

1 **Monday, 26 September 2022**

2 **(10.00 am)**

3 **(Proceedings delayed)**

4 **(10.30 am)**

5 **SIR BRIAN LANGSTAFF:** Welcome to the six of you and the

6 seventh who is anonymous. Let me deal with the

7 position of that anonymous witness first, if you don't

8 mind.

9 My apologies though to you and to those who are

10 listening for the delay there has been this morning.

11 It has been for logistical reasons. I don't think --

12 it may be a reflection of the fact that we have quite

13 a number of you together, which will make for a very

14 interesting day talking about the Skipton Fund and

15 refusals and lack of records in particular, but

16 telling your stories as well.

17 But first let me speak about that witness, the

18 witness who is anonymous. You will not see that

19 witness on screen, I will. For that reason, although

20 Mary will administer the oaths and affirmations in the

21 usual way to those witnesses that we have on the panel

22 before you, I will be swearing in the witness who is

23 in this building but is not seen.

24 I have granted that witness anonymity and so

25 I make this order: the name and address of witness

1

1 **MS RACHAEL JOY TERSTEEG (sworn)**

2 **SIR BRIAN LANGSTAFF:** Robert Bamforth.

3 **MR ROBERT NORMAN BAMFORTH (sworn)**

4 **SIR BRIAN LANGSTAFF:** Now, Ms Fraser Butlin, we are not

5 going to hear I think from our anonymous witness this

6 morning and so that witness will take the oath, or the

7 affirmation I should say, at the start of this

8 afternoon's session.

9 **MS FRASER BUTLIN:** Yes, sir, that is correct.

10 **SIR BRIAN LANGSTAFF:** Very well.

11 **MS FRASER BUTLIN:** Thank you.

12 **Examined by MS FRASER BUTLIN**

13 **MS FRASER BUTLIN:** Sir, just so that those listening will

14 understand the plan this morning, we are going to hear

15 from each witness individually and then we will move

16 to a more thematic discussion together.

17 Robert, if we can start with you. You had

18 an accident in 1986 when you were skateboarding with

19 your sons; is that right?

20 **MR ROBERT BAMFORTH:** Yes.

21 **MS FRASER BUTLIN:** Can you tell us what happened?

22 **MR ROBERT BAMFORTH:** Well, I broke my ankle right off, my

23 foot right off, and it was really bad and I got taken

24 to the hospital.

25 **MS FRASER BUTLIN:** Just while you are speaking, would you

3

1 W4211 and any other identifying information, such as

2 the witness's image or a description of their

3 appearance, cannot be disclosed or published in any

4 form unless express permission is given by me or by

5 the solicitor to the Inquiry acting on my behalf.

6 Witness W4211 must be referred to only as Mr BD.

7 That's bravo delta -- BD. This order remains in force

8 for the duration of the Inquiry and at all times

9 thereafter unless otherwise ordered, and I may vary or

10 revoke the order at any time by making a further order

11 during the course of this Inquiry. As always, it is

12 vital that you respect and everyone listening online

13 respects the anonymity of our anonymous witness.

14 Mary, would you administer please the oaths to

15 those who are on the panel. Can we start with Andrew

16 Bragg, please.

17 **MR ANDREW JAMES BRAGG (sworn)**

18 **SIR BRIAN LANGSTAFF:** Gary McKelvey.

19 **MR GARY HUGH MCKELVEY (affirmed)**

20 **SIR BRIAN LANGSTAFF:** Ruby Gilkes.

21 **MS RUBY PERLINE GILKES (affirmed)**

22 **SIR BRIAN LANGSTAFF:** Peter Frith.

23 **MR PETER FRITH (affirmed)**

24 **SIR BRIAN LANGSTAFF:** Rachael Tersteeg.

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2

1 mind being a little closer to the microphone. That's

2 perfect, thank you.

3 You had a broken ankle but it was quite a severe

4 break?

5 **MR ROBERT BAMFORTH:** Oh, yeah, everything was broke right

6 across. It was hanging one -- a different way. Then

7 I shouldn't have been skateboarding at 40, really,

8 should I?

9 **MS FRASER BUTLIN:** You were taken off to hospital and you

10 required surgery to repair it?

11 **MR ROBERT BAMFORTH:** Yes.

12 **MS FRASER BUTLIN:** Bolting the ankle back together; is

13 that right?

14 **MR ROBERT BAMFORTH:** Yes, they done about 20-odd screws

15 and bolts in it and plates and everything.

16 **MS FRASER BUTLIN:** Your recollection is that you were then

17 unable to work for about eight months after the

18 accident?

19 **MR ROBERT BAMFORTH:** Yes.

20 **MS FRASER BUTLIN:** Why was that?

21 **MR ROBERT BAMFORTH:** Well, I just got so ill. It was not

22 the leg, the leg's never been right but it wasn't

23 that. I was just ill from everything. I caught

24 everything while I was in the hospital and I just was

25 ill for eight months.

4

1 **MS FRASER BUTLIN:** After the operation to bolt back the
 2 ankle, what were you told about giving blood in the
 3 future?
 4 **MR ROBERT BAMFORTH:** Well, they said when you have had
 5 an operation you shouldn't give blood for -- they
 6 didn't say forever, they just said you shouldn't give
 7 blood for a while, you know, a year or something like
 8 that.
 9 **MS FRASER BUTLIN:** At the time of the operation, were you
 10 told anything about having blood transfusions? Sorry,
 11 you will need to --
 12 **MR ROBERT BAMFORTH:** No. Sorry. No.
 13 **MS FRASER BUTLIN:** Thank you. About two years after the
 14 operation you decided to give blood again?
 15 **MR ROBERT BAMFORTH:** Yes.
 16 **MS FRASER BUTLIN:** And you did so again in 1993 as well
 17 is that right?
 18 **MR ROBERT BAMFORTH:** Yes.
 19 **MS FRASER BUTLIN:** Can you tell us what happened after you
 20 gave blood in 1993?
 21 **MR ROBERT BAMFORTH:** Well, I got a letter from the blood
 22 transfusion people telling me I've got, what's it, HC
 23 something or other --
 24 **MS FRASER BUTLIN:** Hepatitis C?
 25 **MR ROBERT BAMFORTH:** No, they didn't say --

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1 Hospital were doing a pilot scheme, doing tests on it,
 2 and he sent me straight there rather than to the local
 3 hospital, which wouldn't have known anything about it.
 4 **MS FRASER BUTLIN:** How much could the GP tell you about
 5 the hepatitis at that point?
 6 **MR ROBERT BAMFORTH:** Not a lot, no. I don't think any of
 7 them knew much about it.
 8 **MS FRASER BUTLIN:** So you went off to King's College,
 9 London, and what happened when you got there?
 10 **MR ROBERT BAMFORTH:** Well, they just -- I saw different
 11 doctors and they just kept me under checkups and all
 12 that and then they invited me to go on the trial,
 13 there was 200 of us or something went on the trial
 14 for, what was it, the ribavirin and ...
 15 **MS FRASER BUTLIN:** And interferon?
 16 **MR ROBERT BAMFORTH:** And interferon.
 17 **MS FRASER BUTLIN:** We will come to the trial in just
 18 a minute but if we just go back to the first
 19 appointment you had at King's. What can you recall
 20 about that appointment in terms of the discussions
 21 with the doctors about how you contracted hepatitis C?
 22 **MR ROBERT BAMFORTH:** I said to them, "How did I get
 23 this?", because I said, "I have never been a junkie;
 24 I'm not promiscuous", and he just said, "Well, you
 25 know" -- he sort of wasn't too clear about how you got

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1 **MS FRASER BUTLIN:** HCV?
 2 **MR ROBERT BAMFORTH:** HCV, that's it. But it said I could
 3 only get it through sharing needles as a drug addict
 4 or sex. So you can imagine what my wife of seven
 5 years thought when she heard that. You know what
 6 I mean.
 7 **MS FRASER BUTLIN:** After you received that letter what
 8 happened with your marriage?
 9 **MR ROBERT BAMFORTH:** It just finished. It broke up.
 10 **MS FRASER BUTLIN:** And how quickly did that --
 11 **MR ROBERT BAMFORTH:** Oh, within weeks. You know,
 12 because -- I don't know, she thought I'd either been
 13 playing around or she just didn't want to know how
 14 I had got the infection. You know?
 15 **MS FRASER BUTLIN:** You then went to live with your mum at
 16 that point?
 17 **MR ROBERT BAMFORTH:** Yes.
 18 **MS FRASER BUTLIN:** You also went to see your GP?
 19 **MR ROBERT BAMFORTH:** Yes.
 20 **MS FRASER BUTLIN:** What did your GP tell you about
 21 hepatitis C?
 22 **MR ROBERT BAMFORTH:** Oh, that's the luckiest thing I had
 23 because he had just read up on -- because they had
 24 only just found out about hepatitis C, they didn't
 25 know what it was, and he found out that King's College

6

1 it neither, you know.
 2 **MS FRASER BUTLIN:** I think at that appointment he asked if
 3 you had had any significant operations?
 4 **MR ROBERT BAMFORTH:** That's it, yes. He did, yes. He
 5 asked me if I had had any operation and I said I had
 6 had my leg -- then it was a few years before and, you
 7 know, he took -- said, "Well, that could have been how
 8 you got it", and that's the first time I knew that you
 9 could get it from anything other than what they had
 10 said you could get it, you know.
 11 **MS FRASER BUTLIN:** At that point you had your liver
 12 function tested and what were the results of that?
 13 **MR ROBERT BAMFORTH:** Weren't too bad at first, you know,
 14 and then slowly it got worse.
 15 **MS FRASER BUTLIN:** So you were monitored for quite
 16 a while, I think, weren't you, until about 2001 when
 17 you started on the ribavirin and interferon?
 18 **MR ROBERT BAMFORTH:** Yes.
 19 **MS FRASER BUTLIN:** I think the delay was because funding
 20 wasn't available until then; is that right?
 21 **MR ROBERT BAMFORTH:** Yes.
 22 **MS FRASER BUTLIN:** With that first round of treatment, was
 23 it successful? Did it clear the virus?
 24 **MR ROBERT BAMFORTH:** Well, they said it did and then
 25 I went back a month later and they said it hadn't,

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1 which was quite devastating because you lose faith in
2 what's happening then, don't you, you know what
3 I mean? Because I was quite happy having the
4 treatment, because anyone who has had the treatment
5 realises it is horrendous and, you know, then you
6 think, well, I'm going to have to have this again
7 or -- well, I didn't know if they would give it to me
8 again or whatever, you know. I asked them what would
9 happen, you know.

10 **MS FRASER BUTLIN:** What can you tell us about how the
11 first treatment round was, what was it like for you?

12 **MR ROBERT BAMFORTH:** The funniest thing was the first day,
13 I went and had the injection, and I got home and they
14 told me not to be on my own that night, but I -- my
15 son was with me and I said to him, "Go home, I feel
16 all right". I said, "I don't feel that good but
17 I feel all right", then about half an hour, an hour
18 after he went I couldn't control my body. I started
19 going into a ball, my muscles -- it was really odd and
20 my arms are coming up, my legs are coming up, and it
21 was really odd. But I never had that after that, you
22 know. The next -- all the other times it was all
23 right. But you are just so tired and you just -- it
24 is a nightmare really.

25 **MS FRASER BUTLIN:** You then had a second course of

9

1 know what I mean. I actually didn't put that in my
2 statement but -- it -- you know, I thought if I'm not
3 going to be able to work -- because I didn't know if
4 I was going to be able to work or not -- I thought if
5 I didn't work how do I pay my bills? I couldn't pay
6 a mortgage, so I bought a one bedroom flat that
7 I didn't have a mortgage on, you know.

8 **MS FRASER BUTLIN:** So you were diagnosed and moved from
9 being an aircraft engineer with a regular salary to
10 being a barber?

11 **MR ROBERT BAMFORTH:** Yes.

12 **MS FRASER BUTLIN:** Where you were, effectively,
13 self-employed?

14 **MR ROBERT BAMFORTH:** Yes.

15 **MS FRASER BUTLIN:** Then you had the treatment?

16 **MR ROBERT BAMFORTH:** Yes.

17 **MS FRASER BUTLIN:** And you were worried you wouldn't meet
18 the bills?

19 **MR ROBERT BAMFORTH:** Well, yes, because I couldn't work
20 every day. I would get up some days, especially when
21 you had to inject, the days you had to inject you have
22 to eat before you do it all. I lived on my own, so
23 you try and cook a meal, get something to eat, then it
24 takes you hours sometimes to get down to eating, you
25 know.

11

1 treatment in 2008 and that did clear the virus?

2 **MR ROBERT BAMFORTH:** Yes, but I had that for 18 months.

3 **MS FRASER BUTLIN:** Were you very unwell for those
4 18 months?

5 **MR ROBERT BAMFORTH:** Yes.

6 **MS FRASER BUTLIN:** In terms of your working life, once you
7 were diagnosed with hepatitis C, at that point you
8 were working as an aircraft engineer?

9 **MR ROBERT BAMFORTH:** Yes.

10 **MS FRASER BUTLIN:** What happened in relation to your
11 working life once you were diagnosed?

12 **MR ROBERT BAMFORTH:** I had to give that up. You know, two
13 things: one, it was physical and I couldn't really do
14 it; and, two, working with metal, you cut yourself and
15 that, and I was terrified that -- because I might work
16 on a bit and someone else has to work on it and I was
17 terrified that I was going to give it to someone else,
18 you know.

19 Lucky, when I left school I learnt to be a barber
20 and I have got -- managed to get a job in a barber
21 shop, so at least I kept working, but it cost me --
22 the first treatment cost me -- I had a house but I had
23 to get rid of that because I was starting to get in
24 financial trouble. And I sold the house and bought
25 a flat because I had to keep a roof over my head, you

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1 **MS FRASER BUTLIN:** How did you come to hear about the
2 Skipton Fund?

3 **MR ROBERT BAMFORTH:** My son had a friend who -- his wife
4 had got infected and she had been gone through the
5 Skipton Fund and got paid out and I never met her but
6 my son found out about it so I just got in touch with
7 them and got the forms through and just sent them off.

8 **MS FRASER BUTLIN:** So before you decided to contact
9 Skipton and make that contact because of the friend of
10 your son, had anybody mentioned the Skipton Fund to
11 you before that?

12 **MR ROBERT BAMFORTH:** Not at all, no.

13 **MS FRASER BUTLIN:** So you applied in 2009?

14 **MR ROBERT BAMFORTH:** Yes.

15 **MS FRASER BUTLIN:** For your application did you have any
16 medical records in relation to your operation?

17 **MR ROBERT BAMFORTH:** I tried to get medical records and
18 then Lister said they didn't have any records.

19 **MS FRASER BUTLIN:** So the hospital said they had no
20 records?

21 **MR ROBERT BAMFORTH:** Yes. Funny enough, the second time
22 they'd got them because they'd got no record of me
23 having any blood, they said they've got no record of
24 me having any blood.

