 1986.
9 Dr Prentice having queried whether it can have been
10 correct that Paul was unaware of his HTLV-III status,
11 this is the answer:

12 "Many thanks for your letter about this boy.
13 I have asked my senior registrar to look out for his
14 notes ... send you further details, et cetera. Of
15 course the young man has been counselled extensively
16 and I've also advised him in some detail about sexual
17 practices, et cetera."

18 TONY: I would challenge extensively. Paul might have
19 a brief discussion with him on sexual practices. From
20 what Paul told me he had no idea why he was being told
21 that at the time, why he should do that, because
22 nobody had told him he was HIV and it never occurred
23 to him that this is what they were talking about.

24 MS RICHARDS: What this letter from Professor Bloom back
25 to Dr Prentice doesn't say is, "Well, of course, he

1 knows he was HTLV-III positive. I informed him myself
2 on such at such a date".

3 TONY: No. I have to say totally untrue.

4 MS RICHARDS: Then we have 2406016, just to complete the
5 exchange of correspondence, 12 January 1987. Here
6 there is a letter from Dr Prentice saying that he is
7 HIV antibody negative and I think Tony, Monica, you
8 have a recollection of when Paul was being tested in
9 Plymouth that there was some ambiguity about test
10 results. He was told it was positive, then told it
11 was negative and then, finally, it was confirmed to
12 him, Monica, that it was indeed positive.

13 MONICA: Correct.

14 MS RICHARDS: Tony, you have recalled in your statement
15 Paul having been given his diagnosis finally when he
16 was studying in Plymouth, tried to make light of the
17 situation and just get on with his life. The two of
18 you went shopping the day he told you.

19 TONY: We stood in the car park, what do we do now?

20 Paul's reaction was, "I could do with a couple of new
21 pairs of jeans and I wouldn't mind a steak before you
22 go back to Cardiff", so that's what we did. We went
23 out and bought two new pairs of jeans, discussed not
24 in detail what was happening because Paul's focus was
25 totally on, "I want to get on with this course". He

1 said, having had a steak, that's the -- he highlighted
2 the fact he wanted to stay and get on with it.

3 His ambition was to become an architect and
4 nothing was going to take that away from him. He was
5 obviously visibly shaken by it but he was quite
6 a strong character. He simply got on with it.

7 MS RICHARDS: Paul, could we have that first photo back on
8 the screen, 2560006. Just turn it round, please.
9 Thank you.

10 Monica, you met Paul in September of 1986.

11 MONICA: Correct.

12 MS RICHARDS: In Plymouth where you were an exchange
13 student.

14 MONICA: Yes.

15 MS RICHARDS: What was your impression of Paul? What was
16 he like as a young man?

17 MONICA: Well, I was -- the School of Architecture on the
18 top two floors housed international students so I was
19 there and he was late deciding whether he was going to
20 come to Plymouth or Manchester, so he got in there and
21 I remember being up in the communal room and the TV
22 and loads of couches and things, and he came in and he
23 was 6-foot 4 and very handsome. I thought, "Wow,
24 who's that guy?" thinking he wouldn't be looking at
25 me, and I got to know him pretty much on that first

1 day. And the phone for the students was on my floor
2 and I felt like I was the only one that could hear it
3 ring, so I would be legging it down, answering it.

4 I think one of the first calls I took was either
5 Pat or Tony looking for Paul and I had to try to find
6 him and there he was down in the kitchen, so I knew
7 him from really my first day there.

8 He enjoyed a lot of American things, you know,
9 we made brownies in the kitchen and he was interested
10 in those type of treats and I even had a baseball sent
11 over for him once because I think he had a glove sent
12 from Philadelphia from his aunt but no baseball so ...

13 MS RICHARDS: You started going out in about May of 1987.

14 MONICA: Yes, he had a girlfriend before and then we were
15 just -- we saw a lot of each other in functions and
16 things and then, yes, we did picnics and the weather
17 was nice and so we went over, did little day trips.
18 He had a car, which was a big deal, so we could, you
19 know, venture out a little bit and it was nice.

20 MS RICHARDS: Then in July of that year, 1987, you left
21 the UK to go back to the States.

22 MONICA: Yeah, I went over to Ireland. My parents were
23 travelling over there and we had family and I sent
24 postcards but I was very careful what I wrote because
25 I didn't know who was going to read it. And

1 I remember keeping a pound coin so I could call him
2 and he was walking the dog and I could hold the phone
3 so it wouldn't lose the amount of money and I'd call
4 back and Bethan said, "No, he's still walking the
5 dog", you know, like jeepers. So I did get to speak
6 to him before I had to fly back to the States.

7 MS RICHARDS: But you stayed in touch and he visited you
8 in March 1988 in Boston.

9 MONICA: Yes, we stayed in touch by letter. There was no
10 email then. I had a few high phone bills my father
11 was a little dismayed at and he flew to Chicago.
12 Their course always did a field trip and it was
13 Chicago that year and then he arranged to come to
14 Boston and I had family there, so I borrowed
15 a friend's car, drove up to Boston and we stayed with
16 my cousin and I tell people as romantic it was that
17 here's this, you know, man that I hadn't seen for so
18 many months, only communicating by letter, my cousin
19 shared a flat with three others girls and the cat had
20 just given birth to kittens, so we're sleeping on the
21 living room floor with kittens crawling all over us,
22 and Paul wasn't a cat person. But we had fun anyway
23 but that wasn't, you know ... as far as from being
24 super romantic.

25 MS RICHARDS: Then in August of 1988 he came to see you

1 again.

2 MONICA: He did. I came in between that one other time
3 because I missed him so much that I wanted -- well,
4 I correct myself. He did come in that August for
5 three weeks. I was very excited and this was a big
6 thing because I didn't have boyfriends so my whole
7 family were, you know, wondering who's coming, what
8 this is all going to be about and he stayed for three
9 weeks. But the sole purpose was to tell me that he
10 was HIV positive.

11 MS RICHARDS: You have said in your witness statement you:

12 "... can still clearly hear and feel how his
13 words changed my life from that moment and have
14 continued to do so to present. I was absolutely
15 devastated that my handsome, kind, gentle, talented
16 man had become infected this horrible virus."

17 Your relationship continued and strengthened and
18 you came over to the UK.

19 MONICA: Yes.

20 MS RICHARDS: You finally returned to make a home in the
21 UK with Paul in the middle of 1989.

22 MONICA: Yes, I came over in the June and stayed after he
23 graduated and we had -- he finally found -- we had
24 a summer of kind of searching for jobs and things and
25 then he found a job over in Bristol and he

1 communicated.

2 During the week he kind of rented a room from
3 a friend and I stayed with Pat and Tony and then he'd
4 come back. Tony would pick him up -- Bristol actually
5 on the way back from Swindon and and then have the
6 weekend and then he would have to go back on the
7 Sunday.

8 MS RICHARDS: Paul had graduated with first class
9 honours --

10 MONICA: He did.

11 MS RICHARDS: -- in architecture and set about
12 establishing himself with a career in architecture and
13 you got married in November 1989 in the UK in a civil
14 wedding ceremony.

15 MONICA: We did, yes.

16 MS RICHARDS: Then there was a ceremony you were trying to
17 arrange in the States but you had a concern about how
18 the HIV status might impact upon that.

19 MONICA: Right. So our church wedding was always for the
20 20 April in 1990 but at the time Connecticut law
21 required a blood test and that was to see for STDs or
22 if for some reason blood from either party would have
23 an effect on future children and naturally I was
24 concerned would they be testing for HIV, so at that
25 point I confided in my best friend can you find this

1 out for me. So we had to be in America a week before
2 our wedding and we did the test and everything and
3 fortunately they did not require, you know, that. So
4 that part was okay.

5 But a lot of that time which should have been
6 just totally euphoria was very stressful.

7 MS RICHARDS: Paul kept his HIV status private.

8 MONICA: Very. My parents knew that he was
9 a haemophiliac. Apart from my best friend, because
10 I needed to confide in her, that is all my family
11 knew.

12 MS RICHARDS: Now, how was Paul's health over the years
13 that followed your marriage?

14 MONICA: I would say for the most part okay. Naturally
15 there would be an occasional bleed in the knee. Nose
16 bleeds I would say were the worst. He suffered from
17 hay fever and he would just have his head hanging over
18 the -- sitting on the edge of the bath and just his
19 head hanging over the sink with the water kind of
20 dripping and his nose would just drip, drip -- hours,
21 through the night.

22 I would, you know, offer suggestions not always
23 well received. After several hours he would be
24 frustrated. I would say, "Let's go to the Heath". He
25 always knew if he got in there he wasn't getting out

1 right away so he would try to do everything he knew to
2 prevent it or to stop it actually. Sometimes it
3 worked.

4 A couple of hospital visits with chest things.
5 Those were always the worst, in the sense of when
6 someone gets a cold and you know that their immune
7 system is lower, you're in -- I basically describe my
8 life as being on constant high alert, extremely
9 vigilant but not letting anybody else know that. So
10 no-one else that would know me and would know our
11 situation would realise that's how I was.

12 You're constantly making sure things are
13 disinfected and tidied and if he had a bleed making
14 sure that was super clean for anyone else that may
15 have come into our home, looking for the best foods,
16 making sure if he was tired -- just, I was always
17 looking for anything to ease any discomfort that he
18 may have been experiencing.

19 MS RICHARDS: When did Paul discover that his liver had
20 been affected?

21 MONICA: We were in Bristol. We had a flat there after we
22 got married in '90. He'd gone up there, so the early
23 '90s he'd gone up for a check-up and he came back and
24 he just said, "This is what I was told, I have
25 cirrhosis of the liver".

1 Again, you're kind of taken aback, you know,
2 what does that mean? What is involved in that? Then
3 it started on the course of different doctors.
4 Nothing was ever said in the sense of urgency, which
5 I took to mean that they weren't overly concerned and
6 whether that was just kind of what I wanted to hear.
7 We did go to London, a liver specialist there. They
8 mentioned transplant but it was kind of something like
9 that would be way in the future, we don't need to be
10 worrying about that now, which in fact turned out to
11 not be way in the future.

12 MS RICHARDS: Do you know when he was informed that he had
13 been infected with hepatitis C?

14 MONICA: No, I don't have that.

15 MS RICHARDS: So it was the cirrhosis of the liver, the
16 damage to the liver that was the first he knew?

17 MONICA: Yes.

18 MS RICHARDS: Paul didn't let any of this stop him from
19 getting on with his life.

20 MONICA: Correct.

21 MS RICHARDS: We'll put up on the screen another photo,
22 please, Paul. It's 2560005. We'll keep this up on
23 the screen now. That's you and that's Paul and that's
24 your daughter.

25 MONICA: Correct, yes. She's about three there.

1 MS RICHARDS: You hadn't been able to have children
2 yourselves and so you adopted.

3 MONICA: We did, yes. We were unique in that respect.
4 I do know that there were -- there's another
5 haemophiliac couple that were successful and we felt
6 encouraged by that. Again, we had to fill out many
7 forms, as any adoptive couple would, and then lots of
8 questions, and then we had to open up our personal
9 life to a stranger, and as we kind of passed each
10 hurdle successfully, in the end they wanted to meet us
11 a 12 panel committee, I guess, and our social worker
12 was very anxious for us because she said this has
13 never happened.

14 Somehow we were okay. I don't know but we did
15 it and we were prepared and really the only thing they
16 were asking us is why did you choose this age group
17 you know, kind of 0 to 3 and we explained that. So it
18 wasn't anything about Paul's health. I mean, we were
19 fine. I think at the end our social worker -- we had
20 to kind of carry her out because she was so nervous
21 for us.

22 We had two failed attempts, they had selected us
23 to be matched with a child and then -- and they would
24 talk about it so when so and so comes and where's the
25 room and, you know, as they were almost coming in the

1 next day and each time for different reasons it wasn't
2 successful and we were pretty wiped out by that.

3 But there was something in me that I knew we
4 were going to have a girl and the social worker came
5 to our house and, you know, wanted to speak to us and
6 Paul was running late and she was like where is he?
7 Where is he? And that's when she told us about our
8 daughter and that it would be pretty much
9 straightforward because her birth mother was very
10 young, had been given several opportunities to kind of
11 collect her life and do the things that she needed to
12 and, unfortunately, she wasn't able to do those
13 things. So they said this will be easy and done and
14 that wasn't the case. It went until December and we
15 couldn't tell anybody and Pat, Tony and Beth were on
16 a rugby tour down under.

17 TONY: We went to Dubai, to the Dubai 7s, came back and
18 wanted to talk so much about it, and they put some --
19 a little piece of paper down on a Christmas surprise
20 present and on each piece of paper we had was
21 a child's name. We didn't know it was a child's name
22 at the time. We were trying to make out what these
23 initials stood for.

24 MONICA: We were saying that for Christmas, because they
25 just went on holiday, that let's pick a name and then

1 that's who you buy for and we wrote our daughter's
2 name on each piece of paper so then when they looked
3 at it and then we told them what it was then that was
4 tears and happiness.

5 So we were allowed to bring her home on
6 [redacted]. Usually they don't allow that at that
7 time of the year but she was only 15 months so we were
8 able to do that and actually we didn't even -- we
9 couldn't even buy a crib or a pushchair anything for
10 her in case something happened at the 11th hour, and
11 a very dear family friend said, "Here's a crib that my
12 daughter never slept in", and Paul had a bleed in his
13 thigh, do you remember?

14 So we were up in the room Pat, Beth, Tony myself
15 and Paul and he's got his leg strapped and he's
16 saying, "Put that in here, tighten it", because he
17 couldn't do it at all and we were all flummoxed and we
18 managed to get the crib together though so ...

19 But again he was worried that they wouldn't let
20 the baby come home to us if they saw he had a bleed.

21 MS RICHARDS: Paul had had -- since late 2001 when you had
22 been I think in the States, he had had the first of
23 a number of episodes of passing out.

24 MONICA: Yes.

25 MS RICHARDS: What happened on that occasion when you were

1 in America?

2 MONICA: Okay, so that was pre-our daughter. He had been
3 working in London very, very long hours, probably
4 drinking coke and eating candy bars instead of
5 a lunch.

6 We flew to the States to surprise my family. It
7 was 23 December. We went for some last minute
8 Christmas shopping. We were in a record store and
9 I hear my younger sister screaming my name and I went
10 legging it back and he told us after that the CDs
11 seemed to be jumping out at him. He fell forward,
12 passed out, basically passed out. He had two huge
13 black eyes, broken nose, fractured jaw and he was
14 shaking on the ground. It looked like he was having
15 a seizure. No idea, he had never done anything like
16 that before. The EMTs came. There was a medical kind
17 of small hospital right near the mall and he was
18 brought right in there.