25 **MS FRASER BUTLIN:** If we just take it sequentially.

12

1 **MR ROBERT BAMFORTH:** Yes, sorry.
 2 **MS FRASER BUTLIN:** It's okay. You applied for your
 3 records first time and what were you told that time
 4 from the Lister?
 5 **MR ROBERT BAMFORTH:** Just didn't have them.
 6 **MS FRASER BUTLIN:** No records. Then you tried to get the
 7 records a second time, and what were you told then?
 8 **MR ROBERT BAMFORTH:** Well, they come up with some records,
 9 but it was only about my broken leg, nothing about --
 10 well, I did think I'd sent you a copy.
 11 **MS FRASER BUTLIN:** Can you recall what those records
 12 contained when you did get a few records from them?
 13 **MR ROBERT BAMFORTH:** Well, it just said about how
 14 they'd -- it's words I don't even understand, you know
 15 what I mean. These doctors use words, you know what
 16 I mean? As far as I was concerned it was a broken
 17 ankle, but it was H, B, C and D, and all that. It
 18 didn't mean a lot to me what it said.
 19 **MS FRASER BUTLIN:** You also obtained your GP records is
 20 that right?
 21 **MR ROBERT BAMFORTH:** Yes.
 22 **MS FRASER BUTLIN:** But there was nothing at all in those
 23 records about blood transfusion?
 24 **MR ROBERT BAMFORTH:** No, I don't think they had anything
 25 there about the broken leg, let alone a blood

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1 presumably as a result of consultation between you and
 2 your doctor. Of course, if you do obtain any other
 3 supporting medical records then please return these
 4 along with your application form and we will consider
 5 it again."
 6 So those letters they are referring to were
 7 letters from your treating doctors in the 2000s?
 8 **MR ROBERT BAMFORTH:** Yes.
 9 **MS FRASER BUTLIN:** Who had said to you the likely cause of
 10 your infection was a transfusion?
 11 **MR ROBERT BAMFORTH:** Yes, or blood product.
 12 **MS FRASER BUTLIN:** That second sentence that says, of
 13 course, if you do obtain any other supporting medical
 14 records, were there any other supporting medical
 15 records that you could have got hold of?
 16 **MR ROBERT BAMFORTH:** No, because the hospital said they
 17 didn't have any at that time.
 18 **MS FRASER BUTLIN:** Did you appeal this decision?
 19 **MR ROBERT BAMFORTH:** No.
 20 **MS FRASER BUTLIN:** Am I right that's because you have
 21 quite severe dyslexia?
 22 **MR ROBERT BAMFORTH:** Yes.
 23 **MS FRASER BUTLIN:** So for you that just wasn't an option?
 24 **MR ROBERT BAMFORTH:** You know, just -- you look at forms
 25 and it just -- it's a nightmare. So I just give it

15

1 transfusion.
 2 **MS FRASER BUTLIN:** Your application was then refused and
 3 you sent further documents to the fund including
 4 letters from doctors since your diagnosis setting out
 5 their view that it had been a transfusion acquired
 6 infection; is that right?
 7 **MR ROBERT BAMFORTH:** Yes. They reckoned because I didn't
 8 have it before I had the broken leg and then I had it
 9 straight afterwards, they said it must have been that
 10 and -- but the Skipton just said no.
 11 **MS FRASER BUTLIN:** So you supplied those letters to
 12 Skipton. Then I just want to look at the refusal from
 13 Skipton, if we can put that on the screen.
 14 WITN4414013, please.
 15 It is just the middle two paragraphs, and reading
 16 out so everyone can follow:
 17 "It is with regret that I must advise you your
 18 application has been declined. This is due to the
 19 lack of supporting confirmation that you were treated
 20 with NHS blood or blood products prior to
 21 September 1991 and that this was therefore the likely
 22 source of your infection with hepatitis C.
 23 "On two of the letters we have received (one from
 24 2000 and one from 2001) it mentions a past transfusion
 25 but in the absence of medical records this was

14

1 up. Everything I have had in life I have had to work
 2 for so I don't expect to get anything from anyone, you
 3 know.
 4 **MS FRASER BUTLIN:** And the Inquiry has seen the forms that
 5 are required for an appeal and so they are familiar
 6 with the detail that is hard to provide.
 7 Thank you.
 8 **MR ROBERT BAMFORTH:** That's all right.
 9 **SIR BRIAN LANGSTAFF:** May I just ask this, looking at the
 10 dates of the information which recorded that the
 11 probable cause was a blood transfusion, both of those
 12 dates are before the Skipton Fund began.
 13 **MS FRASER BUTLIN:** Yes.
 14 **SIR BRIAN LANGSTAFF:** And indeed before it had been
 15 announced. So there could have been no prospect of
 16 that being said for gain at all.
 17 **MS FRASER BUTLIN:** Indeed.
 18 **SIR BRIAN LANGSTAFF:** Thank you.
 19 **MS FRASER BUTLIN:** Thank you, Robert.
 20 Rachael, you are here to talk about your late
 21 husband Cornelius, who was always referred to as Con
 22 by you and the family.
 23 **MS RACHAEL TERSTEEG:** That's right, yes.
 24 **MS FRASER BUTLIN:** So we will also refer to him as Con, as
 25 you wish.

16

1 **MS RACHAEL TERSTEEG:** Thank you.
 2 **MS FRASER BUTLIN:** Con was admitted to hospital on
 3 10 April 1987, is that right?
 4 **MS RACHAEL TERSTEEG:** That is correct.
 5 **MS FRASER BUTLIN:** Why was that?
 6 **MS RACHAEL TERSTEEG:** He had flu-like symptoms, he was
 7 feeling very unwell, he wasn't able to walk very well.
 8 It was as if he was having a stroke. Wycombe Hospital
 9 transferred him during the night because he
 10 deteriorated. He went to Oxford, Radcliffe Infirmary.
 11 They did scans and, when I arrived the next morning,
 12 they said he had an abscess and that was growing
 13 underneath the skull and on his brain, and they were
 14 going to monitor the abscess and then they were going
 15 to operate when they felt that that was the right
 16 time.
 17 **MS FRASER BUTLIN:** And the cerebral abscesses had
 18 developed because he had contracted beta-haemolytic
 19 streptococcus, is that right?
 20 **MS RACHAEL TERSTEEG:** That's right.
 21 **MS FRASER BUTLIN:** A craniotomy was planned for 13 April
 22 1987, but it didn't actually take place until
 23 15 April, is that right?
 24 **MS RACHAEL TERSTEEG:** That's right, yes.
 25 **MS FRASER BUTLIN:** What was the reason for the delay?

17

1 Your understanding of this form is that some form
 2 of blood product or packed cells had been ordered for
 3 13 April for that date of an operation?
 4 **MS RACHAEL TERSTEEG:** Yes, yes.
 5 **MS FRASER BUTLIN:** We can also see, just to give it some
 6 context, on the right-hand side, under the heading
 7 "For laboratory use only", Con's blood group there as
 8 well.
 9 **MS RACHAEL TERSTEEG:** Yes.
 10 **MS FRASER BUTLIN:** So your understanding, Rachael, was
 11 that blood had been ordered in advance of the
 12 operation?
 13 **MS RACHAEL TERSTEEG:** Yes. I didn't know that at the time
 14 though.
 15 **MS FRASER BUTLIN:** No, but subsequently that's what you
 16 managed to piece together?
 17 **MS RACHAEL TERSTEEG:** Yes.
 18 **MS FRASER BUTLIN:** Con had the surgery on 15 April.
 19 **MS RACHAEL TERSTEEG:** Correct.
 20 **MS FRASER BUTLIN:** Then in the recovery room the surgeon,
 21 Dr Teddy, came to talk to you?
 22 **MS RACHAEL TERSTEEG:** He did.
 23 **MS FRASER BUTLIN:** What did he tell you?
 24 **MS RACHAEL TERSTEEG:** He told me the operation had gone
 25 well but they'd had to give him a blood transfusion,

19

1 **MS RACHAEL TERSTEEG:** The doctor first of all had said
 2 that he they wanted the abscess to get a little bit
 3 bigger so that when they would drain the abscess they
 4 would be able to hopefully aspirate as much of the pus
 5 as possible, and they were doing a CT scan to monitor
 6 that progress.
 7 As we were waiting for that decision to be made,
 8 which was then two days, he wasn't able to see out of
 9 his left eye because the abscess was on the right side
 10 of his brain and the whole of his left side was
 11 paralysed. He couldn't speak properly, the side of
 12 his mouth was turned up, so it was as if he had had
 13 a stroke. Those were all of his symptoms.
 14 **MS FRASER BUTLIN:** Can I just turn to a document,
 15 WITN2720002.
 16 It is what looks to be the blood ordering form for
 17 13 April.
 18 The next page, please.
 19 It is not entirely straightforward to read but we
 20 can see the date of 13 April 1987 that blood had been
 21 requested.
 22 **MS RACHAEL TERSTEEG:** Yes.
 23 **MS FRASER BUTLIN:** On the left of the date there is a box
 24 where a number 2 has been written, and below and to
 25 the left we can see cells.

18

1 but they would have to wait and see how his recovery
 2 would be because they didn't know what damage may have
 3 been done with the paralysis and how his body would
 4 respond, how he would come out of that, how much
 5 physiotherapy he would need.
 6 **MS FRASER BUTLIN:** Did Dr Teddy explain to you why they
 7 had given a blood transfusion?
 8 **MS RACHAEL TERSTEEG:** No.
 9 **MS FRASER BUTLIN:** Can you tell us a little bit about how
 10 Con was after that operation?
 11 **MS RACHAEL TERSTEEG:** Not -- well, initially, sort of it
 12 took -- not very with it, of course. His head had
 13 been shaved and he had bandages around his head. He
 14 was in intensive care. He was -- he asked how the
 15 operation had gone. So, yes, just asking me really as
 16 much information as I knew about the operation.
 17 **MS FRASER BUTLIN:** But gradually Con recovered from the
 18 operation, didn't he? To a degree where he was back
 19 to work and enjoying family life?
 20 **MS RACHAEL TERSTEEG:** Yes, but in between times, while he
 21 was still in hospital, they -- he had a seizure, pre
 22 the main operation, but there was also another
 23 seizure, and they felt when they did another CT scan
 24 that he needed a second aspiration of the abscess to
 25 be done, and they wanted to do this as an experiment

20

1 with a local anesthetic under the scanner to see how
2 a patient would respond without having to go through a
3 general anaesthetic. But he said it was the
4 absolutely worst thing he had ever been through.
5 The -- all the things you could see around you, the
6 noise, the fact that, although you couldn't feel
7 anything, it was a traumatic experience, in hindsight,
8 yes.

9 **MS FRASER BUTLIN:** Between 1987, when he had that surgery,
10 and 2008, when we are going to come onto about
11 hepatitis C, can you tell us what Con was like and
12 what life was like together with him?

13 **MS RACHAEL TERSTEEG:** He was a lovely husband. He was
14 really, yes, just so special. The first year was so
15 difficult because he was recovering from all the
16 procedures, from the anesthetic, from the emotional
17 trauma. He would try to walk himself a little bit
18 further each day to try to help the mobility of his
19 left leg, which he was able to walk, which was
20 amazing. He did as much as he could do improve
21 himself. And as the -- I mean, there was one time
22 I remember, he was -- he got down on his knees on the
23 floor, he was banging on the floor, like this, and he
24 said, "Why me? Why did I have to go through this?"
25 But that was just getting through that -- that first

21

1 see Dr Gorard.

2 **MS FRASER BUTLIN:** We will come to that in just a moment,
3 but if we go back to that letter with the blood test
4 form in, did you ever get to the bottom of why that
5 was sent to Con?

6 **MS RACHAEL TERSTEEG:** Not at all. The -- Dr Graham, he
7 didn't know why it had been sent from Oxford, no idea
8 at all. There was nothing in his records of why it
9 should be sent to us. We didn't have any idea.

10 **MS FRASER BUTLIN:** At that point was he still under any
11 follow up from the craniotomy?

12 **MS RACHAEL TERSTEEG:** No.

13 **MS FRASER BUTLIN:** He wasn't under followup from the
14 craniotomy and his GP hadn't requested that blood
15 test?

16 **MS RACHAEL TERSTEEG:** That is correct.

17 **MS FRASER BUTLIN:** So as far as you're concerned, that
18 request was a complete surprise?

19 **MS RACHAEL TERSTEEG:** Absolutely, out of the blue.

20 **MS FRASER BUTLIN:** You have put in your statement you
21 think that was about March/April 2008?

22 **MS RACHAEL TERSTEEG:** Yes.

23 **MS FRASER BUTLIN:** As you said, you then had a private
24 referral to a liver specialist?

25 **MS RACHAEL TERSTEEG:** Yes.

23

1 year was really, really tough.

2 We had our two daughters who were young. Yeah, as
3 he improved, we had a sort of small vegetable area
4 garden, he would plant runner beans. We would go out
5 sometimes as a family. We would just do things with
6 the children. And those years weren't always easy but
7 we got through them. He wasn't allowed to drive for
8 the first year. I would take him to work every day
9 and pick him up from work.

10 **MS FRASER BUTLIN:** But he was working through that time?

11 **MS RACHAEL TERSTEEG:** Through that year, yes.

12 **MS FRASER BUTLIN:** How did Con come to know that he had
13 hepatitis C?

14 **MS RACHAEL TERSTEEG:** Out of the blue. We had a letter
15 one day from Oxford Hospital with a form in it saying
16 to just go and get a blood test done. So we duly went
17 to Wycombe Hospital, the blood test was done, and we
18 had a letter from the GP saying, "Please can you come
19 in and see me". We went to see Dr Graham, and he
20 said, "We need you to go and have another blood test
21 because this is indicating that you may have
22 hepatitis C". So we were really shocked about that.
23 Con went and had another blood test done. Now that
24 was confirmed. And at the time, because he had got
25 private medical insurance, we privately went to go and

22

1 **MS FRASER BUTLIN:** And a liver biopsy was performed?

2 **MS RACHAEL TERSTEEG:** Yes.

3 **MS FRASER BUTLIN:** And what did that show?

4 **MS RACHAEL TERSTEEG:** That Con was positive for
5 hepatitis C, genotype 1 I think, yes.

6 **MS FRASER BUTLIN:** That's what you've put here.

7 Do you recall whether they said anything about how
8 much damage to Con's liver there was at that point?

9 **MS RACHAEL TERSTEEG:** No.

10 **MS FRASER BUTLIN:** The biopsy was on 21 May 2008. Then
11 Con started treatment with interferon and ribavirin in
12 the August.

13 **MS RACHAEL TERSTEEG:** Yes, that's right. Yes.

14 **MS FRASER BUTLIN:** How did Con cope with that treatment?
15 How --

16 **MS RACHAEL TERSTEEG:** He had 48 treatments. He had to
17 inject himself once a week, he had the interferon
18 tablets daily to back that up, and it was an awful
19 year. On a Friday evening, he'd -- he'd already
20 planned and thought through that he would have the
21 injection on the Friday evening because of the side
22 effects of feeling poorly, flu, bad headaches, aches
23 and pains, so that on a Monday morning he would have
24 been through the worst to be able to go back in to
25 work. And when he was having very bad days, again

24

1 I would take him into work and pick him up.
 2 **MS FRASER BUTLIN:** Con cleared the hepatitis with that
 3 treatment.
 4 **MS RACHAEL TERSTEEG:** He did, yes.
 5 **MS FRASER BUTLIN:** But he was then very unwell after that?
 6 **MS RACHAEL TERSTEEG:** Yes, that's correct.
 7 **MS FRASER BUTLIN:** And he was diagnosed with oesophageal
 8 stricture, leading to cancer of the larynx --
 9 **MS RACHAEL TERSTEEG:** That was just a year later, yes.
 10 **MS FRASER BUTLIN:** In 2010. And then porphyria cutanea
 11 tarda, a skin condition with painful lesions on some
 12 exposed skin.
 13 **MS RACHAEL TERSTEEG:** Yes.
 14 **MS FRASER BUTLIN:** In terms of your home, in 2011 you
 15 moved house.
 16 **MS RACHAEL TERSTEEG:** That's right.
 17 **MS FRASER BUTLIN:** Why was that?
 18 **MS RACHAEL TERSTEEG:** We moved because Con's health had
 19 deteriorated. He was struggling getting up and down
 20 the stairs. We only had a bathroom upstairs and
 21 I know that he would used to -- he would say, "Well,
 22 I'll try and hang on as long as I can before I need to
 23 use the bathroom because then I don't have to go up
 24 the stairs". And in the afternoons he would -- oh,
 25 every weekend, you know, when he wasn't working, he

25

1 to the ICU ward. He had got influenza A, very badly,
 2 and he was just very poorly.
 3 **MS FRASER BUTLIN:** He had major organ failure at that
 4 point?
 5 **MS RACHAEL TERSTEEG:** Yes.
 6 **MS FRASER BUTLIN:** But somehow he pulled through that?
 7 **MS RACHAEL TERSTEEG:** Yes.
 8 **MS FRASER BUTLIN:** But had quite complex ongoing health
 9 difficulties?
 10 **MS RACHAEL TERSTEEG:** Yes.
 11 **MS FRASER BUTLIN:** Can you tell us what they were.
 12 I think he had myasthenia gravis?
 13 **MS RACHAEL TERSTEEG:** Yes, that's right. Being in
 14 hospital I would go to the hospital every -- well,
 15 three times a day, visiting hours, once I was allowed
 16 to anyway, and his health -- he wasn't able to swallow
 17 properly. He had pains in his hands, in his muscles,
 18 walking was very, very difficult for him. Life was
 19 a real challenge.
 20 **MS FRASER BUTLIN:** And Con had a tube fitted so that he
 21 didn't have to eat through the mouth. It was a PEG
 22 fitted.
 23 **MS RACHAEL TERSTEEG:** That's right.
 24 **MS FRASER BUTLIN:** And he had polyneuropathy, the pain in
 25 his hands and feet, myasthenia gravis?

27

1 would have to go to bed, lie down and rest.
 2 **MS FRASER BUTLIN:** So you moved to a flat in 2011 to avoid
 3 that problem?
 4 **MS RACHAEL TERSTEEG:** Yes, we sold the house, it was
 5 a semi-detached house. We sold the house and moved to
 6 a flat and -- so that there was -- it was just easy
 7 access for him to get to the bathrooms.
 8 **MS FRASER BUTLIN:** Then in 2013 you went to Holland for
 9 a funeral of a friend?
 10 **MS RACHAEL TERSTEEG:** Correct.
 11 **MS FRASER BUTLIN:** And Con collapsed?
 12 **MS RACHAEL TERSTEEG:** Yes.
 13 **MS FRASER BUTLIN:** Again, can you tell us what happened
 14 then?
 15 **MS RACHAEL TERSTEEG:** Yes. He had flu-like symptoms on
 16 the Saturday evening, Easter Saturday. He felt
 17 really -- really quite poorly. He had a slight
 18 temperature and by the evening he seemed completely
 19 disorientated. He didn't really -- he wasn't coherent
 20 in his speech. He was really poorly. And I phoned
 21 the ambulance. They did all the obs, vital obs. His
 22 blood pressure was really, really low. His heart rate
 23 was racing. He was very poorly. They took him in to
 24 the Apeldoorn Hospital. Within minutes there was
 25 a whole team around him and -- anyway, he was taken up

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1 **MS RACHAEL TERSTEEG:** Yes.
 2 **MS FRASER BUTLIN:** Con also struggled significantly
 3 mentally. Do you want to tell us something about that
 4 and how it was for you and the family?
 5 **MS RACHAEL TERSTEEG:** He struggled again with all -- you
 6 know, what he had been through, felt that he had been
 7 dealt a bad lot in life really regarding his health.
 8 He got very depressed. We got some private
 9 counselling to try to help him through the emotional
 10 and the physical side effects of what he had been
 11 through. We found a very good therapist.
 12 **MS FRASER BUTLIN:** Then in 2016 Con fell and had an open
 13 wound from his shoulder to the elbow which wouldn't
 14 heal?
 15 **MS RACHAEL TERSTEEG:** Yes.
 16 **MS FRASER BUTLIN:** From that wound he developed sepsis?
 17 **MS RACHAEL TERSTEEG:** Yes.
 18 **MS FRASER BUTLIN:** And he died from organ failure on
 19 5 September 2016.
 20 **MS RACHAEL TERSTEEG:** Yes, that's right.
 21 **MS FRASER BUTLIN:** Throughout all of these illnesses and
 22 the ongoing ill health, was there ever a discussion
 23 with you about the relevance of hepatitis C in Con's
 24 immune system and ability to cope with viruses?
 25 **MS RACHAEL TERSTEEG:** We did go and see an immunologist

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1 and she recorded that because of what he had been
 2 through, that it can affect your immune system. When
 3 Con first had the treatment, we had to sign
 4 a disclaimer that he wouldn't father any children. We
 5 had to -- we were just aware that any colds that he
 6 got could easily become pneumonia, chest infections
 7 and throughout the period of -- from 2013 to 2016 we
 8 always had antibiotics at home. He could
 9 self-medicate. He was often on -- there was periods
 10 when he had to take steroids to help him out of the
 11 infection and his immune system was just -- and
 12 anything that was going he would pick it up.
 13 **MS FRASER BUTLIN:** In 2016, before he was -- had the
 14 wound, Con had made an application to the Skipton
 15 Fund?
 16 **MS RACHAEL TERSTEEG:** Yes.
 17 **MS FRASER BUTLIN:** When he made that application, what
 18 medical records had Con been able to obtain?
 19 **MS RACHAEL TERSTEEG:** At the point of first application we
 20 hadn't applied for any. He took a great interest in
 21 news and he had read that the Skipton Fund had been
 22 set up and that the government had now recognised
 23 about the contamination, the Infected Blood Inquiry.
 24 So he applied for an application form which was filled
 25 in by the GP and we sent that to the Skipton Fund.

29

1 **MS FRASER BUTLIN:** Just a complete blank. Then if we pick
 2 up the letter again:
 3 "Due to my hospitalisation I do not have enough
 4 time to get any more supporting information regarding
 5 the Craniotomy procedure but I want to put the
 6 following to the panel for consideration:
 7 "1. My wife was informed by the doctor after the
 8 procedure that I was given blood and I have enclosed
 9 her statement. She is willing to testify under oath
 10 if required.
 11 "2. I was informed of the blood transfusion at
 12 a later stage when they explained the procedure
 13 (Craniotomy) to me. Again I am also willing to
 14 testify.
 15 "3. I was also told that there is always loss of
 16 blood during the Craniotomy procedure and does often
 17 required additional blood products.
 18 "It is difficult to obtain further information due
 19 to the long time elapsed and the fact that the
 20 Radcliffe Infirmary no longer exists and the records
 21 were stored by the Oxfordshire University Hospitals
 22 NHS Trust."
 23 If we just go back to the top of this letter, sir.
 24 I misled you. This is 2014. Apologies.
 25 **SIR BRIAN LANGSTAFF:** Yes, it is 2014, that statement.

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1 They said to us in the Skipton Fund that we would need
 2 to have more evidence and suggested we write to Oxford
 3 Health Authority.
 4 **MS FRASER BUTLIN:** So once the first application had been
 5 declined, Con then wrote back to the Skipton Fund.
 6 I just want to look at that letter.
 7 COLL0000014, please, page 9.
 8 We see there, again I will just read it out:
 9 "I have only been able to obtain documents showing
 10 the blood products were delivered but unfortunately
 11 I have not been able to find any confirmation that
 12 they were administered during the procedure as the
 13 'Recovery Area Record Sheet' was left completely blank
 14 (copy's already forwarded)."
 15 We will come to the next bit in a moment. All
 16 that Con had been able to obtain was the document we
 17 looked at earlier and a blank recovery area form; is
 18 that right?
 19 **MS RACHAEL TERSTEEG:** Yes.
 20 **MS FRASER BUTLIN:** And there were no notes from the
 21 operation and for the full 12 hours later?
 22 **MS RACHAEL TERSTEEG:** That is correct.
 23 **MS FRASER BUTLIN:** The first record was just returned from
 24 ICU?
 25 **MS RACHAEL TERSTEEG:** Correct yes.

30

1 **MS FRASER BUTLIN:** Apologies, indeed it was my
 2 typographical error in my notes, apologies. So 2014.
 3 We see there that Con has offered a statement from
 4 you and if we could turn to that, it is page 10 of the
 5 same document please, Lawrence.
 6 We have a short statement which is signed by you,
 7 we've just redacted the signature. You have set out
 8 what happened to Con and five lines from the bottom:
 9 "After the operation the doctor told me that the
 10 operation had gone well and that they had given my
 11 husband a blood transfusion during the procedure."
 12 So that's what Con provided to Skipton, but that
 13 application was also declined.
 14 **MS RACHAEL TERSTEEG:** Yes, it was.
 15 **MS FRASER BUTLIN:** If we carry on to page 13 of this
 16 document we see the refusal. The first part is
 17 largely a standard form letter, but if we go across
 18 the page -- sorry, to the next page, we see that the
 19 appeal panel had met.
 20 "At the meeting yesterday the Panel reviewed the
 21 entire file of papers held by the Skipton Fund in
 22 connection with your application and all the
 23 additional information supplied for the purpose of the
 24 appeal. We noted that there was no record of any
 25 transfusion in your notes. The Panel, including our

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1 expert members, was of the view, supported by the
2 clinical records we have seen, that there is
3 insufficient evidence to show that you were treated by
4 a blood transfusion.

5 "The hospital records show that you underwent
6 a successful drainage of a brain abscess in 1987.
7 This is a procedure for which a transfusion would only
8 rarely be necessary. The hospital discharge record
9 gives full details of the procedure and does not
10 mention any complication which might necessitate
11 a transfusion. You had a good haemoglobin level of
12 13.5 before surgery; that would make a transfusion
13 less likely to be needed.

14 "As a result of these considerations we were not
15 satisfied that it is probable that the infection
16 resulted from qualifying NHS treatment and accordingly
17 regret that we must refuse your appeal."

18 Con then challenged that response from the
19 Skipton, particularly that it made no reference at all
20 to your witness statement, your note of what you had
21 been told; is that right?

22 **MS RACHAEL TERSTEEG:** That's right, yes.

23 **MS FRASER BUTLIN:** If we go to page 25, Con responded
24 again, and this time you provided a very lengthy
25 witness statement of what had happened?

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1 has reconsidered your appeal after one of the
2 specialist medical members reviewed the whole file of
3 your medical records. The conclusion is that on the
4 existing records there is still no reason to conclude
5 that it is probable that you were given a blood
6 transfusion.

7 "There was no operation or anaesthetic record and
8 it is uncertain why they should be missing. The
9 post-operational neurosurgical notes were also
10 missing. We concluded that this is because they are
11 normally kept separately from other records (partly
12 because the paper on which they are written is too
13 large to fit into the general records file).

14 "It is worth pointing out that the blood
15 transfusion records are often kept separately within
16 the hospital. You may wish to approach the Manager of
17 the John Radcliffe blood service and ask for a check
18 to be made for the relevant dates. If any information
19 becomes available, the Panel will of course consider
20 it. In the meantime the Panel's decision must stand."

21 So even in this refusal there is still no
22 reference to your sworn witness statement.

23 **MS RACHAEL TERSTEEG:** No. No. That was never recognised
24 or acknowledged at all.

25 **MS FRASER BUTLIN:** There's nothing in the correspondence

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1 **MS RACHAEL TERSTEEG:** Yes.

2 **MS FRASER BUTLIN:** That's what we have on the screen. If
3 we -- it sets out what had happened. In fact, if we
4 turn over the page, we have the paragraph dealing with
5 your conversation with Dr Teddy:

6 "Dr Teddy, the surgeon, was also present and he
7 told me that the surgery had gone well but they had
8 given him a blood transfusion during the operation."

9 If we go to the next page. You had taken this
10 statement and it was sworn in front of solicitors.

11 **MS RACHAEL TERSTEEG:** Yes.

12 **MS FRASER BUTLIN:** So it was effectively a sworn witness
13 statement?

14 **MS RACHAEL TERSTEEG:** Yes, it was. Definitely.

15 **MS FRASER BUTLIN:** And this whole statement, with the note
16 that it had been sworn, was provided to the Skipton
17 Fund?

18 **MS RACHAEL TERSTEEG:** Yes.

19 **MS FRASER BUTLIN:** The appeal was then reconsidered but
20 still refused?

21 **MS RACHAEL TERSTEEG:** Yes, that's right.

22 **MS FRASER BUTLIN:** If we can go to a final document,
23 page 35 of this document. We pick up the second,
24 third and fourth paragraphs:

25 "The Chair has asked me to tell you that the Panel

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1 with the Skipton Fund in relation to the nature of the
2 hepatitis C test, that it was out of the blue and
3 unexpected?

4 **MS RACHAEL TERSTEEG:** That's right. Nothing at all. No.

5 **MS FRASER BUTLIN:** How did that make you and Con feel
6 about the process?

7 **MS RACHAEL TERSTEEG:** Well, we were just devastated each
8 time. He was -- four times he was rejected by the
9 Skipton Trust. He wasn't well. I know that sometimes
10 he would start a letter and because of the problem
11 with his hands, he would come back to it and do it in
12 sort of stages on the computer. It does mention
13 that -- the operation, the abscess was drained, but
14 Con actually, as far as I understand it, had sort of
15 a full head surgery. He had -- it was about a three
16 or four inch scar on his head.