19 I had many frightening moments with him but that
20 was extremely frightening because he wasn't
21 recognising me. My parents came. I mean, I had to
22 take the pictures for the insurance company after but
23 it looked like someone literally had taken a baseball
24 bat to his face. It was that bad.

25 MS RICHARDS: He had after that a number of episodes of

1 passing out.

2 MONICA: He did. It was where -- one in Cardiff when we
3 had come back from the States where he was walking
4 around. Fortunately, this time he could feel it
5 coming on so he managed to sit down and then kind of
6 called me to say, "Hey, this is what happened". We
7 never really knew if it was a sugar level type thing
8 so we started carrying glucose tablets in my handbag,
9 in the car, in his work bag. Certain stores he
10 decided that maybe it was the fluorescent lighting
11 that was affecting him.

12 He was still working in London and I was always
13 fearful that something would happen there and our
14 routine would be that he'd call me when he was --
15 because we had a cellphone then, when he was leaving
16 work and I roughly knew that it would take him so much
17 time from office, the train, and then to walk, he was
18 staying with a friend, to get to that flat and I even
19 allowed extra time and I remember one time he didn't
20 call me.

21 I can only imagine -- I equate it to what
22 someone who needed drugs and was looking for a fix.
23 I was hitting that redial button so many times. I was
24 working myself up, like where could he be? What's
25 happened? He's passed out. Someone's stepping over

1 him. No-one's going to help him. You know, it was
2 just awful.

3 Then, of course, when he finally answered
4 I wanted to kill him because I was, you know, "Where
5 have you been", and he's like, "Mons, the train was
6 late", or whatever but he couldn't communicate that to
7 me.

8 Moments like that, very stressful. I realise
9 obviously it's not intentional but not knowing was
10 very difficult.

11 MS RICHARDS: You've described in your statement these
12 episodes, from Paul's perspective he would have
13 difficulty speaking, forming words, he would sweat and
14 experience heart palpitations. He said it was like
15 being paralysed during that episode.

16 MONICA: Yes, so for those they had him on beta blockers
17 and he would be talking to you and all of a sudden you
18 could see there would be fear, perspiration above his
19 upper lip, his forehead and he was frozen. So he
20 could not speak and sometimes -- I know it happened
21 one time in a meeting and he was beside himself. It
22 wasn't just a case of kind of going out of the room,
23 shaking it off and going back in because he didn't
24 know exactly what was happening.

25 On two separate occasions we were walking -- we

1 were working in Cardiff, we were walking down Queen
2 Street heading to our car and all of a sudden I could
3 tell it was happening. I was able to get to our car,
4 got him in and I was heading to the Heath and he was
5 saying like, "Mons, where are we going?" I said, "We
6 need to go to the Heath because we need to have you
7 checked out", and he's saying, "Is it because I've
8 been bad", and that's not something that he would say.
9 I said, "Oh no, we just need to get this taken care
10 of", and I was, you know, saying my prayers, please
11 let me get there safely and calmly. As we got there
12 he was kind of coming out of it and he's like, "We're
13 not going through the A&E. I know the back way up to
14 the ward", so that's what we did. He wanted to avoid
15 that.

16 They kind of talked to him, gave him some water
17 and stuff, then made sure he wasn't on those again.
18 But another time he did manage to call me and he was
19 on the bus and he was afraid, and I said -- I was
20 saying to him, "Can you get off it somewhere", so he
21 could like make a sound "mm", so I knew I got in the
22 car, flew through the lanes and, basically, picked him
23 up down Culverhouse Cross. He was very frightened.

24 MS RICHARDS: You have recorded an observation he made to
25 you on one occasion where he said, "Mons, I'm the one

1 with the question mark over my head".

2 MONICA: Yes. We didn't -- I always say up until probably
3 the last year that the HIV and the haemophilia
4 certainly were a part of our life but they weren't our
5 life. We had to deal with those things but sometimes
6 we had those moments of reprieve where they weren't
7 front and centre, and that was probably one of the few
8 times that he said, really talked about the fact
9 that -- the unknown.

10 MS RICHARDS: Paul had been receiving medication for HIV,
11 a range of different medications for a number of
12 years.

13 MONICA: Yes.

14 MS RICHARDS: But he also was prescribed interferon for
15 his hepatitis C.

16 MONICA: Yes.

17 MS RICHARDS: What can you recall about that course of
18 treatment and its effect on him?

19 MONICA: Initially they suggested to take four to six
20 weeks off from work. The practice that he was at was
21 pretty good about that. I honestly can't remember
22 what -- I'm going to have to use the word "story" we
23 told, but something that was factual but not maybe the
24 complete story.

25 He did great. You know, he was coming home, he

1 would cook something, the yard was tidy, and I was
2 like okay and then he went back to work and then it --
3 that's really when all the side effects kicked in and
4 he was cold and achey and he couldn't sleep and it was
5 just very difficult. But he had to go into work and
6 so he did every day.

7 MS RICHARDS: You have described in your statement he had
8 trouble sleeping, he was run down, but he ended up
9 just battling through it.

10 MONICA: Absolutely, yes.

11 MS RICHARDS: Now, in 2008 Paul had an assessment at the
12 Queen Elizabeth Hospital Birmingham in relation to
13 a liver transplant.

14 MONICA: Correct.

15 MS RICHARDS: How had it come about that or how was he
16 informed that his liver had deteriorated to the extent
17 that he needed to be placed on the transplant list?

18 MONICA: So we -- our first holiday with our daughter we
19 couldn't leave -- she didn't have a passport so we
20 went to Jersey because we can go on the ferry and we
21 had a nice holiday on the beach and this particular
22 beach you had to walk up a large flight of steps and
23 the car park was up top. So I had tonnes of stuff and
24 Paul was holding our daughter and he got to the top
25 and she was a solid little girl and he got to the top

1 and he was -- he was more than out of breath.

2 Me being me and I knew something wasn't right so
3 we finished our holiday, he made a point of going into
4 the centre and, you know, telling the doctors what had
5 happened and they said, "Okay, we're going to set up
6 a series of tests", and one of them was it was inject
7 a dye in and the idea was to see what was going on,
8 obviously, in his lungs and things like that.

9 I remember he said the technician said to him
10 these things are never positive, like don't worry
11 about it. When he came home he was lying on our couch
12 kind of telling me the story and he said the guy's
13 face just dropped because the dye indicated that there
14 were some severe problems there and that's when
15 Dr Dasani and Dr Collins became -- I mean, they were
16 always involved in Paul's healthcare but now we were
17 looking -- we saw a liver specialist in Cardiff, then
18 in London and then we were recommended up to a clinic
19 at the Queen Elizabeth Hospital and had to be decided,
20 one, to be on a waiting list just to be on the
21 assessment. It was a huge process.

22 MS RICHARDS: The assessment was carried out and Paul was
23 placed on the waiting list for a liver transplant.

24 MONICA: Correct.

25 MS RICHARDS: You have said in your statement from that

1 point onwards anything approaching normality that you
2 had in your lives ceased to exist. You spent your
3 life waiting for the phone call.

4 MONICA: We did. So Paul was still working, everything
5 with our daughter and our activities continued but it
6 was -- we were heightened because anywhere we went
7 that was somewhere different we were making sure we
8 had signal on our phone, that our phones were charged
9 because the call literally could come at any time and
10 we already had, like, a bag packed ready to go.
11 Obviously, Pat and Tony knew that if we called them
12 they may have to come and get our daughter or she
13 would come with us and then they would follow up, you
14 know, to care for her.

15 So it was very stressful.

16 MS RICHARDS: You had a couple of calls in which you
17 packed up, drove to Birmingham in the middle of the
18 night but you were told the liver wasn't right.

19 MONICA: Correct -- twice.

20 MS RICHARDS: Then the third call came on 8 December 2008
21 and you packed everything up and you've said in your
22 statement you remember thinking that this was the
23 surgery that was going to help you get your lives
24 back.

25 MONICA: I did.

1 MS RICHARDS: Can you tell us what happened after that?

2 MONICA: So we got up there, our daughter was with us, her
3 pink bath robe, Pat and Tony were on their way, and we
4 were kind of brought -- Paul and I and our daughter
5 were brought into like a little family room. Excuse
6 me.

7 And we talked a little bit and she liked to do
8 group hugs, so we did a group hug, talked a little
9 bit, but it was late, probably after 10. So she
10 toddled off with you guys and stayed. Because the
11 assessment had been done, obviously it was successful.
12 I stayed with him that night, just sat in the chair
13 next to him and not really talked because they were
14 coming in and out for blood pressure and, you know,
15 those kind of things, gave me his watch, wedding
16 rings, you know, to hold and the social worker came to
17 see us in early hours, as it were, and as Paul was
18 being led down to the operating room with the surgeon
19 team I was able to follow down and I remember being
20 just in that room before they took him in and
21 I quickly kissed him. I said, "I love you", and then
22 you know he was whisked away.

23 I was like, okay, now the people that know what
24 they are doing are in charge and, you know, this is
25 going to be a way we're going to get our life back.

1 Although we were under no illusion that after the
2 transplant what would be involved because they were
3 very descriptive about that in the assessment.

4 45 minutes later the social worker came looking
5 for me saying the surgeon has not started the
6 operation because they feel that the portal pulmonary
7 hypertension that Paul suffered from, that they
8 initially diagnosed as mild to moderate was now severe
9 and they didn't feel that his own body would be able
10 to bring him out if they didn't operate and if they
11 did operate really the same result, would he live
12 through it.

13 My first thought was please do not make me make
14 that decision. I was, you know, very frightened.
15 I was frightened because I could think what if
16 I didn't see him again. They made -- Paul had a split
17 liver, so the other half went to save a child's life,
18 which was successful I found out later. They did do
19 it. We waited a very long time. Paul's boyhood
20 friend, James, came up on a train to be with us. And
21 we just waited and waited and waited and he did come
22 through and when we went in, they had explained too
23 that when someone has a liver transplant when they
24 come out of it they are kind of disorientated, they
25 seem almost like they're a little, I won't say drunk

1 but they're not sure of things and then it quickly as
2 the liver's kind of getting used to the body. Well,
3 he wasn't coming round, he wasn't coming round.

4 His blood pressure was very high. It did go
5 down if I held his hand and I was allowed to be in
6 there and talk to him, and he did eventually come
7 round and they did take the tube out. He recognised
8 me. He said, "Hi". They asked him some questions and
9 they accepted that when he nodded yes or shook his
10 head no, that he was compos and understood where he
11 was and what was going on. He lived for about a week
12 after. I was staying on the grounds there and so
13 every two hours I was getting an update of his health,
14 you know, through either the nurses or the doctor on
15 call.

16 So on 15 December the on-call doctor said,
17 "Mrs Summers, your husband is extremely ill. He has
18 pneumonia", and he started listing all these things.
19 I was beside myself because I thought I know he's
20 taking some time to come round but -- and I wasn't
21 allowed to always be in the room but -- so I was back
22 in my room, as it were, and my cell phone rang and the
23 nurse said, "Paul isn't doing well. You need to get
24 over here". I ran pretty fast, climbed a lot of
25 stairs two at a time and the nurse and the doctor met

1 me and they just said, "He's deteriorating and we're
2 going to try a couple of things". And I said, can
3 I -- they said, "You can go in and see him", and
4 I said, "Well, he's going to wonder what I'm doing
5 here at 1.00 in the morning. He'll be worried
6 something's wrong", and they said, "Oh no, he already
7 knows".

8 So I went in, he had the oxygen mask on.
9 Earlier that day I had taken a picture of our daughter
10 with a Santa hat on lit up. I asked if he wanted to
11 see it and he said no. He had other pictures of her
12 he could see from his bedside. They wanted to tube
13 him again and he shook his head no.

14 I said to him, "We've been through bumpy
15 patches. We're going to have to do this". I hugged
16 him, obviously. I had to leave the room. I then
17 called for a priest. Paul wasn't Catholic but he was
18 cool with that. He did have the last rites. My
19 sister-in-law was in Birmingham staying with family so
20 she came. My in-laws were in Wales and a family
21 friend very kindly drove them at top speed up.
22 I think Beth was with me in the room when they came
23 out and they basically said, "We have shocked his
24 heart 20 times", and although it would come down into
25 normal rhythm, it could not maintain it and there

1 wasn't anything else they could do.

2 MS RICHARDS: The four of you, the three of you here and
3 Paul's Mum, were around Paul's bed when he died early
4 in the morning on 16 December 2008.

5 MONICA: Yes.

6 MS RICHARDS: You have never talked with him about what
7 you describe in your statement as the "what if",
8 because when he went into hospital for the transplant
9 you weren't expecting things to be easy but you were
10 expecting him to come out.

11 MONICA: Absolutely. When we -- the next morning when the
12 surgeon who had operated on him came in and was
13 surprised that his patient had passed. I answer
14 people when they say to me, "Oh, Monica, you must have
15 known how ill he was". Well I certainly knew that he
16 wasn't a well man but I wasn't expecting that. So if
17 the surgeon didn't realise, then I kind of felt that
18 was okay that I didn't and at no point in the
19 counselling that we did receive and they were very --
20 you know, they didn't pull any punches at the Queen
21 Elizabeth. They explained what that medication could
22 do and how you would feel and -- so they were making
23 everyone fully aware that if you were chosen, this is
24 what you can expect initially.

25 It wasn't that we were naive. I mean, there was

1 one time when we were waiting to hear and Paul did
2 have a lot of trouble sleeping so it wasn't uncommon
3 to find him on the couch with the TV on, I went down
4 into our extension that he'd built and he was crying
5 and he said, "I'm so afraid I won't watch our daughter
6 grow up". Really that was the first kind of time he
7 showed anything of fear through all our marriage
8 really.

9 He didn't ever blame anybody for being HIV or
10 hep C because that wasn't his focus. His focus was to
11 live life. You know, he would say to me, "Whatever
12 our daughter's in, we got to be involved in that too",
13 you know. I do long for having more conversations
14 like that.

15 MS RICHARDS: In that period of time between Paul going
16 down for the transplant surgery and Paul's death,
17 although you had been able to communicate with him
18 through him shaking his head or nodding his head to
19 answer questions, the only and the last word he spoke
20 was that "Hi" to you after he came round from surgery?