17 When -- you know, as his health deteriorated
18 really in the last sort of two years, his hair thinned
19 so much and you could see the scar on his head. You
20 could always feel this little sort of indentation on
21 his skull as if there was a tiny piece of bone
22 missing. But I'm not a medic, I don't know, but the
23 way that the operation was explained by the medical
24 member on the Panel, to me, didn't feel quite right
25 and it was just really frustrating. You know, we just

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1 felt all the while -- just never being believed. And
 2 then when they said -- here -- where is it? Well,
 3 they couldn't understand why the existing records
 4 weren't there, as if we had taken them out ourselves
 5 or something. It was just awful.
 6 **MS FRASER BUTLIN:** I think Con felt quite strongly that
 7 they were minimising the surgery that he had
 8 undergone; is that right?
 9 **MS RACHAEL TERSTEEG:** Yes.
 10 **MS FRASER BUTLIN:** That they seem to be suggesting it was
 11 a simple abscess drainage when, as you said, he had
 12 a very significant scar?
 13 **MS RACHAEL TERSTEEG:** Yes. He did, yes.
 14 **MS FRASER BUTLIN:** Sir, I note the time that we would
 15 normally take our morning break, but, given that we
 16 started a little late, I wonder if I might take one
 17 more person through their --
 18 **SIR BRIAN LANGSTAFF:** Yes, that will be a good idea
 19 I think.
 20 **MS FRASER BUTLIN:** Thank you.
 21 Gary, you are here to speak about your late
 22 father -- yes, I'm sorry, we still have a slight
 23 problem with some documents so I'm going to move on to
 24 speak to Gary and then after the break we should all
 25 be sorted out and we will return to the other three of

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1 of blood?
 2 **MR GARY MCKELVEY:** Yes, I believe it was 18 pints.
 3 **MS FRASER BUTLIN:** How did you and your mum know that he
 4 had been given that amount of blood?
 5 **MR GARY MCKELVEY:** I have got to say I wasn't in the
 6 country at the time. I was in the United States. But
 7 she was told by the medical professionals at the time,
 8 you know, with that type of surgery, the seriousness
 9 of that ulcer, that he had been given significant
 10 blood and it was 18 pints and she confirmed that again
 11 yesterday. Because I said, "I have got 18 pints in my
 12 head", and she said, "Yes, that's correct, that's my
 13 understanding".
 14 **MS FRASER BUTLIN:** Your dad recovered fairly well?
 15 **MR GARY MCKELVEY:** He recovered totally, you know.
 16 **MS FRASER BUTLIN:** And what was his health like then until
 17 about 1990?
 18 **MR GARY MCKELVEY:** Health was fine, returned to work, no
 19 issues, no other health problems, dental problems.
 20 Back to his usual self and, you know, what we've got
 21 to say is we were very grateful for the skills of the
 22 surgeons who did the job in 1981.
 23 **MS FRASER BUTLIN:** And he was working in a shipping yard?
 24 **MR GARY MCKELVEY:** Yes, he was working in Harland & Wolff
 25 and I noticed in the -- there is a montage of certain

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1 you.
 2 Apologies, I should have said that. That was what
 3 the whispering behind me was, they just haven't quite
 4 reached everybody who needs them.
 5 Gary, you are here to speak about your late
 6 father, Henry.
 7 **MR GARY MCKELVEY:** *(Inaudible)*
 8 **SIR BRIAN LANGSTAFF:** You will have to bring that a little
 9 bit closer to you. It is difficult because you are
 10 talking across. So if you speak into it, that will
 11 help. If you can.
 12 **MR GARY MCKELVEY:** Thank you.
 13 Yes, sorry, on behalf of my mother who is unable
 14 to make the trip. So yes, my father.
 15 **MS FRASER BUTLIN:** In 1980 your dad developed a stomach
 16 ulcer which later ruptured?
 17 **MR GARY MCKELVEY:** Yes, I would like to correct something
 18 maybe within the statement.
 19 **MS FRASER BUTLIN:** Of course.
 20 **MR GARY MCKELVEY:** I read it in detail over the weekend
 21 and it mentions 1980, 1981. I did speak with my
 22 mother yesterday. She tells me it was 1981. So just
 23 to make that clear.
 24 **MS FRASER BUTLIN:** During treatment for that ruptured
 25 stomach ulcer, your dad was given a significant amount

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1 areas of the UK and the Harland & Wolff cranes are
 2 there, so thank you.
 3 **MS FRASER BUTLIN:** Then in 1990 you noticed something
 4 wasn't quite right with him?
 5 **MR GARY MCKELVEY:** Yes, okay, he is in Belfast. I'm at
 6 that time living near Luton so I wasn't there, but he
 7 locked himself out of the house, yeah, and he climbed
 8 over the back fence and he bruised his thigh. And
 9 that bruising was excessive, much more than one would
 10 have expected, and it didn't heal up. So he went to
 11 his GP.
 12 Again, my understanding at the time, it is a long
 13 time ago, that he had some blood tests and the blood
 14 platelet count was apparently very low.
 15 **MS FRASER BUTLIN:** So for a period he was then given some
 16 transfusions; is that right?
 17 **MR GARY MCKELVEY:** Yes, he would have been given and
 18 I don't know how many but some blood platelet
 19 transfusions to boost that blood platelet level, yes.
 20 **MS FRASER BUTLIN:** You were then back in Belfast around
 21 Christmas 1990?
 22 **MR GARY MCKELVEY:** Correct.
 23 **MS FRASER BUTLIN:** And your dad was taken into accident
 24 and emergency on New Year's eve?
 25 **MR GARY MCKELVEY:** Yes, I did take him myself, yes.

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1 **MS FRASER BUTLIN:** What was wrong at that point?
 2 **MR GARY MCKELVEY:** Just his ankles, both, were very, very
 3 swollen, excessively swollen, and he was just weak.
 4 I can't remember whether he struggled to work to be
 5 honest but I felt it was serious enough on New Year's
 6 eve to take him to A&E.
 7 **MS FRASER BUTLIN:** Your dad then had a stroke in
 8 January 1991?
 9 **MR GARY MCKELVEY:** Correct, he did, yes.
 10 **MS FRASER BUTLIN:** But how did your dad's hepatitis C come
 11 to be diagnosed?
 12 **MR GARY MCKELVEY:** Honestly spoken, it was -- we were
 13 never told it was hepatitis C until -- my mother
 14 recalls this as 17 March. Whether that is exactly
 15 correct, I don't know but that's what she remembers
 16 and the registrar or the junior registrar and, again,
 17 I don't know, a Dr Paul Kettle had been to
 18 a conference apparently in London and, again, I don't
 19 know how accurate that is but he told her that having
 20 been and having listened he was of the opinion that my
 21 father had contracted hepatitis C through the blood
 22 transfusions that he would have had in 1981.
 23 There was no explanation of what hepatitis C was.
 24 That's the first time we had ever heard the term.
 25 **MS FRASER BUTLIN:** And that was told to your mum after the

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1 **MS FRASER BUTLIN:** And he died on 9 June 1991.
 2 **MR GARY MCKELVEY:** Correct, yes.
 3 **MS FRASER BUTLIN:** Could we turn to your father's death
 4 certificate.
 5 WITN0525003, please.
 6 We see in section 10 the cause of death:
 7 "I(a) Hepatic failure.
 8 "(b) Viral hepatitis.
 9 "II Cerebrovascular accident.
 10 "Thrombocytopenia."
 11 I'm indicating that because obviously it is
 12 relevant to the Skipton Fund discussions but that's
 13 how the death certificate was certified.
 14 How did you come to hear about the Skipton Fund?
 15 **MR GARY MCKELVEY:** Okay. I'm not 100 per cent sure,
 16 I have got to be honest. But, you know, on one of
 17 those few occasions when Northern Ireland has
 18 a functioning Assembly, there was a Health Minister,
 19 Michelle O'Neill, and I remember reading something
 20 online that within Northern Ireland they were looking
 21 at some compensation or recognition of people who had
 22 been infected by so-called contaminated infected
 23 blood. And, again, up until that point, let's say
 24 within the media, I hadn't heard of this at all, and
 25 it was only then that I'd spoke with my mother and

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1 stroke, so it was March 1991?
 2 **MR GARY MCKELVEY:** Yes, it was a couple of months after
 3 the stroke, yes.
 4 **MS FRASER BUTLIN:** Your dad was extremely unwell from then
 5 on?
 6 **MR GARY MCKELVEY:** Yes, he was.
 7 **MS FRASER BUTLIN:** What can you tell us about that?
 8 **MR GARY MCKELVEY:** After the stroke he had come home but
 9 frankly he just slept most of the time. He wasn't
 10 able to do anything. I did come home on a few
 11 occasions because he didn't know how unwell he was,
 12 and we didn't tell him how unwell he was. We knew, or
 13 we had been told that it was terminal, yeah, but we
 14 didn't tell him that. So let's say the level of his
 15 unwellness was that, you know, I had to toilet him.
 16 And it is not a pleasant thing to do, you know, with
 17 a 57 year old man, and, yes, he was only 57 at the
 18 time.
 19 At the time I probably thought that was quite old,
 20 you know, but on reflection I'm now four years older,
 21 almost to the day, than he was when he died. So you
 22 have a different perspective as time goes on.
 23 **MS FRASER BUTLIN:** Your dad then was taken back into
 24 hospital --
 25 **MR GARY MCKELVEY:** He was.

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1 said, "Listen, remember what was spoken all those
 2 years ago, that my dad received this blood which
 3 Dr Kettle believed was infected from the surgery in
 4 1981. Let's get some details on the Skipton Fund and
 5 make an application".
 6 **MS FRASER BUTLIN:** And you placed that sort of
 7 announcement from Michelle O'Neill to have been around
 8 2017, when the announcement was for improved financial
 9 support --
 10 **MR GARY MCKELVEY:** Yes.
 11 **MS FRASER BUTLIN:** -- in Northern Ireland?
 12 **MR GARY MCKELVEY:** Correct, yes. I think it was December,
 13 yes.
 14 **MS FRASER BUTLIN:** Had your mum or you been told anything
 15 before about the Skipton Fund at any time?
 16 **MR GARY MCKELVEY:** No, nothing. Never.
 17 **MS FRASER BUTLIN:** Can you tell us what happened then in
 18 terms of getting the form completed?
 19 **MR GARY MCKELVEY:** Right. My mother tried to complete it.
 20 Basically we didn't have the medical records that were
 21 required and then we were told that there was going to
 22 be a change in how it was administered and it would be
 23 administered locally in Northern Ireland, and then we
 24 would need to apply through this -- I can't remember,
 25 the -- the BSO?

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1 **MS FRASER BUTLIN:** It is the Business Services
 2 Organisation who run the Northern Ireland Blood
 3 Support Scheme, NIBS.
 4 In terms of the records your mum, I think, went to
 5 her own GP.
 6 **MR GARY MCKELVEY:** She did.
 7 **MS FRASER BUTLIN:** What did her own GP said about
 8 completing the form?
 9 **MR GARY MCKELVEY:** He said he could not complete the form
 10 because he was not my father's GP at the time and
 11 there were no records so it was not practicable for
 12 him to do that.
 13 **MS FRASER BUTLIN:** She had also written to the Belfast
 14 Hospital?
 15 **MR GARY MCKELVEY:** She had.
 16 **MS FRASER BUTLIN:** What did they say?
 17 **MR GARY MCKELVEY:** No medical records existed.
 18 **MS FRASER BUTLIN:** You then wrote to the Belfast Health
 19 and Social Trust?
 20 **MR GARY MCKELVEY:** I did, yes.
 21 **MS FRASER BUTLIN:** Again, what did they say?
 22 **MR GARY MCKELVEY:** They said:
 23 "A further search was completed for any electronic
 24 records, ie laboratory results, and nothing was found.
 25 The requested notes have been destroyed in line with

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1 it is WITN0525002, please. It is the second and third
 2 paragraphs:
 3 "While I appreciate that it may be frustrating and
 4 distressing for Mrs McKelvey as she tries to retrieve
 5 her late husband's medical records, the retention and
 6 destruction of medical records are governed by Good
 7 Management, Good Records, the record schedule for
 8 Health and Social Care organisations and the
 9 Department. This provides a framework for consistent
 10 and effective records management based on advice and
 11 publications from the Ministry of Justice and the
 12 Public Records Office Northern Ireland. Medical
 13 records are usually destroyed 10 years after death.
 14 "It is against this background that officials in
 15 the Department have contacted the Belfast Trust and
 16 the Northern Ireland Blood Transfusion Service to look
 17 into this matter. The Department has established that
 18 further information is needed in order to progress the
 19 case. Mr McKelvey's family should contact the manager
 20 of the Infected Blood Payment Scheme for Northern
 21 Ireland, Mr Colin Murray ... He will liaise with the
 22 relevant officials in the Department, Health and
 23 Social Trusts and NIBTS to see if any other records
 24 can be retrieved."
 25 So you were referred back to Mr Murray, who you

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1 the Trust's policy."
 2 They spelt retention wrong, but "retention and
 3 destruction of records". Yeah. I also wrote to the
 4 Northern Health and Social Care Trust and had exactly
 5 the same response.
 6 **MS FRASER BUTLIN:** So GPs couldn't help, hospital records
 7 had been destroyed. At that point you then contacted
 8 the Business Services Organisation on 5 December 2017
 9 because it had shifted across?
 10 **MR GARY MCKELVEY:** Yes.
 11 **MS FRASER BUTLIN:** What were you advised by them?
 12 **MR GARY MCKELVEY:** I spoke with Mr Colin Murray at the BSO
 13 and, you know, actually, he was very helpful on the
 14 phone, which was the first time anyone had been
 15 helpful. But ultimately he was only able to come back
 16 with the same response: no medical records, there was
 17 no way forward, and that we should contact -- and my
 18 mother should contact her local Assembly Member,
 19 called Stephen Farry, which is what she did, yeah --
 20 who in turn contacted Richard Pengelly, who was --
 21 I have forgotten his title.
 22 **MS FRASER BUTLIN:** He is the Permanent Secretary and HSE
 23 Chief Executive.
 24 **MR GARY MCKELVEY:** Thank you very much, yes.
 25 **MS FRASER BUTLIN:** If we look at his letter in response,

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1 had already spoken to?
 2 **MR GARY MCKELVEY:** Yes, he was.
 3 **MS FRASER BUTLIN:** Has there been any progress at all
 4 since then?
 5 **MR GARY MCKELVEY:** Out of the blue about three months ago
 6 Mr Murray contacted my mother and said, "Look, someone
 7 from the Health Service is going to contact you", but
 8 it hasn't happened. So no progress.
 9 At the same time I did contact the Northern
 10 Ireland Blood Transfusion Service as well and again it
 11 was, you know, just running down a blind alley. We
 12 just seem to go in ever-decreasing circles.
 13 **MS FRASER BUTLIN:** During these conversations, during
 14 trying to get records and speaking to Mr Murray, did
 15 you provide them with a copy of the death certificate
 16 and an indication of what the death certificate said?
 17 **MR GARY MCKELVEY:** Yes, absolutely.
 18 **MS FRASER BUTLIN:** So a death certificate indicating that
 19 your dad had died of hepatic failure and viral
 20 hepatitis --
 21 **MR GARY MCKELVEY:** For sure.
 22 **MS FRASER BUTLIN:** -- was not considered to be enough?
 23 **MR GARY MCKELVEY:** It was not considered to be enough, no.
 24 **MS FRASER BUTLIN:** Sir, I wonder if that's a good place to
 25 take a break for the morning before we hear from our

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1 other panellists.
 2 **SIR BRIAN LANGSTAFF:** Yes, it is. Let's take a break then
 3 until 12.05 pm. I hope that gives you long enough.
 4 **MS FRASER BUTLIN:** Sir *(break in audio transmission)* the
 5 usual witness rule.
 6 **SIR BRIAN LANGSTAFF:** No, I won't.
 7 (11.36 am)
 8 (A short break)
 9 (12.05 pm)
 10 **SIR BRIAN LANGSTAFF:** Yes.
 11 **MS FRASER BUTLIN:** Andrew, if we can start this session
 12 with your evidence. You are a chartered chemical
 13 engineer?
 14 **MR ANDREW BRAGG:** I am.
 15 **MS FRASER BUTLIN:** And before you started work after
 16 university in 1986 you went on a long holiday in
 17 Norway?
 18 **MR ANDREW BRAGG:** Yes, I graduated in 1986 as a chemical
 19 engineer. I had had a chemical engineering
 20 scholarship from ICI. That meant I worked through
 21 university as well as studied, so I was looking
 22 forward to having a break before I started work in
 23 September. I have a lot of Norwegian friends so
 24 I went to Norway.
 25 **MS FRASER BUTLIN:** But while you were there you had a road

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1 **MS FRASER BUTLIN:** You were treated at Haukeland Sykehus
 2 in Bergen; is that right?
 3 **MR ANDREW BRAGG:** Correct, yes.
 4 **MS FRASER BUTLIN:** You were then transferred back to
 5 Liverpool.
 6 **MR ANDREW BRAGG:** Yes, I was flown home. I had a night at
 7 home. The GP came out to see me because the
 8 Norwegians just gave me one day's worth of drugs, took
 9 one look at me and called an ambulance. I went to
 10 Broadgreen Hospital in Liverpool. Bit of a culture
 11 shock. First time I had actually been on the
 12 receiving end in a UK hospital, and compared to Norway
 13 it was -- I will call it second world but certainly
 14 Norway was far more impressive as a place to be.
 15 **MS FRASER BUTLIN:** And when you were in Norway you were
 16 given blood transfusions in Norway.
 17 **MR ANDREW BRAGG:** Yes.
 18 **MS FRASER BUTLIN:** You were then in Broadgreen Hospital
 19 for a while and then subsequently, in November 1986
 20 and December 1986, you had further surgery.
 21 **MR ANDREW BRAGG:** Yes, they needed to remove the fixings
 22 through the tibial nail. I have no idea if I had
 23 a blood transfusion in the theatre. I can't remember
 24 having a blood transfusion when I was on the ward
 25 after I came out of theatre. I was in a world of pain

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1 traffic accident?
 2 **MR ANDREW BRAGG:** Yes, I discovered a very interesting
 3 tunnel up in the mountains near Bergen which had no
 4 lights in it and it turned right on entry so I went
 5 straight into the wall.
 6 **MS FRASER BUTLIN:** In terms of the injuries you sustained,
 7 can you tell us about those?
 8 **MR ANDREW BRAGG:** First point of contact was my head and
 9 face. Then my motorbike landed on my leg and crushed
 10 my right leg, so the estimate was I had something like
 11 17 fractures below the knee. It was two and a half
 12 hours to extract me from my hole in the ground, get me
 13 to Bergen, but the medical treatment in Bergen was
 14 fantastic. They had a major trauma unit, so there was
 15 everybody on hand when I arrived. They stabilised me.
 16 I had an operation that night.
 17 **MS FRASER BUTLIN:** You had a tibial nail inserted?
 18 **MR ANDREW BRAGG:** Absolutely, yes. Unusual procedure at
 19 the time, but I had so many fractures to my tibia that
 20 they put a titanium nail from my knee to my ankle, and
 21 basically realigned all the fractures around it and
 22 then fixed it.
 23 **MS FRASER BUTLIN:** You also had fractures in your foot and
 24 ankle and they were secured with wires?
 25 **MR ANDREW BRAGG:** Yes.

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1 so I wasn't really paying much attention to that.
 2 **MS FRASER BUTLIN:** The two surgeries, the first one was to
 3 remove the wires in your foot and ankle and then the
 4 December surgery was to remove the screws from the
 5 tibial nail.
 6 **MR ANDREW BRAGG:** Yes.
 7 **MS FRASER BUTLIN:** When you were there do you recall if
 8 that was considered to be quite major surgery or
 9 whether it was relatively routine?
 10 **MR ANDREW BRAGG:** It certainly wasn't routine. I was out
 11 for -- well, they put me out. When I came to I had
 12 a bruise from my shoulder to my groin, because -- the
 13 Norwegians had told me the screws needed to come out
 14 after eight weeks, and it was 17 weeks, so they had
 15 quite a struggle, and they had also opened up all the
 16 fractures in my tibia again, so I wasn't in great
 17 shape.
 18 **MS FRASER BUTLIN:** Then in October 1987 you were treated
 19 in Blackburn Royal Infirmary and they removed the
 20 tibial nail at that point?
 21 **MR ANDREW BRAGG:** Yes, I was getting a lot of pain in my
 22 knee, so walking was very, very painful because it was
 23 metal on bone, so it was agreed to take the nail out.
 24 **MS FRASER BUTLIN:** Do you know whether in that surgery you
 25 had a blood transfusion?

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1 **MR ANDREW BRAGG:** I definitely -- I remember coming to and
 2 seeing the bags of blood hanging up around me.
 3 **MS FRASER BUTLIN:** You were then readmitted two weeks
 4 later because of more complications?
 5 **MR ANDREW BRAGG:** Yes. My knee swelled up really, really
 6 badly. I'd attended the fracture clinic. The
 7 solution seemed to be that the doctor got hold of my
 8 knee and pressed, so that burst all the stitches and
 9 emptied the -- certainly effective in draining my knee
 10 but it meant I was readmitted.
 11 **MS FRASER BUTLIN:** That was 1987.
 12 **MR ANDREW BRAGG:** Yes.
 13 **MS FRASER BUTLIN:** How did you then come to find out you
 14 had hepatitis C?
 15 **MR ANDREW BRAGG:** Working for ICI from -- in the
 16 mid-1990s, I started working on the more international
 17 side of the business and I was working with ICI India
 18 to establish a business in India, so late 1998 I was
 19 having a meeting in New Delhi and I became quite ill.
 20 It was about a week before I was well enough to fly
 21 home.
 22 That sort of passed but I felt ill. I never felt
 23 well again. My GP basically said, "Well, you've been
 24 in India, you have got something. It will go". But
 25 the occupational health department in ICI wanted to

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1 the NHS."
 2 I asked them how much it cost and they said about
 3 £20,000. I said, "Well, can I pay for it?"
 4 "No."
 5 So I was then in a dilemma. I couldn't get
 6 treatment through the NHS and they wouldn't allow me
 7 treatment through any other route, so, you know,
 8 presumably I just had to sit there and die. I had
 9 some conversations with my MP about it but that didn't
 10 lead anywhere.
 11 **MS FRASER BUTLIN:** Then in 2000 you were able to join
 12 a trial of pegylated interferon and ribavirin?
 13 **MR ANDREW BRAGG:** Yeah, Professor Bassendine in Newcastle
 14 was aware of my persistence in looking for treatment
 15 and made me aware that there was a trial coming up on
 16 peg interferon and ribavirin and asked me if I was
 17 prepared to take part, which I was. I didn't fit the
 18 trial criteria because apparently male and over 40
 19 wasn't a good -- but I got onto the trial so --
 20 started in 2001.
 21 **MS FRASER BUTLIN:** You had 48 weeks of treatment and
 22 managed to clear the virus?
 23 **MR ANDREW BRAGG:** Yes. Yeah, I didn't -- yeah. I was
 24 having -- after three months it still hadn't cleared
 25 so they threatened to withdraw treatment. Fortunately

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1 know what I had, so they started a very extensive set
 2 of tests to establish what I might have had in India.
 3 After about two months they said, "We can't actually
 4 detect anything that you might have caught in India
 5 but there doesn't seem to be something right with your
 6 liver. Give it" -- I think it was another month and
 7 they came back and said, "Here's a letter. Go to see
 8 your GP. You've got hepatitis C".
 9 **MS FRASER BUTLIN:** So once you were diagnosed with
 10 hepatitis C, effectively through the tests that the
 11 occupational health team had done, you were then
 12 referred to the Freeman Hospital.
 13 **MR ANDREW BRAGG:** In Newcastle, yes.
 14 **MS FRASER BUTLIN:** What were you told then about the
 15 availability of treatment?
 16 **MR ANDREW BRAGG:** Well, they reconfirmed the diagnosis by
 17 PCR and they also did a liver biopsy. So the feedback
 18 from that was that I definitely had hepatitis C, that
 19 I had fibrosis to the liver. I asked them what the
 20 implications was for me and they said, "Well, based on
 21 what we have seen, you have probably got five to seven
 22 years to live".
 23 So obvious next question is, "What treatment are
 24 you going to give?"
 25 And the answer was, "None, it is too expensive for

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1 after four months, 16 weeks, I had cleared. So
 2 I continued to the end.
 3 **MS FRASER BUTLIN:** Since that treatment, what's your
 4 health been like?
 5 **MR ANDREW BRAGG:** Well, I have cleared the virus but my
 6 immune system is quite comprehensively damaged so
 7 I get infections regularly. Typically a major
 8 infection every year, two or three small ones. So
 9 I have had sepsis three times. I've had pneumonia.
 10 I'm a regular visitor to hospitals with infections.
 11 **MS FRASER BUTLIN:** You have also got raised blood pressure
 12 and heart rate.
 13 **MR ANDREW BRAGG:** Yeah. That was interesting because all
 14 the way through treatment they never once did obs,
 15 standard obs. So I think it was after two or three
 16 PCRs I was discharged from Newcastle and picked up
 17 again by my GP. The first thing he did was check my
 18 blood pressure and it was very high. And my resting
 19 heart rate was over 100.
 20 **MS FRASER BUTLIN:** You were also diagnosed with
 21 Type 2 diabetes in 2017.
 22 **MR ANDREW BRAGG:** Yes.
 23 **MS FRASER BUTLIN:** And you said you've had sepsis. It was
 24 biliary sepsis in -- twice in 2013 and then again in
 25 2016, is that right?

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1 **MR ANDREW BRAGG:** Yes.

2 **MS FRASER BUTLIN:** In terms of your immune system, you

3 went to see an immunologist about that.

4 **MR ANDREW BRAGG:** Yes, I did.

5 **MS FRASER BUTLIN:** What were you told?

6 **MR ANDREW BRAGG:** That basically there's four proteins

7 that form the basis of your immune system, and two of

8 them in my case were at very low levels. One of them

9 is called C-reactive -- it's CRP, C-reactive protein,

10 is what doctors use to establish whether you have

11 an infection or not. And the immunologist told me

12 that my base levels were so low that even if they went

13 up a hundred-fold, I still wouldn't pass the test that

14 a standard doctor would recognise that I had

15 an infection. So I have a history of knowing I have

16 an infection but not getting a doctor to believe me

17 that I have an infection. So usually I have to wait

18 until I get seriously ill before they'll intervene.

19 **MS FRASER BUTLIN:** What has the impact been on your work

20 with all of these health difficulties?

21 **MR ANDREW BRAGG:** What effectively it's done is I -- since

22 I had treatment I've not been able to do a responsible

23 role. So I have not been able to run a business.

24 I have not been able to have a team of people. I have

25 really not been able to manage a line budget, so

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1 I should have a go at this.

2 **MS FRASER BUTLIN:** With your application for the Skipton

3 Fund, you provided a letter from Norway which you had

4 obtained in 2001.

5 **MR ANDREW BRAGG:** For the initial application, yeah.

6 **MS FRASER BUTLIN:** Can we --

7 **MR ANDREW BRAGG:** So I was of the understanding that

8 hepatitis C was, like, something you had to register

9 as a serious illness, that -- you know, it's -- you

10 can communicate it therefore. So I asked at Freemans

11 who had they told that I had hepatitis C? And they

12 hadn't told anyone. So, "Have you written to Norway?"

13 No. So I wrote to the Norwegians to say, "I have been

14 diagnosed with hep C", just to make them aware, and

15 they responded with a letter that basically said I'd

16 received blood transfusions from four donors when

17 I was in Norway, that three of those donors were still

18 donors now and were testing negative and that the

19 fourth donor they were looking to -- had no trace.

20 **MS FRASER BUTLIN:** If you want we will look at the letter.

21 Probably easier.

22 WITN0195005.

23 Before we look at the terms of the letter, this

24 only arose though, Andrew, because you had contacted

25 the Norwegians to tell them you had hepatitis C?

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1 effectively my career in the company came to an end

2 when I had treatment. Because, you know, if you are

3 having six, eight, ten weeks a year off sick, then you

4 are not a reliable employee. So I am more in

5 a skilled -- you know, so I advise the company on

6 things. But it means, you know, I've just not been

7 able to progress.

8 **MS FRASER BUTLIN:** I think you described that you are

9 doing a sort of technical role but you can't do any of

10 the managerial or business work that you were

11 previously doing?

12 **MR ANDREW BRAGG:** No.

13 **MS FRASER BUTLIN:** In terms of the Skipton Fund, can you

14 tell us how you came to hear about it?

15 **MR ANDREW BRAGG:** Through The Hepatitis C Trust. One of

16 the things that I did carry on after I was discharged

17 from Newcastle was that there was a charity called

18 Liver News which gives you booklets and informs you

19 what is going on at the Freeman, and one of the

20 articles in there was around a survey that this

21 hepatitis C Trust was doing, to which I signed up for.

22 It was looking for what was the ongoing effects of

23 treatment. And in one of the articles in one of their

24 magazines it mentioned the Skipton Fund, which I had

25 never heard of. So I looked it up more and thought

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1 **MR ANDREW BRAGG:** Yes.

2 **MS FRASER BUTLIN:** We see their response:

3 "I am sorry to hear that you have got the

4 diagnoses hepatitis C. During your hospital stay in

5 Bergen you received blood from 4 donors. The

6 Haukeland University Hospital Bloodbank started

7 hepatitis C-testing in October 1990. In 1986 the

8 hepatitis C virus was unknown and consequently there

9 was not any test available.