21 MONICA: Correct, yes.

22 MS RICHARDS: You had to tell your daughter who then was
23 five that her daddy wasn't coming home.

24 MONICA: I did, yes. It was up in our bedroom. I put her
25 on our bed. I knelt in front of her. I'm going to

1 say one thing before that prior. I did, when we were
2 up at the hospital, Paul was asleep and he had his
3 mask on and I did have her come in. It was -- the
4 curtains were up and I wanted her to see him. It
5 wasn't a frightening setting. I would never, you
6 know, do that and Tony held her and she saw him and
7 I felt that was important. I guess for me I'm
8 thinking there's always going to be that later in
9 life.

10 So when she was sitting on the bed and I was
11 kneeling in front of her, and I just said, you know,
12 "Daddy's heart was pumping and it stopped and he won't
13 be coming home", she became physically sick.
14 Naturally she was upset. She cried. She slept with
15 me that night and she was sick again the next morning.

16 She did see him. I know it's not traditional
17 here for wakes and things but my brother and my best
18 friend and my mother were flying over and the funeral
19 home allowed it that we could see Paul any time that
20 we wanted, and I did, but they would not embalm his
21 body because of everything that he'd been through.

22 Anyone that knows Paul, there's a couple of
23 things, he liked to dress smartly. He always had his
24 hair -- apart from two little marks because the oxygen
25 mask was so tight on his forehead he look perfect and

1 his body was -- I was worried but our daughter was
2 able to see him then and she put some drawings in his
3 casket as well.

4 MS RICHARDS: You have described in your statement the
5 days and weeks and months that followed being almost
6 more than you could bear.

7 MONICA: Yes. I found an old diary that I had started
8 after he died saying I just want to physically step
9 out of my skin. The physical pain of trying to
10 comprehend one life without him and the enormity of my
11 responsibility now for my daughter. Just realising,
12 you know, when you are looking at pictures when you
13 have been at holiday together and you know that's
14 Italy but where or what time. I'm not able to turn to
15 anybody else and say, "Hey, remind me of when we did
16 this" or "wasn't that funny", you know.

17 I realise I'm not necessarily unique in that but
18 there's a lot of memories there that sometimes I think
19 I'm going to start writing on the back of those so
20 that I can remember when I get older or to share with
21 my daughter.

22 MS RICHARDS: You and your daughter ended up moving back
23 to the States.

24 MONICA: I did.

25 MS RICHARDS: Again, you say in your statement you have

1 had to make all the big decisions now for her and for
2 yourself without Paul on your own.

3 MONICA: Yes. I mean had it not been for Paul's health
4 issues we would have lived in the States. He loved
5 it, all the aspects of it and, yes, moving back I did
6 my research about what I would and wouldn't be allowed
7 to do.

8 I was able to have the widow's pension allowance
9 as far as help. The Trust was allowing me to still
10 continue to have a payment monthly and I was -- made
11 sure that what we chose we would be able to do. My
12 plan was that once I lived there for about a year and
13 got everybody settled, [my daughter] in school, that
14 I would look for a job and, unfortunately, that didn't
15 transpire the way I had hoped just due to restrictions
16 of the trust. Although they had never said you
17 couldn't work, they said, "If you work then we would
18 reduce any monies that we give you", and I couldn't do
19 that.

20 MS RICHARDS: You've struggled financially since Paul's
21 death. He had been the main breadwinner for your
22 family.

23 MONICA: Yes.

24 MS RICHARDS: You have found it very difficult to survive
25 on what you're able to earn and what you receive from

1 the Macfarlane Trust and now from the Welsh Infected
2 Blood Support Scheme.

3 MONICA: Yes. Obviously the Macfarlane Trust is no
4 longer. The Welsh scheme they have allowed certain
5 funds to the widows and then that is it. That's not
6 an ongoing ... so I do have a job that's full time and
7 I'm very blessed to have that and I have health
8 insurance with that, which is key if you live in the
9 States. But I do have concern for the future.

10 MS RICHARDS: What's your experience been in general of
11 your dealings with the Macfarlane Trust and now the
12 Welsh Infected Blood Support Scheme?

13 MONICA: It would have to say in the beginning the
14 Macfarlane Trust was helpful. You know, I'm going
15 back with Paul alive. If we were requesting something
16 that we were allowed to they used to have a booklet
17 which was great. You could say, okay, I would be
18 allowed to ask for a washing machine if I was moving
19 into a new home or they would help with legal payments
20 again if we were buying a home. Then they got rid of
21 that book.

22 As the years went on, things that we were asking
23 for we had asked for before became more difficult.
24 I had a lovely social worker who's actually here today
25 who was very helpful mediating. I was able to claim

1 say a school uniform allowance for [my daughter] which
2 wasn't a lot of money but still that helped and one
3 time I went to claim they said, "We don't do that
4 anymore", but I didn't know that.

5 I had asked for help with eyeglasses and I don't
6 know if it was more myself or my daughter because she
7 does wear them and I was told that, "No, you should be
8 able to budget that out of the money that you are
9 given a month", and that monthly figure I can say was
10 to cover food, any activities for [my daughter],
11 basically the running of the house and that figure's
12 pretty low.

13 MS RICHARDS: You have had a number of difficulties when
14 you have, in your dealings with the Macfarlane Trust,
15 in getting information, getting responses to your
16 concerns. You were also told on one occasion when you
17 were going to be interviewed for the purposes of an
18 application, this was after Paul's death, that there
19 was a quota in terms of the number of interviews that
20 could be conducted.

21 MONICA: They were going to -- they had some sum of money
22 that they needed to spend and then they had hired an
23 I referring to the right --

24 MS RICHARDS: I think that's the email that you've shown
25 me.

1 MONICA: Yes, and they were going to -- they wanted to
2 disburse this money fairly but you would have to, you
3 know, fill out lengthy forms, be interviewed and then
4 it actually went out to an outside marketing company
5 in the end, that the Trust itself was no longer
6 carrying out those interviews.

7 I found that interesting because if this is an
8 organisation that was supposed to be looking after
9 funds for people who were infected and, hopefully,
10 their widows and dependants, that they were using some
11 of that fund to spend on another company taking over.

12 It was an arduous process but that's really what
13 it was with the Trust all the time, form-filling,
14 proving yourself. They may give you a grant for
15 something but then they wanted you to pay for it first
16 and prove that you had paid for it with a receipt and
17 then they would give you the funds.

18 MS RICHARDS: Monica, I know that you have something you
19 are going to read at the end of the evidence from
20 [your daughter] and indeed from yourself.

21 MONICA: Yes.

22 MS RICHARDS: Is there anything in particular you would
23 want to tell us before we get to that stage about the
24 life that you and [your daughter] have been leading
25 together without Paul and the effect upon her of not

1 having her father there?

2 MONICA: Sure. She was five when he passed away. She
3 will be 16 in October. It's very difficult for her to
4 talk about him without becoming upset. I do my best
5 not to cry. It's not because I don't want to cry but
6 to try to be able to help her talk about him without
7 being so distraught.

8 We have pictures in our home of -- like the one
9 on the screen here and other things, she has them in
10 her room. We are limited to what we do. I'd like to
11 be able to take her and come here, you know, to see
12 her grandparents and her aunt. Tony doesn't enjoy the
13 best of health so coming to Stateside, although they
14 have done that, is not really something that can
15 really happen in the future, so we're pretty good
16 FaceTiming and stuff.

17 She has some emotional difficulties, anxiety,
18 and I do my best to help her with that and find help
19 for her with that. I think it's the one thing that
20 she wants and I cannot do it, she says to me,
21 "Sometimes I can't remember his voice".

22 I have some videos somewhere which I will dig
23 out to find for her but how do you give somebody the
24 impossible?

25 MS RICHARDS: Tony, you and Pat and Bethan lost a very

1 much loved son and brother. What, if anything, would
2 you like to tell us about that?

3 TONY: I never thought we'd come to this day. Relieved
4 we're telling our story. Just across from here
5 there's a park bench and there's a memorial on it and
6 it says:

7 "To Paul Summers, a talented architect who loved
8 this city", and I think I missed something off it. He
9 loved life and his family as well.

10 MS RICHARDS: Tony, you've got some experiences of your
11 own in relation to the Macfarlane Trust and the Welsh
12 Infected Blood Support Scheme, not directly through or
13 not only directly through Monica and Paul but also
14 through works you do as part of campaigning and
15 support activities.

16 TONY: I never saw myself as a campaigner. In
17 October 1986 when it all fell apart, I just felt that
18 we had to do something and initially my focus was how
19 do we meet the finances that Paul's going to need.
20 The difficulty was because Paul wanted anonymity in
21 everything to appeal for support for people like Paul.
22 The more I asked about, the more I began to realise
23 there were more and more people in this situation.

24 Approaches to MPs for support and guidance
25 always a smile of sympathy but nothing ever happened.

1 Publicity, they wanted a photograph with Paul.
2 Impossible because of the anonymity. That went on for
3 20 years trying to get some feeling of support, of --
4 it was almost as though they didn't realise it had
5 happened. Many of them didn't understand that it was
6 even happening and there were so many people in this
7 country suffering.

8 But when Paul died, I just felt initially can't
9 do this but I did and I joined up with
10 Haemophilia Wales and I felt that really meant I was
11 able to campaign more actively, carried banners
12 outside Westminster, make a nuisance of myself with
13 MPs. You could always see the expression on their
14 faces, "Oh God, it's that man again. He's come to
15 harass us and chase us for" -- it wasn't money by this
16 time. It was really justice. Yes, money's an issue
17 for many people. For me it was never, ever the money
18 it was how on earth could this happen. Two questions:
19 why and how? It's only, I would say in the last two
20 to three years have I felt that the country
21 understands, the Government understands.

22 There's a relief of getting here today, there
23 truly is, and I'm so grateful. I think we've reached
24 the end of the beginning and I think this is the
25 beginning of the end, hopefully, and that we will

1 eventually ... and more than anything else I want to
2 live long enough to see it. Thank you.

3 MS RICHARDS: Monica, we're going to put one final
4 photograph up on the screen.

5 MONICA: Okay.

6 MS RICHARDS: This is Paul and [your daughter] at the
7 London Eye.

8 MONICA: Correct.

9 MS RICHARDS: You have got something you want to read from
10 [your daughter] and yourself.

11 MONICA: Yes, I do. Excuse me for just one moment.

12 I'd like to take this opportunity to thank
13 Sir Brian and the Inquiry team for selecting me to be
14 here today. I feel very fortunate to have this
15 opportunity to represent Paul not just as a victim.
16 I'm going to share with you some memories and emotions
17 in the hope you're able to formulate a picture of what
18 type of person Paul was. Over the last three weeks
19 I've spent my commute to and from work thinking solely
20 about this moment and knowing it would be my one
21 chance to speak freely about Paul.

22 Our relationship endured distance and absence.
23 It was based on respect, trust, determination,
24 laughter and, above all, a deep unyielding love for
25 one another. Paul's first visit to Connecticut to

1 meet my family was in August of '88. Everyone took to
2 him immediately, especially my father. Putting him to
3 work assembly a bike rack in 90-degree heat while we
4 all watched from inside the air conditioned house,
5 from that initial visit my parents always had the
6 Welsh flag flying whenever we came home.

7 Paul's happiest day was when we were given
8 a photo of our daughter, knowing she would complete
9 our family. He slept with the photo by the side of
10 his bed so if he woke up, he could look at it in the
11 middle of the night.

12 Our daughter brought an immeasurable amount of
13 joy to Paul's life. He took pleasure in every aspect
14 of being a parent but his favourite moment was hearing
15 her say "daddy" for the first time. Paul was
16 courageous, witty, a great dancer, softly spoken. He
17 loved music; he was loyal; he was passionate about his
18 career as an architect; he loved the beach, both here
19 in Wales and the States. He had a great sense of
20 humour, a warm smile, he was a Bluebirds fan and loved
21 watching Wales play rugby. He was known to be
22 fashionably late. He could be stubborn. He was
23 a wonderful father and husband.

24 I'm going to read you a little excerpt from
25 Paul's eulogy which was given by his former boss,

1 Gareth.

2 Paul: what a guy. Here are just some of the
3 words colleagues, clients and fellow professionals
4 have written about him. Gentle, friendly,
5 warm-hearted, funny, creative, immensely talented,
6 respected, highly valued, noble, one of life's
7 gentlemen, a fine architect, a credit to his
8 profession and someone who'd stand by his word.

9 I saw other attributes in Paul. I saw his
10 incredible bravery in his face of debilitating
11 haemophilia and his liver tumour. He did not moan.
12 He did not use it as an excuse. He just got on with
13 life and his work as best he could. He did this so
14 quietly you often -- excuse me. He did this so
15 quietly you often didn't know he was there. I worked
16 next to Paul for two years, often engaging him in
17 conversation for quite some time before realising he
18 was actually on the phone to someone.

19 There was a project that Paul worked on. It's
20 the homeless centre in Butetown and they had emailed
21 Paul's work practice to say that they would like to
22 put up a plaque in his honour, and it said:

23 "We would like to commemorate the contribution
24 that Paul made to the development by unveiling
25 a plaque as part of the opening ceremony" and this is

1 what the plaque says.

2 "Paul Summers, architect. This plaque is in the
3 recognition of the important contribution made by Paul
4 Summers to the planning and realisation of the Single
5 Assessment Centre, a ground-breaking development.
6 Sadly, Paul passed away before the buildings were
7 completed but has left a legacy for the City of
8 Cardiff. He will be sadly missed by all those who
9 knew him."

10 I have a few more things but they are brief.

11 When he passed, his practice sent out an email
12 to fellow architect practices, clients and anyone who
13 may have had interaction with Paul. They all
14 responded and our friend Vicky made a beautiful book
15 and I've just made a copy of some of the things that
16 people have said.

17 This is someone from the United Welsh Housing
18 Association:

19 "He was so good to work with and the design for
20 Northlands reflected his ability to both listen to
21 what we wanted and produced a very high quality
22 design."

23 This is from the Housing Strategy Section of
24 Cardiff Council:

25 "Paul was a very special person. If it wasn't

1 for his input, guidance and support, the Single
2 Assessment Centre would have been abandoned long ago.
3 It was a pleasure to work with him and he has set an
4 impossibly high standard for partnership working."

5 This is from Swansea Council Education
6 Department:

7 "I had the privilege of meeting Paul on a number
8 of occasions whilst he was working on the
9 comprehensive school project in Swansea. Paul was so
10 professional but, above all, a perfect gentleman. He
11 spoke fondly of his family and his beautiful
12 daughter."