10 "We have examined through our donor files. Three

11 of the four donors have tested anti-hepatitis C

12 negative. The fourth donor has not given blood since

13 1987, and she has not tested hepatitis C positive as

14 a patient."

15 So you sent this letter with your application to

16 the Skipton Fund but your application was refused.

17 **MR ANDREW BRAGG:** Yes.

18 **MS FRASER BUTLIN:** If we can turn to that.

19 EIBS0000148, please, _061.

20 We see a response if we look down towards the

21 middle of the page:

22 "The supporting medical information submitted in

23 your application did not provide sufficient evidence

24 that ..."

25 On the balance of probabilities that you had

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1 contracted hepatitis C through NHS blood or blood
2 products.
3 "I understand from the documentation provided that
4 you received blood transfusions from four donors in
5 Norway and three of the four donors were Anti-HCV
6 negative but the fourth cannot be ruled out as
7 a potential source of infection. The medical
8 assessors could find no record of your receipt of NHS
9 blood or blood products in the documentation
10 provided."

11 You sought your records from Blackburn Hospital.

12 **MR ANDREW BRAGG:** I did.

13 **MS FRASER BUTLIN:** What were you told about that?

14 **MR ANDREW BRAGG:** I had a letter saying that, in
15 accordance with hospital policy, my records had been
16 destroyed.

17 **MS FRASER BUTLIN:** And in relation to Broadgreen Hospital,
18 what notes did you get from them?

19 **MR ANDREW BRAGG:** They sent some records. I wouldn't
20 describe them as comprehensive but they had actually
21 something on file. But it was quite difficult to
22 really establish in detail what had happened.

23 **MS FRASER BUTLIN:** And in those records there wasn't any
24 indication of a blood transfusion in those records?

25 **MR ANDREW BRAGG:** No.

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1 **MS FRASER BUTLIN:** And appealed their decision. If we can
2 look at your appeal email.

3 EIBS0000148_064, please.

4 We can see there that you had provided the three
5 responses, the Haukeland Sykehus Bergen response, the
6 Royal Liverpool Hospital's response and the East
7 Lancashire Hospital response, and then you wrote this:
8 "It is very disappointing that East Lancashire
9 trust has destroyed my records because I had
10 a significant operation to remove the tibial nail at
11 Blackburn Royal Infirmary in 1987. This surgery was
12 followed by readmission to deal with the complications
13 which followed.

14 "A summary of my case for inclusion in the EIBSS
15 scheme was that;

16 "1. The Norwegian authorities have extensive
17 records of my treatment and all blood donors involved
18 and they believe that it is highly unlikely that
19 I could have contracted Hepatitis C during their
20 treatment.

21 "2. I had two surgical procedures in Broadgreen
22 Hospital in Liverpool in 1986 for which some limited
23 records are available and are attached.

24 "3. I had one major surgical procedure in
25 Blackburn Royal Infirmary in 1987 for which all

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1 **MS FRASER BUTLIN:** You also obtained a further letter from
2 the Norwegian Hospital Trust.

3 **MR ANDREW BRAGG:** Well, I got in touch with the Norwegians
4 to tell them what EIBSS had said.

5 **MS FRASER BUTLIN:** We have got their response, the
6 Norwegian response.

7 WITN0195002, please.

8 Dated April 2018. Is this the response that you
9 got? It says:

10 "This is a response to your letter of March 20th
11 2018 concerning further information on the donor about
12 whom we had no definite information about hepatitis C
13 status in 2001.

14 "She has now been repeatedly [I think it should
15 say 'tested'] for antibodies to hepatitis C in
16 relation to multiple hospital visits since 2005, all
17 tests for anti-HCV have been negative.

18 "As mentioned in the letter from prof Hervig in
19 2001 the other three donors of the 4 units of blood
20 you received in 1986 were repeat donors beyond our
21 testing for hepatitis C and testing negative.

22 "It is highly unlikely that you have contracted
23 hepatitis C from the transfusions in 1986."

24 So, you provided that to EIBSS.

25 **MR ANDREW BRAGG:** Yes.

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1 records have been destroyed. I was admitted for
2 surgery to remove the tibial nail from my right leg on
3 12th October 1987 and had the operation the following
4 day. The date is very clear to me because my step
5 father had a heart attack at the hospital after
6 dropping me at the ward. I was allowed out of bed for
7 the first time to visit him on October 23rd. He died
8 that evening. I was readmitted to BRI a week later
9 following complications with my right knee.

10 "Contracting hepatitis C has been a major event in
11 my life which has severely impacted on my health,
12 quality of life and work prospects. I am sure that
13 this was contracted during one of the medical
14 procedures I underwent during treatment within the UK.
15 On this basis I am appealing your earlier decision."

16 That appeal was unsuccessful and we will just, if
17 we may, turn to the rejection of the appeal.

18 WITN0195006.

19 There are the standard provisions -- standard
20 letter on the first page, but if we turn to page 2,
21 and it is the third paragraph:

22 "The Panel noted that your appeal was based on
23 a transfusion you received on returning home following
24 a road traffic accident in 1986 in Norway.

25 Unfortunately, due to the lack of supporting evidence

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1 including medical records confirming that you were
2 treated with NHS blood or blood products prior to 1991
3 in England, the Panel were not satisfied that it was
4 more probable than not that your Hepatitis C infection
5 resulted from qualifying NHS treatment. Accordingly
6 we regret that we must refuse your appeal."

7 Andrew, were there any more records that you could
8 have obtained?

9 **MR ANDREW BRAGG:** Not that I was aware of. I would have
10 pursued it if I thought I could find more evidence.

11 It doesn't help that the system is quite diffuse,
12 there is no clear pathway of how to obtain this
13 evidence, so it's quite difficult and challenging to
14 be outside of the system and then try and find it.

15 **MS FRASER BUTLIN:** I think that's something we will come
16 back to in our thematic conversation shortly.

17 If we could then turn, Ruby, to talk to you
18 a little bit about your situation. You are here to
19 speak about your late sister, Anne, Ruby?

20 She had a road traffic accident in 1982; is that
21 right?

22 **MS RUBY GILKES:** Yes.

23 **MS FRASER BUTLIN:** And she sustained some very serious
24 injuries in that accident?

25 **MS RUBY GILKES:** According to the record, I didn't know

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1 details of it.

2 **MS FRASER BUTLIN:** In 2003 Anne developed rectal cancer as
3 well.

4 **MS RUBY GILKES:** Yes.

5 **MS FRASER BUTLIN:** She was also diabetic.

6 **MS RUBY GILKES:** She was a diabetic. After the transplant
7 she got diabetes.

8 **MS FRASER BUTLIN:** And in 2007 her transplanted kidney
9 began to fail; is that right?

10 **MS RUBY GILKES:** It would be 2006. Yes.

11 **MS FRASER BUTLIN:** Then in February 2007 I think you
12 received a telephone call from her neighbour?

13 **MS RUBY GILKES:** Her neighbour, yeah.

14 **MS FRASER BUTLIN:** At that point you were in Barbados?

15 **MS RUBY GILKES:** I was in Barbados. I did missionary work
16 there for the church.

17 **MS FRASER BUTLIN:** What was the situation with Anne, what
18 had happened with her?

19 **MS RUBY GILKES:** Well, the neighbours who called me and
20 told me that the taxi that takes her to the unit for
21 the -- renal unit -- and that the taxi man could not
22 get into the house. So he called a neighbour and the
23 neighbour of course had the keys and she went in and
24 her words were, to me, they found her on the floor
25 unconscious in a pool of blood. That was her words to

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1 about it until I saw the record. She did tell me that
2 she had an accident. But she was not eager to sort of
3 explain anything. She was still a bit sad about it,
4 so she didn't and I didn't press on it, but I knew she
5 had an accident where she had a very terrible time in
6 the hospital.

7 **MS FRASER BUTLIN:** In your statement you've said that she
8 had an operation to have her spleen removed and part
9 of her stomach removed.

10 **MS RUBY GILKES:** Yes.

11 **MS FRASER BUTLIN:** And your understanding is that she had
12 multiple blood transfusions at that point in time?

13 **MS RUBY GILKES:** At that time, yes.

14 **MS FRASER BUTLIN:** And through them she contracted
15 hepatitis C?

16 **MS RUBY GILKES:** Yes.

17 **MS FRASER BUTLIN:** And also suffered renal failure and
18 required a kidney transplant in 1989?

19 **MS RUBY GILKES:** Yes.

20 **MS FRASER BUTLIN:** And in 1999 Anne was told she had
21 contracted hepatitis C but the family weren't aware of
22 that at the time; is that right?

23 **MS RUBY GILKES:** No, we weren't aware of it. I just
24 happened to see when I was -- after she died and I was
25 cleaning the house out, that I came across all the

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1 me. And so she gave me the telephone number of the
2 hospital, so I called the hospital the day and the
3 doctor -- the nurse that was attending in ICU
4 confirmed that, yes, Anne was unconscious at the time.
5 So just during the time I was ringing they never
6 called me to find out what -- or give me any
7 information, so I had no information.

8 **MS FRASER BUTLIN:** Anne had septicaemia?

9 **MS RUBY GILKES:** She contracted septicaemia and she also
10 had a stroke.

11 **MS FRASER BUTLIN:** And she also had bleeding in the colon
12 as well.

13 **MS RUBY GILKES:** She was ...?

14 **MS FRASER BUTLIN:** Her colon, there was bleeding in her
15 colon, in her lower intestine.

16 **MS RUBY GILKES:** Yes, she had serious bleeding in the
17 colon, that's it.

18 **MS FRASER BUTLIN:** You got back to the UK in March, not
19 very long after that, and you found Anne was really
20 very unwell at that point?

21 **MS RUBY GILKES:** Well, she was very unwell. I spent
22 three days with her. On Monday I got back from
23 Barbados, the earliest flight I could get back, and
24 I spent Monday, Tuesday and Wednesday in Norwich and
25 I told her I would come back because she was telling

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1 me about that they were going to do an operation on
2 her and her words were they were going to bring part
3 of her belly out on the top and she said to me,
4 "I never -- I could never live with that. I could
5 never live with that. No, no, I could never". So
6 anyhow, to start a story, I told her I would come back
7 on the next week, the Monday, and see the doctor
8 because up until then I had no communication with the
9 hospital, nothing. So I told her I would come back on
10 the Monday and see her.

11 And, unfortunately, on the Monday I was -- we
12 went -- I came back, on the coach again, and it was my
13 daughter and my sister, and I got a telephone message
14 to say that my -- Anne was taken to the operating
15 theatre the night and that she -- unfortunately, they
16 couldn't stop the bleeding and they let her go. She
17 died.

18 So we still carry on, the three of us, to the
19 hospital. We got to the administrative office and by
20 the time we go into operation -- the office, saw the
21 nurse sitting there and she told me, she never even
22 said -- no sorry, nothing. She just said -- give us
23 the belongings to Anne and she gave the certificate
24 and whatever. I never even looked at it because the
25 shock of it. But what she said is -- then she told me

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1 me and she was so determined, she said, "I will never
2 have that. I will never have that. No, I can't live
3 with that", and I said I would go back on the Monday
4 to see the doctor myself, and I didn't let her know
5 that is what I was coming back to do, but
6 unfortunately we never got there. She died before.

7 **MS FRASER BUTLIN:** Anne had applied to the Skipton Fund
8 before she died.

9 **MS RUBY GILKES:** Yes, she did. The consultant that looked
10 after her in hospital -- I saw the letters, that's
11 where I got the material from. I didn't -- no-one
12 told me anything. I just got from the notes that
13 I saw in the house and I saw he had written to Skipton
14 Fund about Anne's condition, that she had contacted
15 hepatitis C. But when she sent the form, Skipton Fund
16 declined the form and they didn't give no -- well,
17 I didn't see any reason for -- but they just -- I saw
18 declined.

19 So I saw all of this information that I got now,
20 the Skipton Fund, within these notes that I saw.
21 I call up Skipton Fund and the guy said -- he asked me
22 first, you know who I was. I give him who I was and
23 I told him Anne had died and he said to me then, "Oh,
24 that's what she told" -- when I told him that I saw
25 hepatitis C in the notes. He said, "That's what she

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1 that a message from the hospital chaplain to say that
2 under no circumstances to see the body, to view the
3 body.

4 So we left the hospital and the time came and we
5 were then -- I went to register the death. I never
6 even looked to see and didn't even realise I gave the
7 wrong -- the lady said, "Clark with an e", and to be
8 quite honest I was -- I just thought she wrote,
9 I think she wrote Clark without the e.

10 Anyhow, the time came for her to be buried and
11 I went then to the funeral director and I took her
12 best clothes because she was a model. She used to
13 model these clothes and catwalk. She was very
14 independent and she was very winning.

15 So I took a very nice dress and say ... you know.
16 Then they told me, no, that, you know, it was no use
17 to bring that because under no circumstances the
18 hospital said to view the body.

19 **MS FRASER BUTLIN:** Anne had undergone an operation to fit
20 a colostomy bag. So it was to have --

21 **MS RUBY GILKES:** Yes, a colostomy bag on the outside, you
22 know.

23 **MS FRASER BUTLIN:** A stoma.

24 **MS RUBY GILKES:** I didn't discuss it with her but I was
25 going back on the Monday to see the -- after she told

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1 told you". I said, "No, she never told me anything
2 about it but I got the record that, you know, that you
3 sent, and I got the information from you that that's
4 how I come to contact you".

5 So he sent me a form and I had to go to the
6 doctor, her GP, and the GP had to wait some time
7 because they said they don't keep the record here, so
8 they would send away for the records.

9 **MS FRASER BUTLIN:** So you re-applied to the Skipton
10 Fund --

11 **MS RUBY GILKES:** Mm.

12 **MS FRASER BUTLIN:** -- in 2013?

13 **MS RUBY GILKES:** Yes.

14 **MS FRASER BUTLIN:** And provided letters from Anne's
15 hepatologist and other medical letters you had managed
16 to gather.

17 **MS RUBY GILKES:** Yes.

18 **MS FRASER BUTLIN:** In 2014 the Skipton Fund accepted the
19 application and paid a stage one payment.

20 **MS RUBY GILKES:** No, first of all, they declined it and
21 I had to -- they said if I did not agree with what
22 they had said, I was to appeal, so I appealed and it
23 was accepted.

24 **MS FRASER BUTLIN:** You then made an application for
25 a stage 2 payment but by then the clinician who had

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1 treated your sister had retired; is that right?
 2 **MS RUBY GILKES:** Yes.
 3 **MS FRASER BUTLIN:** So the form was completed by
 4 a clinician on the basis of the records they had but
 5 had never treated Anne?
 6 **MS RUBY GILKES:** No, that's what it said. He never
 7 treated Anne, he didn't know Anne but that's what the
 8 record says so he ...
 9 **MS FRASER BUTLIN:** He sent the form as Skipton required
 10 directly to Skipton?
 11 **MS RUBY GILKES:** Yes.
 12 **MS FRASER BUTLIN:** But that meant you didn't see what he
 13 had written?
 14 **MS RUBY GILKES:** I didn't see what he write, no.
 15 **MS FRASER BUTLIN:** And you had concerns about what he
 16 might have written?
 17 **MS RUBY GILKES:** Yes.
 18 **MS FRASER BUTLIN:** If we can look at -- if you are
 19 comfortable with this, look at Anne's death
 20 certificate.
 21 WITN0805008, please.
 22 We have towards the -- just below halfway, the
 23 cause of death is marked as:
 24 "(a) Lower Gastrointestinal bleed.
 25 "(b) Angiodysplasia of colon.

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1 **MS RUBY GILKES:** Yes.
 2 **MS FRASER BUTLIN:** But that wasn't upheld?
 3 **MS RUBY GILKES:** What they say, they did an investigation,
 4 they say. In paragraphs they said -- in one paragraph
 5 they said that she did -- acknowledged that she had
 6 been to the operating theatre on 12 March. And then
 7 further down into another category they said that
 8 she -- that Mrs Anne Jordan-Clarke sadly died in
 9 hospital on 6 March. So that caused two deaths: she
 10 had one on the 12th and one on the 6th. So they
 11 didn't agree with me that, you know -- they were not
 12 in agreement with me at all. They didn't do anything
 13 about it.
 14 **MS FRASER BUTLIN:** I think you have tried to challenge the
 15 death certificate because you feel that hepatitis C
 16 played a more significant part in your sister's death
 17 than we see here, particularly in relation to the
 18 gastrointestinal bleed, is that right?
 19 **MS RUBY GILKES:** Yes, the bleeding, and they could not
 20 stop the bleeding in the operating theatre. Now, I'm
 21 a nurse and I worked in operating theatres for
 22 30-something years and I knew that -- knew when you
 23 can't stop the bleeding, when the liver is involved.
 24 So I challenged that. I told them no, something wrong
 25 because they did not do a coroner's report to find

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1 "II End stage Renal failure, Diabetes, Hepatitis
 2 C, Carcinoma Rectum, Sarcoid Liver."
 3 Because the death certificate didn't say that
 4 liver failure had caused her death then the
 5 application for a stage 2 payment was refused; is that
 6 right?
 7 **MS RUBY GILKES:** That is correct.
 8 **MS FRASER BUTLIN:** But you have sought to challenge the
 9 death certificate?
 10 **MS RUBY GILKES:** Sorry?
 11 **MS FRASER BUTLIN:** You weren't happy with what was put on
 12 the death certificate?
 13 **MS RUBY GILKES:** No, at that point I looked at it because
 14 I didn't see -- before that I didn't observe the death
 15 certificate. But at that point, after he said that,
 16 you know, what was written on the death certificate
 17 wasn't the criteria of what he wanted, I looked at it
 18 and then I saw, no, that is -- what they have there
 19 for the cause of death is not really what happened.
 20 And also I said -- you know, I write to him and I told
 21 him that. It wasn't like that. It wasn't -- she had
 22 an operation that caused her death. So he didn't
 23 agree, doesn't agree with it. He just doesn't.
 24 **MS FRASER BUTLIN:** You have sought to -- you have made
 25 a complaint to the Parliamentary Ombudsman?

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1 out, you know, what happened during the operation. So
 2 I told them -- told Mr -- the Skipton Fund that I did
 3 not agree with what they were saying, as he was trying
 4 to convince me that she died of problems with her
 5 intestines. I told him no, it is not so.
 6 **MS FRASER BUTLIN:** Thank you. We can take that down.
 7 Peter. You work as an architect.
 8 **MR PETER FRITH:** I'm a chartered architect, yes.
 9 **MS FRASER BUTLIN:** During your training in August 1974 you
 10 were on a work placement when you had a --
 11 **MR PETER FRITH:** Yes, it's actually -- I put that down --
 12 it is actually April.
 13 **MS FRASER BUTLIN:** April 1974, apologies.
 14 You were on a work placement when you had
 15 a nosebleed.
 16 **MR PETER FRITH:** That is correct.
 17 **MS FRASER BUTLIN:** That wouldn't stop?
 18 **MR PETER FRITH:** It wouldn't stop, yeah.
 19 **MS FRASER BUTLIN:** So you were taken to hospital.
 20 **MR PETER FRITH:** I was taken to the North Lonsdale
 21 Hospital at A&E.
 22 **MS FRASER BUTLIN:** What can you tell us about what
 23 happened at --
 24 **MR PETER FRITH:** I was admitted to A&E. They performed
 25 a packing of my nose and I was left there for a couple

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1 of hours and it seemed to be under control and I was
 2 discharged home later that day. I went home. The
 3 bleeding continued, the blood running down the back of
 4 my throat. My mother called an ambulance and I was
 5 readmitted and I was admitted onto the ENT ward at
 6 North Lonsdale Hospital. I was there under the ENT
 7 consultant, Mr Potter. Kept in bed, still, not to
 8 move until the blood had stopped. He then took me --
 9 I can't recall the exact sequence of events on that
 10 particular instance but I think I was taken down for
 11 an investigation and they determined I had a fibroma
 12 of some sort and felt it would, I think, at that time,
 13 would subside.

14 **MS FRASER BUTLIN:** You were diagnosed with nasopharyngeal
 15 angiofibroma, which is a benign tumour.

16 **MR PETER FRITH:** Yes, that was -- so I went back to
 17 college in September and the nose bleeds restarted.
 18 I was then referred back to the ward and I was
 19 re-examined and the nasopharyngeal angiofibroma was
 20 determined, a benign tumour.

21 **MS FRASER BUTLIN:** And you had surgery to remove the
 22 tumour.

23 **MR PETER FRITH:** Yes.

24 **MS FRASER BUTLIN:** And at that time you think you received
 25 eight units of blood.

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1 tumour.

2 **MR PETER FRITH:** Yes, I was advised in Birmingham this was
 3 a very rare tumour, one in five million.

4 **MS FRASER BUTLIN:** You asked, in fact, to be referred back
 5 to North Lonsdale.

6 **MR PETER FRITH:** I did, so I could be at home.

7 **MS FRASER BUTLIN:** And you underwent further surgery.

8 **MR PETER FRITH:** I went -- I was admitted almost
 9 immediately, again given more blood, prior to the
 10 operation, and then went under again -- and went for
 11 second lot of surgery.

12 **MS FRASER BUTLIN:** You were then monitored for the next
 13 three to four years.

14 **MR PETER FRITH:** I was, yes.

15 **MS FRASER BUTLIN:** And it didn't recur.

16 **MR PETER FRITH:** It didn't recur, it regressed again.

17 **MS FRASER BUTLIN:** During that time of being treated in
 18 North Lonsdale and Birmingham what interactions there
 19 were with the Christie Hospital?

20 **MR PETER FRITH:** Well, after every surgical operation by
 21 Mr Potter, he was concerned that because he hadn't
 22 been able to retract the whole of the tumour, that it
 23 could recur, and to try to prevent it recurring he
 24 referred me to the Christie Hospital in Manchester for
 25 radiotherapy. I was -- went down on two -- after --

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1 **MR PETER FRITH:** Yes. I received blood before and after.

2 **MS FRASER BUTLIN:** Had you seen that you were receiving
 3 blood or is that a recollection of
 4 -- (overspeaking) --

5 **MR PETER FRITH:** Yes, when I was admitted to the hospital
 6 because I had been losing so much blood I can recall
 7 them putting the drip in my arm. Because I am very
 8 adverse to needles.

9 **MS FRASER BUTLIN:** In the autumn of 1975 the nose bleeds
 10 recurred again.

11 **MR PETER FRITH:** They did.

12 **MS FRASER BUTLIN:** And you were referred on that occasion
 13 to Birmingham.

14 **MR PETER FRITH:** Because I was in college in Birmingham,
 15 the GP I had in Birmingham referred me to the
 16 Steelhouse Lane Hospital in Birmingham where I saw
 17 a ENT consultant there. It so happens my previous ENT
 18 consultant had issued me with a letter -- which
 19 I don't have because it went to the hospital -- which
 20 had explained in case of recurrence -- because
 21 apparently these tumours are prone to recurrence --
 22 that I'd been operated on for this procedure. When
 23 I gave this to the consultants they were sort of
 24 overjoyed. They had never seen this before.

25 **MS FRASER BUTLIN:** Even in Birmingham this was a very rare

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1 following both operations and spent a week at the
 2 hospital there undergoing masses of amount of x-rays,
 3 research, and at the end of which they concluded that
 4 I would suffer more damage to my face and scarring and
 5 loss of teeth than was reasonable to be expected and
 6 their recommendation was to go back and have further
 7 surgery.

8 **MS FRASER BUTLIN:** Can you tell us what your health was
 9 like before the operations?

10 **MR PETER FRITH:** I was fit. I was very active. I would
 11 go climbing mountains, play squash, and potholing.
 12 I was very active, yeah.

13 **MS FRASER BUTLIN:** And afterwards?

14 **MR PETER FRITH:** After the operations? The operations
 15 were successful and I returned to a normal -- returned
 16 to normal health really.

17 **MS FRASER BUTLIN:** How did you come to find out you had
 18 hepatitis C?

19 **MR PETER FRITH:** In about 2009 I had my own small
 20 architectural practice and myself and my business
 21 partner at the time, we had an insurance policy,
 22 a cross partnership insurance policy, to insure our
 23 joint lives, and we were seeking to get better terms,
 24 and as part of that we were both required to have
 25 a medical examination. I went to my local GP to have

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1 a medical and he carried out the medical, at the end
2 of which he said, "Everything is fine, except your
3 liver seems very enlarged". He says, "It is nothing
4 to worry about, what we will do is we will get you
5 referred to a consultant and see what we can find
6 out".

7 Consequent to that I was referred to Gillian
8 Townsend, a consultant at the Princess Royal Hospital
9 in Telford. I visited her and sat there for about
10 an hour. She took a very detailed medical history,
11 asked me lots of detailed questions about my previous
12 health and about the operations I had had. I then
13 went under MRI scans, ultrasound scans and lots of
14 blood test.

15 Following that, one morning a letter arrived at
16 home and it was a letter from the hospital saying,
17 "You have tested positive for HCV, we would like to
18 have you back for another test just to make sure this
19 is not a false positive". At that time, heaven knows
20 I didn't know what HCV stood for, so what's the first
21 thing you do? You go and Google HCV. And then all
22 this stuff about hepatitis C comes up on the screen.

23 Wife was at work. I just rang her up and said,
24 "I have just had this, I don't know what to think".
25 Anyway, I went for the second blood test and then

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1 **MS FRASER BUTLIN:** You underwent treatment with interferon
2 and ribavirin.

3 **MR PETER FRITH:** I did.

4 **MS FRASER BUTLIN:** And cleared the hepatitis C.

5 **MR PETER FRITH:** I've never been told officially that
6 I have cleared. Those are words have never been used.
7 I discussed this with my wife and all we can recall
8 being told is that the viral load has managed to go
9 down to such a microscopic level that it is now
10 undetectable.

11 **MS FRASER BUTLIN:** You have said, though, that you don't
12 feel as physically fit.

13 **MR PETER FRITH:** Now, beyond the treatment. My wife will
14 tell you I'm not the same person. I can't do sport.
15 I'm not -- I can't maintain a level of fitness.
16 I used to play a lot of tennis prior to it. I used to
17 play for the club. I used to be a very avid
18 windsurfer. I've tried, it's just not possible.
19 I still suffer from the brain fogs and lack of
20 concentration that occurred during the treatment, and
21 there are aspects like my taste has been destroyed,
22 I can't eat food and enjoy food the same way I used
23 to. I can't drink tea at all.

24 **MS FRASER BUTLIN:** I think you said in your statement that
25 mentally it affected you very severely.

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1 a week or so later I had a phone call at the office
2 from my GP.

3 **MS FRASER BUTLIN:** He asked you to go straight down.

4 **MR PETER FRITH:** Yes, can I go straight to his, please,
5 "Tell the receptionist I phoned you". I went to see
6 him and he said, "You've tested positive for
7 hepatitis C", and he admitted that he did not know
8 a lot about it himself and that he had been contacted
9 by this consultant because she was on holiday and was
10 anxious that I should know straightaway.

11 **MS FRASER BUTLIN:** Take your time.

12 **MR PETER FRITH:** Anyway, I eventually got back to see
13 Gillian Townsend and she explained about hepatitis C
14 and most likely cause, from the history she had taken,
15 was from the blood transfusions I had had back in 1974
16 and 1975.

17 I was immediately transferred under the care of
18 a specialist hepatitis C nurse, which they had at
19 Princess Royal, a lady by the name of Sandra Taylor,
20 who was absolutely brilliant. And I was very
21 fortunate to have had her. I didn't realise that
22 a lot of authorities didn't have that facility. And
23 she was totally dedicated to dealing with patients
24 with hepatitis C, whether it be needlestick injuries,
25 drug addicts, whatever. And she was very good.

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1 **MR PETER FRITH:** Yes, it does. I am very -- get
2 depressed, feeling of loneliness.

3 **MS FRASER BUTLIN:** Thinking about the Skipton Fund, how
4 did you find out about the Skipton Fund?

5 **MR PETER FRITH:** Well, it was Sandra really, the
6 hepatitis C nurse, the first time I went to see her
7 and she was explaining about the options we had. It's
8 worth saying one of the first things she said to me
9 was, "Look, you are 54. You haven't had any trouble
10 now but you're getting to an age where things might
11 start going wrong and you could be dead this time next
12 year", which is quite a mental blow. But she was very
13 good. She told us about the Skipton Fund. She had
14 the form. She filled the form in, in the first
15 instance, and she returned the form on my behalf.

16 **MS FRASER BUTLIN:** But that first application was
17 rejected?

18 **MR PETER FRITH:** It was rejected on the basis that there
19 was no evidence that I had had an operation or
20 received blood products.

21 **MS FRASER BUTLIN:** You sought your medical records from
22 the North Lonsdale Hospital, and what was their
23 response?

24 **MR PETER FRITH:** The first thing I did was I rang Mr Fish
25 to find out why.