13 There's a planning company:

14 "Yesterday we learned that the appeal for the
15 Northlands Hostel was granted. Paul had worked
16 alongside us on this project and led the design work.
17 I am deeply saddened that Paul is not here to
18 appreciate the outcome, which reflected his hard work
19 and commitment to the scheme. As you rightly say, the
20 redevelopment of the Northlands will be amongst Paul's
21 many legacies."

22 This is from a client:

23 "I could not say I knew Paul very well. The
24 dealings I had with him were always relaxed in that
25 I knew I was dealing with someone who knew his

1 business and would stand by his word, qualities rare
2 in this day and age."

3 Sorry, I have two left. This is from
4 a colleague:

5 "Paul's dedication, vision, integrity affected
6 me deeply and will act as a constant inspiration, not
7 only to me but to all the people who knew him
8 personally and inhabit the space he created. I will
9 miss him. His guidance and presence will always
10 remind me to remain firm to my convictions and to
11 never settle for good enough."

12 This is from another of architect practice:

13 "Although I didn't know Paul personally, within
14 the industry I had heard of his reputation and
15 professionalism. Some of his schemes are well known
16 to us in South Wales and I am sure will act as a
17 legacy to Paul."

18 Finally, this was a former colleague:

19 "We all take different paths in life but no
20 matter where we go, we take a little of each other
21 everywhere. I am privileged to have worked within
22 your shadow, not only as an architect but as a man
23 with greater compassion and character. Frank Lloyd
24 Wright once wrote 'a great architect is not made by
25 the way of the brain nearly as much as he is made by

1 the way of a cultivated heart'. Your warmth,
2 creativity and passion are evident in all that you
3 have portrayed, a testament to your title as one of
4 the best architects I've ever had the pleasure to work
5 alongside and call a friend. You leave behind your
6 legacy for others to witness and view in awe."

7 I'm just reading what my daughter wrote:

8 "What daddy meant to me. Even though daddy died
9 when I was young, I still have many happy memories
10 about the two of us. Some of my favourite memories
11 were going to see Cardiff City Bluebirds, learning how
12 to ride my bike, and going to see Chitty Chitty Bang
13 Bang. These are only a few of the many happy memories
14 I have with daddy. Though I have so many positive
15 memories of the two of us, there are still sad
16 memories. They are all of the times we had to bring
17 him to hospital."

18 As I reflect on the last ten years since Paul's
19 death -- excuse me -- my thoughts, feelings and
20 emotions are many and varied. I am forever changed as
21 a person for having known him and changed by his
22 death. Although I no longer cry every day and I am
23 able, most of the time, to talk about him without
24 breaking down there are sometimes when it still feels
25 unreal to me.

1 This journey of grief and loss has left me
2 physically, mentally and emotionally exhausted at
3 times. The realisation that there are still years
4 ahead before we have the answers we all seek is
5 daunting to say the least. However, my love and
6 loyalty for Paul and my determination to witness
7 justice outweigh any overwhelming emotions. It is my
8 sincere wish that my statement and the words I have
9 just spoken will leave a lasting impact on Sir Brian
10 and the Inquiry team. I would like to thank them
11 again for allowing me this additional time to speak
12 about Paul.

13 I'm going to end with a quote I found on a scrap
14 of paper at my Mum's house several months ago.
15 I don't know the author but the words really resonated
16 with me:

17 "Grief never ends but it changes. It's
18 a passage, not a place to stay. Grief is not a sign
19 of weakness nor a lack of faith, it's the price of
20 love."

21 Thank you.

22 MS RICHARDS: No further questions, sir.

23 SIR BRIAN LANGSTAFF: I don't have any questions. I would
24 like to say that when your evidence is over, your
25 witness statement will be put out on the web, as is

1 our practice. But anyone who's listened to you today
2 will have realised that you've done exactly what you
3 set out to do, which is to tell us what Paul was
4 really like. In what you said, I think you've painted
5 not only a compelling picture but a much more vivid
6 picture than ever comes out of the printed word of
7 what Paul was really like, a picture every bit as
8 vivid as the photographs we have seen painted with
9 words, and described a person who, I think in Tony's
10 words, loved life and his family.

11 I would just like to thank you both for that.

12 MONICA: Thank you.

13 TONY: Thank you.

14 SIR BRIAN LANGSTAFF: We'll take a break until 12.15.

15 MS RICHARDS: Thank you, sir.

16 **(11.38 am)**

17 **(A short break)**

18 **(12.19 pm)**

19 SIR BRIAN LANGSTAFF: Our next witness is anonymous. In
20 his case, there will be no live streaming.

21 As with the previous anonymous witness, I will
22 make an order and the terms of that order will
23 probably be familiar to you but I will read it out
24 nonetheless.

25 The name and address of witness W1275 (that's

1 Mr AF to you and me), the name of his brother who died
2 and the name of any other member of the witness's
3 family and any other identifying information such as
4 the witness's image or a description of their
5 appearance cannot be disclosed or published in any
6 form unless express permission is given by me or by
7 the solicitor to the Inquiry acting on my behalf.

8 Witness W1275 must be referred to only as Mr AF.
9 The order remains in force for the duration of the
10 Inquiry and at all times thereafter unless otherwise
11 ordered and I may vary or revoke the order by making
12 a further order during the course of the Inquiry.

13 So, as before, not only please respect that
14 order but that is something which binds us all.

15 Mr AF.

16 MS RICHARDS: Sir, I should say whilst Mr AF and his wife
17 make their way up, Mr AF may use the names of family
18 members during the course of his evidence. It is
19 because of that that there is no live streaming of his
20 evidence but the order that you have made obviously
21 prevents anyone who is hearing those names, listening
22 to the evidence here, is prohibited from disclosing or
23 publishing that information.

24 SIR BRIAN LANGSTAFF: Yes, thank you for that.

25 **MR AF, sworn**

Questioned by MS RICHARDS

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Q. You're here to talk about how you were infected with HIV and hepatitis C and also to talk about your brother, who died of AIDS.

A. Yes.

Q. You have severe haemophilia A?

A. I do.

Q. Your older brother also had severe haemophilia A.

A. Yes.

Q. Your treatment at all the times with which we are concerned was at the Cardiff Haemophilia Centre under the care of Professor Bloom.

A. Yes.

Q. So too was your brother's but because he was older than you, as a child he had had some treatment elsewhere; is that right?

A. Yes, at the Royal Infirmary.

Q. Also some treatment in Oxford prior to that?

A. That's right, yes.

Q. In your childhood, you were treated largely with cryoprecipitate, I think?

A. Yes, always with cryo.

Q. What did that involve?

A. Lengthy stays in hospital, sometimes weeks on end and having big batches of cryoprecipitate which I tried to

1 avoid as much as possible, so a lot of bleeds I had
2 I didn't report. It was just a case of hot and cold
3 water and carry on like that until the bleed subsided.

4 Q. You've described in your statement that when you were
5 about 10 or 11 years old you became jaundiced and you
6 subsequently learnt that that was hepatitis B that you
7 had experienced?

8 A. Yes.

9 Q. Your brother also in his teens had had hepatitis B?

10 A. He did, yes.

11 Q. That had cleared in both your cases?

12 A. Yes.

13 Q. Was there ever any discussion with you or with your
14 parents at the time about the hepatitis B and the
15 cause of it?

16 A. No, it was just as if it was another bleed, really.
17 It was just turned yellow for a couple of weeks and it
18 cleared.

19 Q. Now, there came a point where your treatment became
20 Factor VIII.

21 A. Yes.

22 Q. As did your brother's. Were you or your brother ever
23 given any warnings or advice or information about any
24 risks of infection associated with the use of the
25 Factor VIII?

1 A. No, nothing. We were just told that -- I never went
2 to school as a youngster. I went for about a month
3 period when I was about five or six and a couple of
4 bleeds occurred in that time, so they refused to take
5 me in the end in school so I had a home tutor.

6 When I was 13, they called us into the hospital
7 to say there was Factor VIII available and it would
8 mean I could go to school and live a much more normal
9 life than what I had done.

10 Q. You said in your statement you were essentially led to
11 believe it was a wonder drug.

12 A. It was a wonder drug, yes.

13 Q. You have also said in your statement that had you or
14 you believe had your brother known of any risks you'd
15 both have chosen not to take those risks but to have
16 cryoprecipitate or bed rest or both?

17 A. Absolutely. Cryoprecipitate worked for me. It worked
18 for my brother, and we would have gladly stayed on it
19 because that's the treatment we knew.

20 Q. We'll just look at some records which show the range
21 of different products that you received.

22 Paul, it's 1275008, please. If we go to the
23 third page, please, Paul.

24 We can see here there's a record 1971
25 cryoprecipitate and then we see the first record of

1 you receiving Factor VIII products in 1978, Travenol,
2 Hyland, Hemofil, Factor VIII then cryoprecipitate
3 again and then if we continue looking up the page we
4 can see you received pretty much every Factor VIII
5 product that there was?

6 A. Yes.

7 Q. Profilate, Koate, Factor VIII, Kryobulin, Travenol, et
8 cetera, BPL Factor VIII.

9 In all that time in the period that we see
10 there, was there ever any discussion with you about
11 different products, NHS BPL Factor VIII as against the
12 commercial products?

13 A. No, it was basically you go to hospital for your
14 appointment, they give you the home treatment, and
15 you'd use whatever was available at the time. So it
16 was, you know, no shock to have different batches or
17 different makes. It was all Factor VIII to us.

18 Q. You and your brother would be given the same batches
19 and if you needed to you would share between
20 yourselves?

21 A. Yes, if one of us run out we would share to save going
22 to Cardiff to pick more treatment up because we lived
23 about 30 miles away.

24 Q. In 1983, your wife was pregnant and you were asked by
25 Professor Bloom to go and see him.

1 A. Yes.

2 Q. What can you recall about that discussion?

3 A. He wanted us to have a termination and the way he put
4 it to us was that to end the haemophilia in our family
5 if we had the termination that would do that. It
6 would be a 50/50 chance otherwise, if it was a boy, of
7 having haemophilia, so he recommended a termination.

8 Q. You and your wife didn't accept that advice in 1983.

9 A. No. Personally I might have. If somebody had said to
10 me to do personally I would have done what he
11 suggested but my wife being my wife questioned it and
12 you wasn't happy with his explanation, so we refused.

13 Q. You observed in your statement that you found the
14 reasoning that he was giving you somewhat strange.
15 You didn't understand why he was saying this.

16 A. No, because things were up in the air. We didn't
17 realise whether it -- I was under the impression that
18 if you had a boy it would be 50/50 chance for the boy
19 having haemophilia, or a girl would be a 50/50 chance
20 of being a carrier and, I mean, I was living, you
21 know, a full life really even though I had haemophilia
22 so it wasn't a good enough reason to not have a child.

23 Q. Just going to look at three documents. Could we have
24 up on screen please, Paul, 1275004. This is from your
25 medical notes. We see 22 September 1983 and we can

1 see the last line of that entry:

2 "Wife pregnant, genetics explained."

3 Your recollection based upon where you were or
4 where your wife was in the pregnancy is, in fact, the
5 discussion you had with Professor Bloom was earlier
6 than that, perhaps in May of 1983.

7 A. Yes because that being too late to have a termination
8 at that date.

9 Q. So you don't understand why it appears in your records
10 for 22 September 1983?

11 A. No.

12 Q. The second document I want us to look at -- Paul, this
13 is a different witness number please -- it's 1656003.

14 Now, this is a letter dated 21 June 1983 and
15 it's sent in respect of your brother and it's
16 exhibited to your sister-in-law's witness statement
17 and it's referring to a review of your brother in
18 Professor Bloom's clinic and reference to prophylactic
19 home treatment. Then it says this halfway down the
20 paragraph:

21 "Further routine bloods were taken and, in
22 addition, a specific investigation of his immune
23 status was undertaken by Dr Moffat as part of a survey
24 of severe haemophiliacs who have required a lot of
25 Factor VIII over the years in view of the possibility

1 of an acquired immune deficiency syndrome", AIDS.

2 Now, that's June 1983 not long after you think
3 you had the discussion with Professor Bloom about
4 a termination and reference there in the letter
5 written about your brother to blood tests being taken
6 because of the possibility of AIDS.

7 If we just look at your records, Mr AF, if we
8 look at 1275003 the bottom entry, please, Paul, if you
9 could highlight, 19 May 1983, so this is around the
10 time you think that you had that conversation, last
11 two lines:

12 "Dr Moffat took bloods for AIDS."

13 Now, were you aware, at the time was your
14 consent sought to blood being taken for the purpose of
15 some form of testing in relation to AIDS?

16 A. No, no.

17 Q. Did you know that this had taken place at all?

18 A. No.

19 Q. As I understand it -- please correct me if I'm
20 wrong -- the suspicion you now have, the two of you,
21 is that the advice that you were being given by
22 Professor Bloom to terminate may not have been because
23 of the genetic consequences of haemophilia but because
24 of the suspicion or possibility that you might have
25 been infected with AIDS?

1 A. Absolutely.

2 Q. But that wasn't told to you?

3 A. No.

4 Q. How did you learn that you had been infected with HIV?

5 A. We were asked to go up, myself, my wife, my brother
6 and his wife to see Professor Bloom. There was
7 a small like anteroom, another treatment room, and he
8 called was it us first or was it -- we went in first
9 and he told us that I was infected. Yes, it's not to
10 discuss it with anyone else at all, not even my
11 brother, and no-one in the waiting room or any of the
12 other boys that we used to see regularly there and
13 that was it, basically.

14 Q. You have said in your statement that the practical
15 advice you were given was to use your own cutlery,
16 toothbrush and towels?

17 A. Yes, towel, toothbrush, cups, saucers.

18 Q. Was there any discussion about sexual practices and
19 the possibility of infecting children?

20 A. No.

21 Q. You have described in your statement that this was
22 delivered in a very matter of fact way but it was
23 a bombshell?

24 A. Yes.

25 Q. Your wife's statement describes it as a short, cold

1 and matter of fact discussion.

2 A. It was. It was just like any other consultation you
3 go in, how are you doing, and this is the treatment
4 regime I want you to stick to now, and that was it.

5 Q. Were you given any information about likely prognosis?

6 A. No. And I didn't ask, to be honest. It was such
7 a shock that it didn't even sink in at the time so
8 I didn't ask any questions.

9 Q. Your brother and his wife were told on the same day?

10 A. Yes, in the same way.

11 Q. Did you know that you had been tested for HTLV-III as
12 it then would have been called?

13 A. No.

14 Q. Just again look at a small number of your records.
15 You have said in your statement you think this was
16 July 1984 that you were told this.

17 A. Yes.

18 Q. If we look at 1275010, this is an extract from the
19 National Haemophilia Database and it certainly records
20 date first positive as 15 July 1984, which accords
21 with your recollection of when you learnt the news.

22 A. Yes.

23 Q. Then if we just have up on screen two further
24 documents. First of all, please, Paul, 1275006.

25 This is a letter of 23 November 1984 and we can

1 see it refers to you having been to out-patients and
2 having been examined by Professor Bloom and then it
3 discussed -- says this:

4 "We discussed your fears about AIDS and hope
5 that we have reassured him to some extent."

6 So it's clear from this document in your records
7 that by November 1984 you had been told.

8 A. Yes.

9 Q. You've got -- thousands of pages of medical records
10 provided to you. There is no record which shows the
11 discussion that you had in July or whenever precisely
12 it was with Professor Bloom telling you your
13 diagnosis?

14 A. No, there's nothing in there.

15 Q. There's no HTLV-III test results from that time in
16 your records?

17 A. No.

18 Q. Those are simply not there?

19 A. No.

20 Q. Then the second letter, please, Paul, 1275005, we can
21 see, if we can just enlarge it, thank you, a letter of
22 4 March 1985. It is from Professor Bloom to a GP and
23 it's really just to pick up what's said in the second
24 paragraph:

25 "As with many of the haemophiliacs he has of

1 course been exposed to the HTLV-III virus, the
2 putative agent of the acquired immune deficiency
3 syndrome. His tests for antibodies to this virus were
4 positive."

5 So that's Professor Bloom's description to your
6 GP of what was known by March 1985.

7 What was the impact of the diagnosis upon you
8 and indeed your wife and your brother and his wife at
9 that early stage?

10 A. As other people have said, it was a bombshell and
11 especially what was going on with the media as well.
12 We knew we had to keep it quiet. No-one else could
13 know, and we had friends at the time, didn't we, they
14 knew -- I never made it public that I was
15 a haemophiliac even because I had some stick in school
16 from it, so there was only a very close few people who
17 knew from being in school with me that I was
18 a haemophiliac and even they started asking questions,
19 you know, "We've seen this advert about AIDS and
20 linked it with haemophiliacs", so they asked did it
21 affect us. They just came out and said it bluntly.

22 So we found ourselves retreating back from life
23 really and everyone. I didn't want to see anybody
24 else and just kept it within the family, didn't we.

25 Q. In 1984, I think your wife's statements suggests 1985

1 but you think now it was 1984, your wife was pregnant
2 again.

3 A. Yes.

4 Q. On this occasion the two of you decided that the
5 pregnancy would be terminated?

6 A. Yes.

7 Q. Why was that?

8 A. Because we knew by that time I was infected and
9 everything we were told and everything we had read
10 about it said that if my wife went through with the
11 pregnancy that the baby would more or less definitely
12 be infected and it could also infect my wife.

13 Q. It was a number of years later that you learnt you had
14 been infected also with hepatitis C.

15 A. Yes.

16 Q. In your statement you thought that you were told that
17 information by Professor Bloom and Dr Dasani together
18 but we have discussed it this morning and you now
19 think that you learnt of your diagnosis with
20 hepatitis C only after your brother died?

21 A. It was definitely, yes.

22 Q. He died in late 1992.

23 A. Yes.

24 Q. So that would put the date upon which you were told as
25 being possibly 1993.

1 A. Yes.

2 Q. You think now it wasn't Professor Bloom but Dr Dasani
3 who gave you the diagnosis?

4 A. Dr Dasani.

5 Q. So that's 1993. We will just look at a test result
6 that is in your medical record.

7 It is 1275007 please, Paul.

8 We can see the date of this is 6 June 1991 and
9 we see at the bottom we have stamped:

10 "Antibody to hepatitis C virus detected."

11 Were you aware in 1991 that tests were being
12 done in relation to hepatitis C?

13 A. No.

14 Q. Were you told in 1991 that this was the result?

15 A. No.

16 Q. When you were told, you think in 1993, about the
17 hepatitis C diagnosis what can you recall about the
18 information you were given?

19 A. We were just told about the tests, that it came back
20 and it was positive and, to be honest, it wasn't even
21 on my radar at the time because it was HIV that was
22 killing everybody so I thought it was just going to be
23 in the background and the way it was explained that it
24 might never come to anything and, if it did, it was
25 years in the future so it really didn't bother me.

1 Q. Were you given any advice about the practicalities of
2 managing hepatitis C, not passing on the infection or
3 lifestyle adjustments that you might want to make?

4 A. I asked about -- because obviously it's to do with the
5 liver -- about drinking and so I stopped drinking
6 straight away and they said about not to have
7 unprotected sex, yes.

8 Q. You have said in your statement that following your
9 diagnosis with HIV, in terms of your physical health
10 you were okay for a while.

11 A. I was fine.

12 Q. It was towards the end of the 1980s that your brother
13 began to fall very ill.

14 A. Yes.

15 Q. Can you tell us how his health deteriorated.

16 A. I think he hid a lot of it from me because obviously
17 we were in the same boat and we grew up -- my mother
18 died when I was young so my brother, my sister looked
19 after me and my other brother. So he shielded me from
20 a lot of it. But I could see he was getting ill and
21 the family could see he was getting ill. They put us
22 on AZT then, that's how it come out, but what they
23 told us was that it would be a blind study that some
24 people would receive AZT, some people would receive
25 a placebo, and as it turned out my brother had the

1 placebo.

2 Q. You had the drug and your brother had the placebo.

3 A. Yes.

4 Q. You obviously didn't know that at the time.

5 A. No, no.

6 Q. You felt guilty --

7 A. Yes.

8 Q. -- about the fact that you received treatment and he
9 didn't?

10 A. Yes. What made it worse that having taken about 15
11 tablets a day and I was well so as far as I was
12 concerned there was nothing to treat really, that's
13 why I was just taking them as and when I was
14 remembering to take them and he took his morning, noon
15 and night by the clock and I think that made it worse.

16 Q. Your statement suggests that you're also troubled that
17 there may have been a deliberate decision to give you
18 as brothers who were infected with the same condition,
19 potentially even from the same batch, given you one
20 deliberately the treatment one deliberately a placebo
21 to see what happened?

22 A. Yes, absolutely. We were too close. We had the same
23 treatment we were, you know, both severe
24 haemophiliacs. We had too much in common for them not
25 to give us one and one placebo.

1 Q. You have described in your statement that although in
2 the late '80s you were physically not at that stage
3 unwell, watching your brother become ill, watching
4 others around you falling ill and dying, you felt you
5 were just waiting for your turn.

6 A. Yes. It was like taking a ticket at Tesco's counter.
7 It was just who's next?

8 Q. You believed your days were numbered?

9 A. Yes.

10 Q. And you didn't think anything mattered?

11 A. No.

12 Q. You have said you, essentially, just took each day as
13 it came.

14 A. I did.

15 Q. You have recollected in your statement when you were
16 on the AZT treatment Dr Dasani taking bloods from you
17 for the purposes various tests but then taking an
18 additional vial of blood.

19 What did he tell you that was for?

20 A. I never questioned it up until all this kicked off.
21 There was always an extra -- when they take blood off
22 you it always goes into little glass vials. It's done
23 direct from the needle, but there was always another 5
24 or 10 ml extra of blood taken in a small syringe. And
25 I did question it only once, and I asked what's the

1 extra blood is for and he said, "This is for our
2 studies. The rest will go to the lab and this is for
3 our studies".

4 Q. Your brother died in late 1992.

5 A. Yes.

6 Q. We have a statement from your sister-in-law and from
7 your nephews but what can you tell us about your
8 brother's illness and his death?

9 A. As I said, he was going downhill rapidly towards the
10 end but he knew that I was in the same boat, as
11 I said. But he never -- he never once moaned. He
12 never asked why me. He never -- he never complained
13 at all. He just tried to carry on as best he could,
14 and to stay have alive as best he could, but he was
15 without a doubt the bravest person I have ever met in
16 my life.

17 Q. He became very physically frail towards the end.

18 A. He did. He lost his sight. It was horrendous. I am
19 ashamed to say that there were times when I thought
20 I couldn't go down to see him because it was hard to
21 watch, but I did go and not long after from that he
22 passed away.

23 Q. You went off the rails after his death.

24 A. I did.

25 Q. You started drinking, although you then later gave

1 that up after you received the hepatitis C diagnosis?

2 A. Yes.

3 Q. In 1993 you developed yourself pneumonia, PCP
4 pneumonia, and you were given only a few weeks to
5 live.

6 A. Yes, I didn't know that at the time. I was in
7 intensive care and [my wife] was coming back and forth
8 to look after me and the family members are coming, my
9 father or my sister-in-law, my sister, whoever it was,
10 and I woke up one day and there was about five or six
11 of them standing round the bed and I can remember
12 looking at them and thinking, "What the hell are you
13 all doing here". I thought they couldn't organise
14 a piss-up in the brewery this lot. Why did they all
15 come at the same time you me? Couldn't they organise,
16 you know, different times? But then I realised later
17 that that's the time when they phoned [my wife] and
18 the family to come in to say goodbye to me, basically.

19 Q. In terms of the emotional and mental effect of the
20 diagnosis, you having been told by Professor Bloom not
21 to tell anyone and aware of the stigma and the abuse
22 that others suffered, you decided, as you have told
23 us, not to the tell anyone other than very close
24 relatives and you essentially shut yourselves away.

25 A. Yes.

1 Q. You cut yourself off from friends because you didn't
2 want them to put two and two together.

3 A. No, to this day I don't -- the only friends I have are
4 involved with this. I don't have any other friends.
5 [My wife] has many friends and her friends' husbands
6 come back and forward to the house, don't they, but
7 I won't make friends. I won't make friends with
8 anyone.

9 Q. You ended up moving away so that people wouldn't know
10 who you were?

11 A. The village where I was born and grew up, we decided
12 to move from there because when I was ill people would
13 come round and they would ask what's wrong with me and
14 they were putting two and two together, basically.

15 Q. You received notification at some stage about the risk
16 of variant CJD.

17 A. Yes.

18 Q. Your statement puts it at 1995 but the medical records
19 suggest, in fact, it was 2001.

20 A. Right.

21 Q. We will just have a look at a document from your
22 medical records, please. It is 1275002. It's the top
23 entry and we can see there it talks about information
24 re vCJD:

25 "I have informed [that was you] that in

1 September 1997 they had been exposed to Replenate
2 Factor VIII [and the batch number is there given].
3 This batch had a donor who has now developed vCJD.
4 The exact implications unknown at the moment. We will
5 keep him informed re new developments."

6 You recall being given this information by was
7 it Dr Dasani?

8 A. Dr Dasani, yes.

9 Q. You said it was this that has frightened you more than
10 anything?

11 A. Yes and it still does now because HIV is under
12 control, it's been up and down over the years but it
13 is under control. I've now cleared hep C but this is
14 still hanging over me.

15 Q. And it's unknown?

16 A. Yes.

17 Q. As you said, you have had various treatments for HIV
18 over the years. The AZT was particularly bad in terms
19 of side effects?

20 A. It was, yes.

21 Q. You experienced diarrhoea, weight loss, sickness and
22 your memory, mood and sleep were affected?

23 A. Yes.

24 Q. You had I think three courses of treatment for
25 hepatitis C?

1 A. That is correct, yes.

2 Q. The first, which was around 2002, was interferon and
3 ribavirin?

4 A. Yes.

5 Q. What can you tell us about that experience?

6 A. We were told at the time it wasn't going to be good
7 but I did not realise how bad it was going to be, and
8 I don't think [my wife] did either because it was
9 horrendous. It changed me as a person. I argued with
10 everyone, our son, which I have never had a cross word
11 with in my life and never since, I argued with him.
12 I wanted to kill everybody that come across my path.
13 I was in a rage all the time to the extent where
14 someone cut across me in a car [redacted].

15 It just went on and on and on like that. It was
16 horrendous.

17 Q. You had that treatment for about four months.

18 A. Yes.

19 Q. It seemed as though it was clearing the virus but, in
20 fact, it hadn't and it returned very quickly. You
21 then developed pancreatitis. What happened then?

22 A. It was the interaction between the treatment and the
23 HIV drugs, that's my take on it, that I was taking and
24 it turned into pancreatitis. So I was in hospital for
25 that and they sent me down to intensive care then.

1 Q. You had to stop the treatments for your HIV for a time
2 because of that?

3 A. Yes.

4 Q. And then you tried a second course of treatment which
5 was just ribavirin, no interferon?

6 A. Yes.

7 Q. You have put it in a very understated way in your
8 witness statement. It was just the normal side
9 effects, night sweats, vomiting --

10 A. It wasn't too bad that one.

11 Q. Because you didn't have the same behavioural mood
12 changes that you'd had before.

13 A. No.

14 Q. You took that for about six months?

15 A. That's right.

16 Q. You thought it had worked?

17 A. Yes, I started feeling better even though the side
18 effects were -- they weren't nothing like the other
19 one.

20 Q. But it hadn't?

21 A. No.

22 Q. The virus came back three weeks later?

23 A. Yes. It was something like a 93 per cent success rate
24 with that particular drug and I remember seeing the
25 consultant and he said to me, he said, "Look, I'm not

1 expecting any bad news at all". He said, "You've got
2 a good clearance rate", he said, "You'll be fine".
3 Then he rung me up and he said, "Remember what I said
4 to you. You're in the 7 per cent, unfortunately".

5 Q. You finally had a third course of treatment in 2017?

6 A. Yes.

7 Q. That was Harvoni?

8 A. Yes.

9 Q. Three months and no ill side effects?

10 A. No, no side effects at all.

11 Q. That has resulted in the virus clearing?

12 A. It has. It's gone.

13 Q. You have made this observation in your statement. You
14 said:

15 "My body is just knackered and has probably now
16 given up. I don't think I even noticed the side
17 effects of treatment."

18 A. If there was I honestly didn't notice anything.

19 Q. You do have ongoing monitoring in relation to your
20 liver.

21 A. I do.

22 Q. Is it fibroscans twice a year?

23 A. Yes.

24 Q. You say that helps your peace of mind.

25 A. It certainly does, yes.

1 Q. You eventually told your son when he was in his teens
2 about your diagnosis and you eventually told your
3 parents in law but your friends still don't know.

4 A. No.

5 Q. What's the effect been on you and indeed your family
6 of living for so many years a life that's partly in
7 secret?

8 A. It's been like living under a cloak is the only way to
9 describe it, because as I said I won't make friends
10 with people because I don't want people getting close
11 because if I became ill again, there would be too many
12 questions asked. I'm lucky now I'm on a different
13 treatment for haemophilia so I don't get hardly any
14 bleeds at all, so that's not an issue. But the first
15 thing I do if I'm ill is lose weight and rapidly and
16 it's so noticeable that I'm worried people will ask
17 questions.

18 Q. Have you or your wife ever been offered any
19 psychological support or counselling?

20 A. Recently, yes, but not up until recently.

21 Q. In the years in which your brother was ill up until
22 his death, was he offered counselling support or his
23 family?

24 A. No.

25 Q. I will ask you, first of all, about the impact that

1 your illness and the treatments you have had for them
2 has had on your ability to work.

3 A. I left school because I went to school with the
4 Factor VIII and I didn't like it at all. I wasn't
5 used to it, so I left school at 15. I went straight
6 into a job working with heavy plant, which is great
7 for a haemophiliac. About a year and a half in I was
8 up a jib of a crane and fell off and injured my knee
9 and that was it. The job was over from that point.
10 But with the ups and downs of the treatment and the
11 side effects and everything I haven't worked since,
12 no.

13 Q. Your wife has described in her statement that because
14 of the ill health and so on, the treatments, the
15 effects of it, that's affected her choices in relation
16 to her work. She had a successful shop but ultimately
17 had to sell that.

18 A. Yeah, we had a [redacted] shop which we built up from
19 nothing. I used to help as much as I could and she
20 worked very hard with it but when I was really ill
21 that time she said, "Right, that's it. We need to
22 sell the shop now because ..." you know, and that's
23 the one thing that I always hoped we would be able to
24 keep because it gave me peace of mind if something
25 happened to me that [my wife] wouldn't be reliant on

1 the Trust or any other money, she would have her own
2 money coming in but even that was taken away from us
3 then.

4 Q. She puts it this way in her statement, she has to
5 change and adapt her plans all the way along.

6 A. Yes. We've become very good at that.

7 Q. I will ask you about your experiences with the trusts
8 and schemes. First of all, you were involved, as was
9 your brother, in the litigation and you referred in
10 your statement to being asked to sign a waiver in
11 1991?

12 A. We were, yes. We were told that there was a waiver
13 that would circulate around all beneficiaries and if
14 one person didn't sign it then nobody would get
15 anything. We waited, we spoke to other people, and
16 we're lucky because in Cardiff there was a couple of
17 high profile campaigners and we decided not to sign
18 the waiver. We waited and we both said, myself and my
19 brother, "If it comes to it that nobody's going to get
20 any money we'll sign it but until that point we're not
21 signing it at all", so we didn't sign it.

22 Q. In fact you did get the payment.

23 A. We did.

24 Q. You had an experience of asking the Macfarlane Trust
25 for a deposit to help you acquire a Motability car?

1 A. Yes.

2 Q. What happened with that?

3 A. The Macfarlane Trust was always yes one day, no the
4 next day. So I asked for -- because where we live you
5 need a four wheel drive and we didn't have money to
6 buy a car so I asked for a deposit and they turned us
7 down, basically. They said, "No, I'm sorry, we don't
8 do that anymore. We used to do it but we've stopped
9 doing it now", so I was really annoyed with it because
10 it's something we needed and it was [redacted] at the
11 Trust that told me they didn't do it anymore, so I put
12 the phone down and I wrote a letter to them saying
13 that on some of the different websites and the
14 Facebook sites somebody had put on there that the
15 widow of someone who had passed away had had a grant
16 for a computer or laptop or whatever it was for her
17 son who wasn't infected, obviously affected but not
18 infected, and I wasn't able to get something being
19 infected, something I needed.

20 Within I think it was three weeks [redacted]
21 *got back to me and said the full grant is now
22 available for you but without the fight I wouldn't,
23 you know they --

24 MRS AF: They wanted to pay the garage direct.

25 A. Yeah, that was the next thing, "We're not going to

1 give the money to you because we can't be guaranteed
2 that that's what you'll use it for", so they said,
3 "We'll pay the garage direct", and I said, "No, you
4 won't pay the garage direct because they won't know
5 where the money's coming from, they'll question me
6 about it and I'm not explaining myself". I said, "You
7 need to send it to me or, simple fact, I will go to
8 the papers with it". I would never go to the papers
9 but the threat was enough for them to send me the
10 cheque.

11 Q. You now receive monthly payments from the Welsh
12 Infected Blood Support Scheme.

13 A. Yes.

14 Q. You have referred to the top-up payment that's started
15 to be made but the uncertainty of knowing whether that
16 will continue to be made.

17 A. Yes.

18 Q. Your overall experience of the trusts as described in
19 your statement is that they weren't fit for purpose.

20 A. No.

21 Q. You are made to feel, you have said, as if you are
22 begging?

23 A. Yes, you have to justify yourselves all the time,
24 every step of the way. As we heard this morning there
25 used to be a booklet they'd send out saying you can

1 claim X amount for this once-a-year, X amount for that
2 and then that went, so it was pot luck. I think if
3 your name fitted, if you hadn't ruffled too many
4 feathers you might be in with a chance of getting
5 something but otherwise you had to fight for every
6 penny.

7 Q. Has that changed? Is your impression any different
8 with the current Welsh scheme?

9 A. I'm not aware there's a mechanism for claiming
10 anything else other than the normal payments now so
11 I haven't -- I can't comment on ...

12 Q. Can I ask you for your perspective on what the effect
13 of your infection and illness and treatment has been
14 on your wife and on your family.

15 A. Yes, I thought about this and it's quite a difficult
16 one really because [my wife] never moans. She has
17 looked after me. She's consoled me. She's done
18 everything. When we married there was not one wedding
19 vow that covers any of this at all and she has,
20 especially with the termination, it absolutely
21 destroyed her. I'll always live with that guilt but
22 I got off lightly. I got off really lightly compared
23 to what she's had to put up with because I just bumble
24 along in life and whatever comes, you know, I'll deal
25 with it other I couldn't do it without [my wife] and

1 so I think the effect has been worse on [my wife] than
2 it has on me without a shadow of a doubt.

3 Q. Your son has provided a very eloquent witness
4 statement to the Inquiry, and he talks about how he
5 was robbed of the time that, as a father and son, the
6 two of you should have been able to do things together
7 that you weren't able to do.

8 A. Yes.

9 Q. Those are the questions I have for you. Is there
10 anything you would like to add?

11 A. I'd like to thank Sir Brian. And I know Sir Brian
12 will say it's his job to do it, but I would like to
13 thank you for the way it's being done because that's
14 what makes the difference; not just that we're being
15 listened to, but the kindness we've been shown by
16 everyone here, yourself and the team as well.

17 Although we've heard a lot about Professor Bloom
18 through the different evidence, I would like to say
19 how well, since Professor Bloom, that we've been
20 treated in Cardiff. They looked after my brother and
21 me and they still do now. They have been fantastic
22 all the way through.

23 Everybody in here today has heard our story and
24 nobody else knows the story. I had to fight my family
25 not to come here today. I could have filled the front

1 row with family. I asked every one of them why they
2 wanted to come and they wanted to come to support us.
3 They didn't want to come for themselves. If they
4 wanted to come for themselves, I would have said, yes,
5 come. But I wasn't willing for them to come to
6 support me, to listen to things and there's things
7 I've said today that they don't even know. There's
8 a couple of people who's come down from London to
9 support us because they know more than anyone else
10 does.

11 So it's something we had to do today but most of
12 all you've heard all the lowlights they are, not
13 highlights. But I want to thank [my wife] publicly
14 for everything she's done for me because, as you've
15 heard, we've adapted to live through everything we've
16 lived through and, believe it or not, a sense of
17 humour is a big part of it for us, isn't it.

18 So thank you all for listening to us. That's
19 all I am going to say.

20 Q. I am just going to ask Mr Snowden if there's anything
21 further he wants me to ask. *(Pause)*

22 Just one question in relation to the documents
23 that Mr Snowden's asked me to ask. Paul, could we
24 have back on screen, please, document 1275005. If we
25 could enlarge it, this is the letter from March 1985

1 that we looked at earlier because of what's said in
2 the second paragraph about "many haemophiliacs of
3 course being exposed to the HTLV-III virus".

4 But if we look just a little further down, we
5 can see that this is some nine months after you were
6 told your diagnosis and it's here that we see
7 Professor Bloom saying:

8 "I've therefore counselled him and his wife
9 regarding the use of barrier contraception, such as
10 condoms, and they may approach you for a prescription
11 for these."

12 There's a reference too in the bottom three
13 lines that Professor Bloom will shortly be talking to
14 your brother and counselling your brother and his wife
15 also.

16 It would appear from this that it's nine months
17 before that kind of advice was being offered to you?

18 A. Yes.

19 Q. Was there ever any more extensive counselling?

20 A. That's when you were pregnant, was it? [My wife] was
21 already pregnant by then.

22 Q. Was there ever any more extensive counselling offered
23 to you by Professor Bloom?

24 A. No, nothing at all.

25 MS RICHARDS: Thank you. Sir, that's everything.

1 SIR BRIAN LANGSTAFF: I just want to thank you very much
2 for coming here, particularly when you have
3 deliberately kept yourself pretty much to yourself as
4 you've described over the years for the reasons you've
5 given us, despite everything that happened to you and
6 your brother or perhaps because of it. But thank you
7 very much for telling us this today because it is
8 important to hear that type of testimony, to hear your
9 story. Thank you.

10 A. Thank you.

11 SIR BRIAN LANGSTAFF: We will take a break until 2.20.

12 MS RICHARDS: Thank you, sir.

13 **(1.08 pm)**

14 **(Luncheon Adjournment)**

15 **(2.22 pm)**

16 SIR BRIAN LANGSTAFF: Our next witness wishes to be known
17 as ...?

18 MS FRASER BUTLIN: Jane, sir.

19 SIR BRIAN LANGSTAFF: Jane.

20 **JANE JONES, sworn**

21 **Questioned by MS FRASER BUTLIN**

22 Q. Jane, you have von Willebrand's disease?

23 A. Yes.

24 Q. How often do you have bleeds?

25 A. When I was younger, fairly often but these days I've

1 had one bleed in the last four years.

2 Q. You had a miscarriage in 1982?

3 A. Yes.

4 Q. On that occasion you received cryoprecipitate?

5 A. I did, yes.

6 Q. When you received cryoprecipitate on that occasion,

7 were you warned about any risks of receiving the

8 products?

9 A. No, none at all.

10 Q. From your records, we can see that you also received

11 blood and blood products, including Factor VIII, in

12 1977, 1979 and 1984.

13 A. Yes.

14 Q. Again, on any of those occasions were you ever warned

15 of any risks of receiving either blood or blood

16 products?

17 A. No.

18 Q. You were infected with hepatitis C?

19 A. Yes.

20 Q. You think it was from the 1982 treatment.

21 A. Yes.

22 Q. Why is that?

23 A. It was because I'd lost so much blood I had to have

24 quite a bit of blood transfusion and a lot of cryo.

25 Q. So because of the volume you received you think that's

1 when you might have been infected but you don't
2 entirely know?

3 A. No.

4 Q. How and when did you come to be diagnosed with
5 hepatitis C?

6 A. Well, I became very lethargic. I was really, really
7 tired and not being able to do the things that I used
8 to do. Along with that, I had pain in my tummy so
9 decided to go and see my GP. That particular day,
10 there was a new GP at the centre and he examined me
11 and the first thing he said was, "And exactly how much
12 alcohol do you drink?" and I was totally gobsmacked
13 because I don't drink.

14 Now, I went home and it was just playing on my
15 mind about why would he ask me such a question so
16 I decided to phone then in Bangor Hospital my
17 haematologist, Dr Tom Korn, and he made an appointment
18 for me to go and see him. So I eventually went to see
19 him and he said, "I'd like to make a blood test, take
20 a blood test, and I'm looking for the virus
21 hepatitis C because [redacted] had previously been
22 diagnosed with hep C".

23 He said, "Don't worry about it, you know,
24 because I don't expect it to be anything other than
25 a negative", so I had the blood test, went back for

1 a scan, so never thought any more about it. I went
2 back for the results and as soon as I walked through
3 the door it was the first thing that hit me there was
4 a yellow sticker on my medical notes which weren't
5 there before.

6 Q. Do you remember what that yellow sticker said?

7 A. Danger of infection.

8 Q. What did Dr Korn tell you at that appointment?

9 A. Well, he sat there for a few minutes not being able to
10 say anything and then he proceeded and told me that
11 I was hepatitis C positive.

12 Q. You were there on your own that day?

13 A. Yes. Because he'd said that he didn't expect it to be
14 anything other than negative. You know, I just went
15 by myself thinking the same thing.

16 Q. What were you told at that point about hepatitis C?

17 A. Nothing, absolutely nothing.

18 Q. Did you know anything about the virus from [redacted]
19 or from anybody else?

20 A. Not a lot. I knew [redacted] had it and I knew the
21 problems that [redacted] had had, and that was one
22 thing after I came out from the consultation room,
23 I just sat in the foyer of the hospital thinking,
24 "Hmm, I can't do this", and from that very moment
25 I just wanted to end it all because [redacted] used to

1 bleed and bring all this blood up and I knew I wasn't
2 strong enough. I couldn't do that, couldn't go
3 through that.

4 But anyway, I decided to go home instead and
5 just, basically, for a few years just carried on with
6 life the way it was and nothing was mentioned of it.

7 Q. You think that was about 1992 --

8 A. Yes.

9 Q. -- that you had that appointment?

10 A. Yes.

11 Q. 1993/1994 you had to have your gall bladder removed?

12 A. Yes.

13 Q. Can you tell us what happened when you were in the
14 hospital.

15 A. I went in and they put me in a cube by myself and
16 I had my operation went back to the cube and
17 I couldn't understand why nobody ever came to the
18 room, not even to help me to go to the toilet because
19 it had it's own toilet in the room where I was, and
20 when my parents and my children used to come and visit
21 me they were gowned up with masks and aprons and
22 I thought, "God, they are treating me as if I've got
23 the plague".

24 They wouldn't even come in and bring my food for
25 me. They'd leave my food outside of the room and it

1 was just pot luck if somebody happened to come in to
2 see me for them to bring me the food otherwise the
3 food would be there, and this all went on for a couple
4 of days and [redacted] came to see me and I said,
5 "[redacted], can you go to the haematology ward and
6 ask Dr Korn to come here".

7 Anyway he came and I said, "You've got two
8 choices, you can either move me from this surgical
9 ward to the haematology ward or I'm signing myself
10 out". I couldn't take any more of it, you know, the
11 way people were treating me. So, eventually, he said,
12 "Fine, I mean, there's no way you're going home", so
13 they moved me and the treatment I had on the
14 haematology ward was fantastic.

15 Q. In about 1999, you went down to the Cardiff
16 Haemophilia Centre with [redacted].

17 A. Yes.

18 Q. Can you remember what happened?

19 A. Well, [redacted] introduced me to Dr Dasani at the
20 Heath and he turned round and he said, "Well, I'm
21 quite happy" -- because Bangor it seemed they were
22 like in the dark ages and down in Cardiff they were
23 more up-to-date with things and he said, "I'm quite
24 happy to take over your care, a shared care between
25 Bangor and Cardiff", so that's how I started coming to

1 Cardiff.

2 Q. Could we have document 2360005, please. It's a letter
3 from Dr Dasani to your doctor in Bangor and you think
4 this is the letter that relates to that first
5 appointment with Dr Dasani?

6 A. Yes.

7 Q. It refers do you seeing him. It goes on to say:

8 "I'd be grateful if you could provide me with
9 detailed information of her hepatitis C, in particular
10 her liver function tests, liver biopsy results and
11 hepatitis C genotype if known. I am interested in
12 learning about hepatitis C in pooled blood products
13 recipients and response to treatment which is
14 different to other patients."

15 Were you aware that Dr Dasani would be asking
16 for this information?

17 A. No.

18 Q. Were you aware that he had an interest in learning
19 about hepatitis C in pooled blood products recipients?

20 A. No.

21 Q. You had treatment for your hepatitis C on a number of
22 occasions?

23 A. Yes.

24 Q. You think the first time you tried the treatment was
25 1996?

1 A. Yes.

2 Q. Dates are a little -- you are a bit unsure about dates
3 but you think it is 1996, the first attempt was with
4 interferon and ribavirin.

5 Can you tell us what happened on your first
6 attempt?

7 A. It was sheer hell. Within half-an-hour of having the
8 first injection, I was -- every bone in my body, every
9 muscle in my body, I couldn't let anybody touch me
10 because I was hurting so much. I used to lie on the
11 sofa and I was just shaking with the shivers. It was
12 horrible, absolutely terrible. I wouldn't wish it on
13 my worst enemy.

14 Q. That series of treatment was unsuccessful.

15 A. Well, after six months they checked my bloods and
16 I was negative and I remember my youngest son saying,
17 "Great, Mam, you can have a party. You've got rid of
18 it", so I said, "No, leave it for now", so I carried
19 on for 12 months. At the end of 12 months I was still
20 negative but within two weeks of finishing the
21 treatment I was back positive.

22 Q. You then started your second attempt very shortly
23 afterwards.

24 A. Yes.

25 Q. Again with interferon and ribavirin.

1 A. Same effects again. I only took it for about six
2 months because I couldn't handle it.

3 Q. Very shortly after that you had a short break and then
4 you had a third attempt?

5 A. Yes, I started the third down in Cardiff and it was
6 just ... it was just suicidal thoughts, you know.
7 I just wanted to die.

8 Q. The third time you said in your statement the
9 treatment destroyed your white blood cells.

10 A. Yes.

11 Q. You lost all your hair.

12 A. Yes.

13 Q. You couldn't cope anymore.

14 A. No.

15 Q. And you became suicidal.

16 A. Yes.

17 Q. You attempted suicide.

18 A. Yes.

19 Q. Can you tell us what happened after that when you were
20 admitted.

21 A. Well, obviously I had some treatment down here at the
22 Heath but when I went back home then there was nothing
23 to be had, so since then I've had to sort of keep
24 everything in and sort of do the best I can.

25 Q. The team at Cardiff were so concerned about you that

1 they admitted you straight into -- as an in-patient?

2 A. Yes.

3 Q. How long did you stay as an in-patient?

4 A. About two weeks, I think.

5 Q. The psychiatrists realised that it was the interferon

6 that was causing your difficulties.

7 A. Yes, because apparently a few people had actually

8 committed suicide whilst on the treatment because it

9 was so bad. It just takes hold of you and because

10 you're so ill you just don't want to carry on.

11 Q. You were then discharged and allowed to go home.

12 A. Yes.

13 Q. And that was the end of the third attempt at

14 treatment.

15 A. Yes.

16 Q. What was your health like after the third attempt at

17 treatment and before you had the fourth?

18 A. It was getting more tired, more pains in my stomach

19 and everything and then we decided -- by then I'd met

20 my partner John here, Johnnie, and he said, you know,

21 give it another go so we decided to give it another go

22 and I said, "Well, if it doesn't work this time that's

23 it, definitely no more". I did the six months but to

24 no avail.

25 Q. That also failed. So you had four rounds of

1 interferon in various combinations and none of them
2 had been successful.

3 A. Yes.

4 Q. In 2009 you became very unwell?

5 A. Yes.

6 Q. Can you tell us what happened?

7 A. Well, I realised at the time that I was so, so tired
8 this time and dizzy, felt faint and I was decorating
9 the bedroom and I'm the type of person if I start
10 a job I want to finish it no matter what, and I was
11 decorating the bedroom and every time I went up the
12 step ladder to sort of measure, as soon as I got down
13 I would have to lie down on the bed for about 20
14 minutes because I was out of breath and giddy and
15 everything, and this carried on for a couple of days.

16 And then Johnny, my partner, he said, "I'm going
17 to take you into Bangor. You need to be checked over.
18 There's something not right here". Anyway, we went
19 there, did some blood samples and they came back and
20 they said, "Jane, your haemoglobin is only 6.2. You
21 need to stay in. You need blood and you need
22 Factor VIII because obviously you are actively
23 bleeding somewhere", and I hadn't realised, lack of
24 knowledge most probably, whenever I used to go to the
25 bathroom my stools were black like tar but I didn't

1 know any different because of what [redacted] was
2 going, she was bringing blood up and it was working
3 the other way round for me you see so I never thought
4 anything of it.

5 So that was the start and then my son became
6 ill, so I was having to try and care for him. He was
7 in Liverpool in, Broadgreen, waiting to go to theatre
8 to have a valve replacement and at the same time I had
9 my partner Johnny was rushed to another hospital in
10 Liverpool. They found out he had cancer. So for
11 about ten days I was running from one hospital to the
12 other all day long from morning until night and having
13 to put myself on the back burner because obviously my
14 son came first, my partner came second and I came
15 last.

16 That nearly killed me. But nevertheless
17 I carried on and then I lost my son in the end and to
18 this day I blame myself because I wasn't there for him
19 100 per cent because there was some days that, do you
20 know what I mean, I was just so tired and I'll never
21 forgive myself for that.

22 I know in a way that it's not my fault but I was
23 his mother, it was my place to be there with him and
24 look after him. So in a way I'm glad he's never seen
25 what I've been through since then because things just

1 went from bad to worse.

2 Q. You continued to have a number of bowel bleeds over
3 a number of years.

4 A. Yes.

5 Q. In 2013 you had a further significant bowel bleed.

6 A. Yes.

7 Q. On that occasion you were told you couldn't have an
8 endoscopy. Why was that?

9 A. Because I was high risk of CJD.

10 Q. Before that, had you ever been told that you were at
11 high risk of variant CJD?

12 A. No.

13 Q. Could we have document 236044, please.

14 It is a letter from Dr Hamilton to your GP. If
15 we look at the second main paragraph it recounts that
16 you'd:

17 "... recently had an episode of gastrointestinal
18 bleeding and was unable to have an endoscope due to
19 her CJD status. She is considered to be at high risk
20 for public health purposes as she did receive an
21 implicated batch of treatment. She doesn't recall
22 receiving the formal notification letters regarding
23 this and I shall send this out again. I've explained
24 that this is a theoretical risk and so far no patient
25 with a bleeding disorder has developed CJD following

1 an implicated batch of the treatment. However, she
2 was understandably concerned regarding this today."

3 When you got your medical records, there were
4 two documents in there dealing particularly with the
5 vCJD, wasn't there? One of them was from Bangor --
6 236006, please -- which shows a note in handwriting
7 against an implicated batch which is where you think
8 your high risk status comes from.

9 A. Mmm.

10 Q. The second document was one from Cardiff. 2360002,
11 please. This is a letter from the University Hospital
12 of Wales and it says that they are enclosing a letter
13 and patient information sheet which is what you think
14 you never received.

15 A. No, I didn't, no, no.

16 Q. But the letter says:

17 "We're enclosing a letter and patient
18 information sheet about vCJD that the Welsh Assembly
19 and Department of Health has instructed us to send to
20 everyone with a bleeding disorder who attends the
21 Haemophilia Centre in Cardiff. The same letter is
22 being sent today to everyone in the UK who has
23 a bleeding disorder. We have not been given any
24 leeway as to when this letter is sent to you and for
25 some people we realise that it will arrive at an

1 inappropriate time."

2 If we continue down the letter notes that:

3 "We have no records of you receiving plasma
4 products in Cardiff during this period."

5 A. No, I didn't.

6 Q. But of course you had received it in Bangor?

7 A. Yes, I had, yeah.

8 Q. They tell you to check with the other centre if you
9 have been treated elsewhere and then the following
10 paragraph:

11 "Many people receiving this letter and
12 information sheet will be worried and we are sorry
13 about causing anxiety. We did not prepare the letter
14 and information sheet and we were not consulted about
15 its contents. We would have tried to make the
16 information easier to understand and more relevant to
17 individuals if we had had the opportunity. We would
18 also have much preferred to give this information to
19 everyone in person. We were unable to do this by the
20 way the Government decided to make the announcement."

21 Then they indicate that they are willing and
22 would be pleased to talk to anyone who has any
23 questions. You found those in your medical records.
24 You don't think you received it at any point but they
25 were there.

1 A. No. Because the reason why, we keep every document
2 that we receive from the hospital and that has been
3 proved to me that I have contracted it through blood
4 products because there are letters and this states up
5 the top that I'm von Willebrand's disease, transfused,
6 hepatitis C positive, so I've got them all, so why
7 would I not keep this if I've had it.

8 MS FRASER BUTLIN: Sorry, I thought, sir, you had
9 a question you wanted to raise.

10 When you were told that you were high risk for
11 vCJD, how did that make you feel?

12 A. It was just another knife in my heart, you know. It
13 was bad enough having hepatitis C and then to be told
14 something like this afterwards.

15 Q. In about 2013, as well as the bowel bleeds that you
16 were having, you were becoming unwell with your liver
17 and you were having to have ascites drained on
18 a regular basis.

19 Can you tell us what was happening in that
20 regard?

21 A. If I was honest, I was in Liverpool, I had been rushed
22 to Liverpool after one of the episodes of the bleeds
23 I had from the bowel. I was unconscious going there.
24 I sort of woke up a couple of days later and
25 I remember the day I was going home the haemophilia

1 nurse, Jane her name was, I was very, very breathless
2 and I was struggling to get up in bed and she said,
3 "How long have you been like this for?" And I said,
4 "What do you mean?"

5 "Well, breathless and struggling to get up."

6 "Oh, I've always been like this", I said to her
7 because I just wanted to go home. So I pushed that to
8 the back of my mind and persuaded her that it was
9 a normal thing, but it wasn't.

10 What it was it was the ascites starting and I'd
11 gone from like 9.5 stone to 13 and I did get weighed
12 at the hospital and I thought there's got to be
13 something wrong with these scales. There is no way
14 I'm 13 stone but what it was, it was all this fluid
15 that I was having in my stomach.

16 Q. So what happened next in relation to your liver?

17 A. I was going in to Bangor then and having the ascites
18 drained and then in the latter part of, you know,
19 before things even got worse, whenever they'd put
20 a drain in me they'd have to put a little nick with
21 a knife first to put the drain in and it was just
22 bleeding everywhere, and I remember a student doctor
23 tried to do it, which I wasn't very comfortable about,
24 seeing that she hadn't done it more than a couple of
25 times, and there was just blood everywhere, and

1 instead of being there for a couple of days I ended up
2 for weeks there because, you know, because my liver
3 wasn't working.

4 Obviously, it was making whatever I had of
5 clotting agent in my blood, which was very little, but
6 it was making it worse because my liver wasn't
7 working, so I was having to have B12 injections and
8 everything to try and help it. So I was going
9 backwards and forwards then to have my stomach
10 drained, yes.

11 Q. On one occasion you have told us in your statement
12 about an occasion when you met a friend and you had
13 a very swollen -- you were very swollen from the
14 ascites?

15 A. Yes, and they thought I was pregnant.

16 Q. What was their response when you told them?

17 A. They couldn't believe it because I hadn't told them
18 anyway that I had hepatitis. But I just said, "Oh,
19 I've got a problem with my liver".

20 Q. They responded, "Gosh, who would have thought, you an
21 alcoholic".

22 A. Yes. Well, that was when I went for a scan to the
23 hospital in Bangor and it was an early scan in the
24 morning and then, "Oh great, we can have cup of tea
25 and something to eat now", so we went to the café and

1 it was somebody that we knew and he said, "Oh, what
2 are you doing here", and I said, "I've just been for
3 a scan".

4 "God, I didn't know you were pregnant", he said.
5 I said, "No, I'm not pregnant". I said, "I've just
6 been for a scan on my liver", not thinking anything.
7 He said, "Oh my God", he said, "Who would have thought
8 that you were an alcoholic", and I thought ... that
9 knocked me for six, that did, to think that somebody
10 thought I had a problem with alcohol and specially
11 what the GP had said some years previously. I thought
12 lack of knowledge.

13 Q. As the ascites got worse there were then discussions
14 as to whether you should have a liver transplant?

15 A. Yes.

16 Q. What can you tell us about that?

17 A. Yes, it was in the August I was then sent to -- August
18 2014, I was sent to Birmingham to the Queen Elizabeth
19 to see somebody there and they said that the best step
20 forward was to have a liver transplant and we went
21 there for the first assessment where you get all these
22 blood tests and x-rays, scans on your heart and so
23 forth, and then you were to go back the following
24 month to have the second part of the assessment.

25 But in between the two assessments I became

1 very, very poorly and Johnny, my partner, he said --
2 I woke up on the Monday morning and I thought today's
3 my last day, I was so, so ill. He said, "You're going
4 in". I said, "Just leave me, you know. Let me be".
5 Anyway he had his own way as usual and I was taken in
6 and within an hour I was in intensive care.

7 What had happened was all this fluid I had in my
8 stomach had punched a hole in my diaphragm and it was
9 slowly drowning me, drowning my lungs, so then I had
10 to start having my lungs drained as well as my
11 stomach.

12 Q. There were discussions about whether you should then
13 be transferred to Birmingham --

14 A. Yes, they wanted -- because I was due to go in for the
15 second assessment while I was in intensive care and
16 Bangor said, "Oh, we'll gets an ambulance and we'll
17 send you over to Birmingham". So they phoned
18 Birmingham up and they said, "Well, it's not fair
19 doing that on her because she won't get a true
20 assessment and the chances are they'd say no, she
21 won't go on the list, she's too poorly", so I had to
22 wait a month to see how I'd be.

23 So I went down to Birmingham in the November and
24 I had the second assessment but they'd found a problem
25 with my heart, because of all the fluid I had in my

1 body it was putting a lot of pressure on my heart.
2 Anyway, they gave me another scan and thankfully
3 because I had been drained, my lungs had been drained
4 and my stomach like two weeks before going to
5 Birmingham, the heart was much better. So we had
6 a phone call at the end of November saying, "Yes,
7 you've made it on the transplant list".

8 Q. Before you could have the transplant the team were
9 keen for you to have further treatment for the
10 hepatitis C.

11 A. Yes.

12 Q. So this time you went on to ribavirin and Sofosbuvir
13 and daclatasvir and what was that treatment like?

14 A. That was fine. I didn't have any problems whatsoever
15 and the best part was it worked.

16 Q. It cleared the virus.

17 A. Yes.

18 Q. You completed that in December 2014.

19 A. Yes.

20 Q. And then in February 2015 you underwent a liver
21 transplant?

22 A. Yes, I did.

23 Q. You were in hospital for nine days.

24 A. Yes.

25 Q. And the transplant was a success.

1 A. Yes.

2 Q. What's your health like now?

3 A. I don't think it's ever been better. I can do things
4 now that I couldn't before and I hadn't done for
5 years. So it made -- I remember when I woke up after
6 the transplant and I thought, "Oh my God, where am I?
7 I'm in somebody else's body". It was like an instant
8 thing because I had been so poorly, it was just
9 unbelievable.

10 Q. Can you tell us a little bit about the impact of your
11 ill health and what the impact has been on your
12 children?

13 A. Well, my son used to say -- well, my youngest son used
14 to say, "Do you know, Mam", he said, "Normal for us
15 was we thought when other people went on holiday our
16 holiday was going to visit you in hospital. That was
17 the normal thing for us", and it's only, you know, the
18 last few years that they've started going on holidays
19 themselves that they realised, yes, this is what
20 normal is, not when we had to go and visit Mam every
21 few months in hospital.

22 But I just feel sorry for them, do you know what
23 I mean, like I said, especially with my eldest son,
24 you know. I've missed out so much with them and with
25 him. Like with my son and my daughter now, my

1 daughter and me we've started going out, like we went
2 to London in February and it was the first time that
3 we've been able to do something together.

4 My youngest son he likes to go abroad so he goes
5 with his daughter but I so miss -- I can't have the
6 time with the son I lost. I can never get that back
7 and try and make it up for him.

8 Q. You say in your statement:

9 "It bothers me greatly. There was a period when
10 I couldn't do things with the kids, go for a walk, go
11 to the park and go and have a picnic on the beach."

12 A. That's true.

13 Q. You were told in about 2005 about The Skipton Fund.

14 A. Yes.

15 Q. And received a payment from them and then received
16 a further payment when your liver deteriorated?

17 A. Yes.

18 Q. You now receive payments from the Velindre Trust?

19 A. Yes.

20 Q. Do you remember applying for the payments?

21 A. No, it was done -- I think it was done -- I think it
22 was Dr Dasani, actually, who done it. He did
23 everything in Cardiff for me so I didn't have to do
24 anything, but the only thing was because there was one
25 stage when we were coming or it was the last one,

1 wasn't it, the fourth one in Cardiff, where --

2 Q. The fourth treatment, fourth attempt at treatment?

3 A. The treatment, sorry, yes, where we had to come down
4 every week for six months. We couldn't miss a week.
5 We had to come down every week and it was like
6 a financial burden for us because Johnny had to take
7 time off work and nobody said that we could claim any
8 money back and it was the same with the cold winter
9 payment, because obviously when you have got something
10 seriously wrong with your liver you feel the cold and
11 I used to sit in the house with my clothes on,
12 a fleece dressing gown on, heating full on and people
13 would say, "God, what's wrong with you? It's
14 sweltering in here", and I used to shiver I was so
15 cold. I'd go to bed in all my clothes and my dressing
16 gown and I'd still be cold. Nobody told us about
17 anything we could claim like that, you see.

18 Q. So while you are grateful the paperwork was done for
19 you, you wish there had been more information about
20 the travel expenses and winter fuel payments?

21 A. Yes.

22 Q. Those are the questions I have for you. Is there
23 anything else you would like to say?

24 A. The only thing I want to say is, first of all, is to
25 thank this man that's sat next to me. If it wasn't

1 for Johnny I wouldn't be here now. He's the one
2 that's pushed me to be where I am today.

3 Secondly, I'd like to thank my donor angel.
4 Without her I wouldn't be here either. I'd like to
5 thank Lynn Kelly, who has been a backbone for us with
6 everything that we've gone through. She's always been
7 there for us. Thanks Sir Brian and the team for
8 letting me have this opportunity to tell you my story.
9 Thank you.

10 Q. I am just going to turn ... there are no further
11 questions.

12 SIR BRIAN LANGSTAFF: Well, thank you very much for not
13 sparing us the brutal reality of your illness and the
14 treatment that you've had and its effects on you.
15 It's important to hear it in the way that you've told
16 it; so thank you.

17 A. Thank you.

18 SIR BRIAN LANGSTAFF: We will take a break until 3.20.

19 **(2.55 pm)**

20 **(A short break)**

21 **(3.27 pm)**

22 SIR BRIAN LANGSTAFF: Now our next witness is the second
23 anonymous witness of the day and will be known as
24 Mrs AG.

25 So I make the order that the name and address of

1 point or was about to do something?

2 A. He'd just finished. He was about to enjoy retirement
3 and do three days a week with some friends working on
4 central heating systems.

5 Q. You have described your Dad as someone who was
6 incredibly fit?

7 A. Incredibly fit. That's the word.

8 Q. Can you tell us how he came to be diagnosed with
9 leukaemia?

10 A. Well, he had a cold sore on his mouth and felt
11 lethargic and went to the doctor who took blood tests
12 and this is when they diagnosed the leukaemia.

13 Q. That was in early 1972?

14 A. That's right.

15 Q. He initially received treatment at the Cardiff
16 Infirmary?

17 A. That's right.

18 Q. He was then transferred to the Heath Hospital?

19 A. It had just opened. It was newly refurbished.

20 Q. Newly built. You know your Dad was given a number of
21 transfusions but particularly one on 17 June 1971.

22 A. Yes.

23 Q. Why does that transfusion particularly stick in your
24 mind?

25 A. Because my father's condition deteriorated after that

1 time.

2 Q. Can you tell us about that.

3 A. Yes. This was [redacted] was his grandson's first
4 birthday, which was my son, and when we went in to
5 visit my Dad that evening, the nurses said he had got
6 out of bed, couldn't walk, and had crawled on his
7 hands and knees to the telephone to ring to wish his
8 and grandson a happy birthday. Up until that time, he
9 had been walking.

10 Q. Do you remember after that when you went to visit him
11 something else had changed as well. You and your Mum
12 had to put on gowns?

13 A. Yes, that happened on one occasion. They told us they
14 didn't want us to transfer any infections to him due
15 to his leukaemia and we wore gowns and masks.

16 Q. From the June/July your Dad's condition just continued
17 to deteriorate?

18 A. Very much so.

19 Q. And he died in September 1972.

20 A. Yes, that's right.

21 Q. After he died, a nursing sister spoke to you and your
22 Mum about a post-mortem. What did she say?

23 A. She spoke to my Mum first and asked if my Mum would
24 agree to a post-mortem and my mother said to me,
25 "I don't think so". She didn't like the thought of

1 him being cut up after his death because she thought
2 he'd gone through enough and the nurse then asked to
3 speak to me and said, "Please, could you ask your Mum
4 to agree to a post-mortem because it would be within
5 her interest because your Dad had suffered asbestosis
6 and also hepatitis", so my Mum reluctantly agreed.

7 Q. Until that point had you or your Mum been told that
8 your Dad had asbestosis?

9 A. No.

10 Q. Or hepatitis?

11 A. No.

12 Q. As far as you are aware, do you think your Dad knew
13 that he had hepatitis?

14 A. No.

15 Q. Why are you so sure he didn't know?

16 A. We think he would have mentioned it. I honestly don't
17 think he was told.

18 Q. Were you ever told about what kind of hepatitis it
19 was?

20 A. No.

21 Q. It was just said to you that he had hepatitis?

22 A. And it was just the nurse. It wasn't a doctor.

23 Q. Your Mum wasn't sure about the post-mortem but then --

24 A. She reluctantly agreed and a short while after,
25 I can't remember how long afterwards, the same nurse

1 came to see me and said, "We're terribly sorry we
2 cannot carry out the post-mortem because the
3 post-mortem room would be out of action for three days
4 to be fumigated because of the hepatitis and the
5 asbestosis and would you please accept leukaemia on
6 his death certificate although that is not what he
7 died of".

8 Q. What happened then?

9 A. We were horrified. We just didn't understand. They'd
10 firstly asked if they could do the post-mortem and
11 then said no. We thought there must be more than one
12 post-mortem room in the Heath Hospital. It's a new
13 hospital, but my mother didn't want to cause any
14 problems and said yes we'll agree to leukaemia on the
15 death certificate and leave things at that, which is
16 what we did.

17 Q. Four months after your Dad's death, a letter arrived
18 at your Mum's home. Could we have document 0695002,
19 please. It says this, it was written to your Dad
20 indicating that he was transfused on 17 June 1972 and
21 it simply says:

22 "We're following up a certain number of
23 recipients of blood transfusion to find out whether
24 they suffered any ill effects after the transfusion.
25 Would you be good enough to complete the enclosed form

1 and return it to me in the stamped addressed envelope
2 provided."

3 We can then see some handwriting underneath
4 that. That's your writing that you put some notes on
5 at a later date.

6 A. That's right.

7 Q. What did you do after you received this letter?

8 A. Well, I must admit it upset my mother terribly,
9 addressed to my Dad. And she telephoned me and I went
10 up to see her and we said, well, what was in this
11 blood transfusion? Why are they writing this letter,
12 and why haven't they checked their records with the
13 Heath, and they would understand my Dad had died three
14 or four months before.

15 So I wrote back to them asking why this letter
16 had been sent to my Dad when he had died, why hadn't
17 they checked their records and what was in that blood
18 transfusion?

19 Q. Did you ever get a response?

20 A. I did not have a reply.

21 Q. Subsequently you found this letter had been kept for
22 all these years?

23 A. I found it after my mother's death and it was -- yes,
24 she'd kept it.

25 Q. But to this day, you still don't know what that letter

1 was really asking about?

2 A. No.

3 Q. You also found out that one of the nurses left shortly
4 after your Dad died?

5 A. She did.

6 Q. Why does that raise concerns for you?

7 A. Well, we felt that the nurses knew more than they were
8 able to say. We couldn't understand why they didn't
9 put hepatitis and asbestosis on the death certificate
10 without the post-mortem because they knew he had it.
11 They told us.

12 The nurses knew and I think some of the nurses
13 got terribly upset at what was going on in the
14 background there and they just couldn't take it
15 anymore. The one nurse did say, "Things are happening
16 here. I can't stay here anymore".

17 Q. But you have never been able to establish what was
18 happening?

19 A. No.

20 Q. Or to have any answers to your questions?

21 A. No.

22 Q. You lost your Dad, your Mum lost her husband. What,
23 if anything, do you want to tell us about that,
24 particularly in relation to your Mum?

25 A. Well, my Mum spent the next 20 years on her own and

1 she -- it upset her terribly, the type of death her
2 husband had had. We saw him deteriorate so rapidly
3 and she would go to bed at night with these horrible
4 thoughts in her head and she didn't sleep very well.
5 It was just something that stayed in her mind until
6 she died.

7 Q. You have described in your statement that your
8 father's death haunted your mother for the rest of her
9 life.

10 A. It did haunt her; it did haunt her.

11 Q. You have said that it was particularly the questions
12 about what had happened that haunted her.

13 A. Things we didn't know. It was the why, the why didn't
14 they put the details on the death certificate because
15 they told us he had it; so they knew that. We just
16 felt that there was a cover-up.

17 Q. Your Mum struggled financially after your Dad's death.
18 Can you tell us about that.

19 A. Well, she just had a widow's pension. She was then 60
20 herself. She did take a three-day week part-time job
21 in a local shop, a newsagents, to help with finances.
22 I think she just found it very difficult because my
23 Dad was going to work three days a week which would
24 have brought an income into the home.

25 Q. She never applied for any financial assistance?

1 A. None whatsoever. We didn't know she could do that.

2 Q. Those are the questions I have for you. Is there
3 anything else you would like to say?

4 A. No, I would just like to thank the Inquiry for
5 bringing this to the fore and hope that something good
6 can come out of it and these cover-ups just won't keep
7 happening.

8 MS FRASER BUTLIN: Sir?

9 SIR BRIAN LANGSTAFF: You have described events 47 years
10 ago with admirable clarity. I have to say that
11 I reckon that you were probably very nervous when you
12 came to give evidence.

13 A. Yes.

14 SIR BRIAN LANGSTAFF: I see you nodding. Everyone must be
15 but you realise how important it is that evidence such
16 as yours is given about a death and a transfusion so
17 long ago all of which is an important part of the
18 picture and I just want to let you know how much your
19 evidence, short though it may have been, has been
20 appreciated. Thank you.

21 A. Thank you very much. It's never gone out of my head.

22 SIR BRIAN LANGSTAFF: Well, I can see that and that's what
23 makes it so useful to hear.

24 A. Thank you.

25 SIR BRIAN LANGSTAFF: If you just want to stay there for

1 a moment while I tell everyone what's happening, or
2 I don't tell everyone what's happening tomorrow,
3 Miss Fraser Butlin will. What is happening tomorrow?

4 MS FRASER BUTLIN: We'll be hearing from Gaynor Lewis,
5 Beverly Tumelty, Huw Thomas and Anthony Lane.

6 SIR BRIAN LANGSTAFF: And we start at 10.00. So
7 10 o'clock tomorrow morning, please.

8 **(3.41 pm)**

9 **(Adjourned until 10.00 am the following day)**

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MONICA SUMMERS, sworn1
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