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1 **MS FRASER BUTLIN:** And what were you told?
 2 **MR PETER FRITH:** I was told they had no evidence. I said ,
 3 "Well, these consultants, they know what they are
 4 talking about". So, yes, they needed physical
 5 evidence I had had an operation and had had blood
 6 products.
 7 So, okay, I then went away and I approached the
 8 North Lonsdale Hospital, which no longer existed, and
 9 the subsequent hospital, the Furness District
 10 Hospital, I rang them and spoke to their records
 11 department and the first thing they asked me was,
 12 "You're not making a claim against us, are you?"
 13 I subsequently got a letter from them saying there
 14 were no records. They had been destroyed.
 15 **MS FRASER BUTLIN:** The Christie Hospital did provide some
 16 information that cross referred?
 17 **MR PETER FRITH:** They did, yes, and there was limited
 18 records from my GP as well.
 19 **MS FRASER BUTLIN:** At that point you sought a private
 20 consultation with an ENT --
 21 **MR PETER FRITH:** No, I submitted -- in the first place,
 22 I submitted those initial records from the Christie
 23 and my GP which clearly showed that I had had
 24 an operation for a nasopharyngeal angiofibroma
 25 removal. Then that was subsequently rejected on the

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1 that the Skipton Fund hadn't grasped --
 2 **MR PETER FRITH:** That's correct.
 3 **MS FRASER BUTLIN:** -- how vascular that area was?
 4 **MR PETER FRITH:** Yes.
 5 **MS FRASER BUTLIN:** If we look at the report produced by
 6 the private surgeon.
 7 SKIP0000088, and it is page 52 that I want to
 8 start with, please.
 9 If we look at the last paragraph of this page we
 10 see, we pick it up five lines down:
 11 "The main treatment for nasopharyngeal
 12 Angiofibroma involves excision of the lesion and
 13 sometimes consideration for radiotherapy. Because of
 14 the degree of vascularity of the lesion, present
 15 treatment in 2009 would normally include embolisation
 16 using interventional radiology to achieve
 17 a significant reduction in the blood supply to the
 18 tumour, prior to considering surgery for removal.
 19 Despite this, the treatment for this lesion would be
 20 highly likely to cause significant bleeding during the
 21 surgical procedure. It is noted however, that this
 22 lesion was excised in 1974 and subsequently required
 23 further excision at a second operation twelve months
 24 later in December 1975. I would therefore expect that
 25 no radiological procedure would have been undertaken

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1 basis they accepted -- that I had not demonstrated
 2 I had any blood products.
 3 **MS FRASER BUTLIN:** So you had a simple rejection because
 4 nothing had been provided. You then provided what you
 5 had and that was still rejected?
 6 **MR PETER FRITH:** That was still rejected.
 7 **MS FRASER BUTLIN:** At that point you decided to appeal?
 8 **MR PETER FRITH:** At that point I then phoned Mr Fish again
 9 to find out what I had to do and I managed to get him
 10 to admit what I had to do was I had to prove that it
 11 was probable that I had had blood products during
 12 these operations, so that's what I set out to do.
 13 **MS FRASER BUTLIN:** Can you tell us, first of all, I think
 14 one of the things you did was sought a private ENT
 15 appointment.
 16 **MR PETER FRITH:** Unfortunately, the consultant -- I had
 17 approached the consultant who did the operation but he
 18 had died. So I then approached -- I got the
 19 impression that the medical people looking at my
 20 records didn't understand what had happened, so
 21 I approached a -- I paid for a private consultation
 22 with an ENT consultant to get an opinion on what he
 23 thought would have happened during that operation.
 24 **MS FRASER BUTLIN:** Because from your perspective the
 25 nasopharyngeal angiofibroma was rare and it appeared

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1 to specifically reduce the vascularity of this lesion
 2 in 1974 or 1975, and therefore one would expect
 3 considerable bleeding at the time of surgery both in
 4 1974 and in 1975. It would therefore seem very highly
 5 probable indeed that [you] would have required at
 6 least one or more blood transfusions at or around the
 7 time of both of these operations."
 8 Then if we carry on to page 56, which is the
 9 second part of the letter:
 10 "[You are yourself] aware of blood transfusions
 11 that occurred at that time. Equally [you are] also
 12 aware that considerable operative measures were taken
 13 to reduce bleeding in this period and this included
 14 packing of the nasal fossa anteriorly and also packing
 15 the nasal fossa and nasopharynx posteriorly. [You
 16 are] aware that after the main operation in 1974 and
 17 1975, that he subsequently required a general
 18 anaesthetic for removal of the packing some two to
 19 three days following the main operation. These packs
 20 were specifically inserted to reduce the postoperative
 21 bleeding, which would have been very highly likely."
 22 So you'd paid privately for this report?
 23 **MR PETER FRITH:** I did.
 24 **MS FRASER BUTLIN:** And provided that in your appeal. You
 25 also obtained statements from your family members?

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1 **MR PETER FRITH:** I did.
 2 **MS FRASER BUTLIN:** Dealing with their recollections of you
 3 receiving blood.
 4 **MR PETER FRITH:** Yes.
 5 **MS FRASER BUTLIN:** And when you --
 6 **SIR BRIAN LANGSTAFF:** I just noticed in the last paragraph
 7 it says:
 8 "... treatment of such a tumour in 1974 would
 9 almost certainly have required blood transfusion at
 10 some stage ..."
 11 So that, again, is -- you didn't draw attention to
 12 that.
 13 **MS FRASER BUTLIN:** Apologies, sir, you are absolutely
 14 right. There is that reference.
 15 When you appealed you provided all of that, and
 16 lots of articles about the condition, running to about
 17 72 pages?
 18 **MR PETER FRITH:** I did. I would have provided more if
 19 I could have had access to the medical websites which
 20 I couldn't get access to. I was determined, if I was
 21 going to go back, I was going to prove that I had
 22 blood products.
 23 **MS FRASER BUTLIN:** Just to give a flavour of what you
 24 provided to the appeal panel, if we could turn to
 25 page 24 of this document, please, Lawrence.

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1 appeal:
 2 "- A copy of my medical records from the Christie
 3 Hospital Manchester, together with some of the ...
 4 correspondence ...
 5 "- A medical opinion provided by Mr Derek Skinner,
 6 ... Consultant ENT Surgeon, as to the high probability
 7 for the need of blood when surgically removing a nasal
 8 pharyngeal angiofibroma.
 9 "- A copy of a letter from my mother and father
 10 ... confirming that I had a blood transfusion during
 11 my operations.
 12 "- A copy of a letter from my brother ...
 13 confirming that I had a blood transfusion during my
 14 operations."
 15 And a copy of a letter from your other brother.
 16 **MR PETER FRITH:** There is another brother who is younger
 17 who couldn't remember.
 18 **MS FRASER BUTLIN:** "- A copy of the following articles
 19 I have managed to obtain from research on the internet
 20 on which I have highlighted the references to the
 21 blood loss and the need for blood transfusions during
 22 surgery for the removal of this type of tumour."
 23 And you have provided them with six medical
 24 articles including a note on MedlinePlus about
 25 juvenile angiofibroma. The MedlinePlus is of course

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1 We have a note here of the information as
 2 previously submitted. Just go down and we have the
 3 bullet points:
 4 "- The Skipton Fund Application Form duly
 5 completed by me and the Medical Team at the Princess
 6 Royal Hospital, Telford, overseeing my hepatitis C
 7 treatment.
 8 "- A letter from my Consultant and Hepatitis C
 9 Screening Nurse confirming their investigations on my
 10 behalf, and that in their opinion there are no other
 11 risk factors evident which would have led to me being
 12 infected by the Hepatitis C virus.
 13 "- A copy of a letter from University Hospitals of
 14 Morecambe Bay, which confirms that the records of my
 15 operations carried out at North Lonsdale Hospital have
 16 been destroyed.
 17 "- A copy of a letter from my current GP, which
 18 confirms that from the records available to him and to
 19 the best of his knowledge I have not had any other
 20 surgical procedures since the above dates."
 21 Then a note of the correspondence. That is what
 22 you previously submitted.
 23 **MR PETER FRITH:** Yes.
 24 **MS FRASER BUTLIN:** If we turn the page we have the
 25 additional information supplied in support of the

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1 the web based provision that all doctors can access.
 2 Having compiled the 72-odd pages you provided that
 3 to Skipton and you were successful in your appeal?
 4 **MR PETER FRITH:** I was.
 5 **MS FRASER BUTLIN:** We will come after the break to discuss
 6 the sort of impact that that process has had on you
 7 and various other thematic discussions we will have
 8 after lunch but I note the time, sir, and I wonder if
 9 it is a good time to break for lunch before we pick up
 10 those themes?
 11 **SIR BRIAN LANGSTAFF:** Yes, it is. We will start again
 12 this afternoon at 2.00. 2.00.
 13 (1.02 pm)
 14 (The short adjournment)
 15 (2.00 pm)
 16 **SIR BRIAN LANGSTAFF:** Yes.
 17 **MS FRASER BUTLIN:** Thank you. A number of you have
 18 noticed -- noted as you have given evidence that you
 19 weren't aware of the Skipton Fund until quite a lot
 20 later than your original hepatitis C diagnosis. What
 21 are your thoughts on what should have been done to
 22 tell people about the fund?
 23 Andrew?
 24 **MR ANDREW BRAGG:** One feature for me was the lack of
 25 follow-through. So we received all the medication,

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1 cleared -- got PCR saying cleared, discharged. There
2 was no support. There was no communication. There
3 was no ongoing testing. So there was almost like you
4 don't -- so, really, given the severity of hep C,
5 given the severity of the treatment, that it would
6 have been far more useful if there had been some
7 continuity of care post-treatment and part of that
8 should have been the Skipton Fund.

9 **MS FRASER BUTLIN:** Robert, I think you were agreeing with
10 that?

11 **MR ROBERT BAMFORTH:** Well, yes, because I was going to
12 King's College Hospital for years, and then suddenly
13 they said, "Oh, you are cured, good-bye", and it was
14 like, hang on, this can't happen. This is part of my
15 life. I have been going here for donkey's years and
16 suddenly they have just said, "That's it, you're
17 finished", and it is just very -- it's like I said,
18 there is no follow-up. I do get my doctor to check me
19 but I have to get him to check me. He doesn't -- no
20 doctors check you. I have to say to him -- I went for
21 a blood test the other week and I had to say to them,
22 "Are you doing hepatitis C", and she says, "I haven't
23 got it on here". I says, "Can you get it on there",
24 and she's got it -- I haven't got the results yet but
25 I think I'm all right.

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1 **MR GARY MCKELVEY:** Okay, retrospectively, yeah, for
2 someone to have said, "Look, here are some options.
3 This is what's happened. You know, we believe, as we
4 were told, the possible cause was the blood that was
5 given in 1981. Here's a route to at least getting
6 some help of some description".

7 **MR PETER FRITH:** I don't think -- I was very fortunate in
8 that my nurse immediately flagged the Skipton Fund,
9 but my GP didn't know anything about it, so whether it
10 is well known, it was flagged across the National
11 Trust(sic) as a whole or it's only a certain few
12 people who were dealing with hepatitis C or -- might
13 have known about it, and perhaps it needs to be more
14 commonly aware. Because my GP didn't really
15 understand what hepatitis C was and that's 2009.

16 **MS FRASER BUTLIN:** And they couldn't assist either on the
17 Skipton Fund if they didn't understand what
18 hepatitis C was? Would that be fair?

19 **MR PETER FRITH:** That would be fair, yeah. I even went
20 back to him after my diagnosis and told him about it
21 and he said, "Oh, perhaps I should get tested because
22 I had a blood transfusion in ..."

23 **MR ROBERT BAMFORTH:** How come somewhere like King's
24 College that was doing the trials, it was the only
25 place doing the trials at first, how come they didn't

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1 **MS FRASER BUTLIN:** And part of that follow-up should, you
2 think, have included discussion about the Skipton Fund
3 and support to apply?

4 **MR ROBERT BAMFORTH:** Yes.

5 **MS FRASER BUTLIN:** Gary, do you have any thoughts on that?

6 **MR GARY MCKELVEY:** I think in my particular case, if we go
7 back to 1991, I'm guessing it didn't exist but it was
8 a case of father dies on the Saturday, come to
9 hospital on the Sunday, it was my signature on the
10 death certificate, yeah, and go home.

11 We were given no advice, support of any
12 description. It was just -- it's you -- yeah, "Move
13 on, get on with your life", yeah. But maybe it was
14 very, very early days and there wasn't the
15 understanding and recognition of -- well, I don't
16 believe hepatitis C was even -- it was non-A, non-B at
17 the time, is my understanding.

18 **MS FRASER BUTLIN:** But given that you had been issued with
19 a death certificate that indicated hepatic failure and
20 viral hepatitis, what follow-up would you have
21 expected in relation to the Skipton Fund for
22 a bereaved family?

23 **MR GARY MCKELVEY:** At that time?

24 **MS FRASER BUTLIN:** What would you have wanted, either at
25 the time or once the fund was set up?

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1 say? I mean, they must have known. How did they not
2 know about the Skipton Fund and say to you, "Well, get
3 in touch with this" -- it was only because my sons
4 knew someone who'd done it. It is just -- I think the
5 Skipton Fund is to not pay money out rather than to
6 pay money out. I think the Skipton Fund was set up to
7 save them money, not to pay out.

8 **MS FRASER BUTLIN:** Andrew?

9 **MR ANDREW BRAGG:** I'm not sure, if hepatitis C had been
10 registered as a communicable disease, then they would
11 have had central record keeping and then that would
12 have actually enabled them to track and follow those
13 members of the population who they were aware of had
14 contracted it. That then would have allowed them to
15 follow up at a later stage when the Skipton -- who
16 they needed to approach and be proactive about it. It
17 is not proactive. You had to find out about it and
18 approach them. Which is the wrong way to do it,
19 I think.

20 **MS FRASER BUTLIN:** When you received the rejection letters
21 from the Skipton Fund in various ways, can you first
22 of all tell us the impact of those rejections on your
23 own mental well being?

24 **MR PETER FRITH:** It is devastating really, you are not
25 lying to them. You are telling the truth and you have

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1 the back up of the consultant and the hep C nurse and
 2 they say, "No, it's not true, it didn't happen", and
 3 on top of the diagnosis it is just soul destroying, it
 4 really is. And on the family as well. I was going
 5 forward to treatment, and I was being told that,
 6 "There is a possibility you could not be working next
 7 year, but there is this possible payment that would
 8 help you". Now, that's -- what do you do?
 9 **MR ROBERT BAMFORTH:** I think it is when you get rejected
 10 it is like, "You are dirty, because you must have got
 11 it some other way". That's what I think is the main
 12 thing. It's nothing to do with the money. It is to
 13 do with the fact you've been rejected to say that you
 14 got it through that. I think that's what it is.
 15 No -- well, it is as good as saying, "Well, you got it
 16 some other way", like the blood transfusion people
 17 said, you know, which was rubbish.
 18 **MS FRASER BUTLIN:** Rachael, do you have any reflections on
 19 that?
 20 **MS RACHAEL TERSTEEG:** I think with the Skipton Fund we
 21 were looking to the Skipton Fund as something as
 22 a support and actually it turned out that it wasn't
 23 a support at all. We had to fight so hard and felt
 24 more like victims instead of people who had, yeah,
 25 been infected by the hepatitis C.

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1 me to prove that the NHS -- they had it the wrong way
 2 round. So the thing that upset me was that implied in
 3 this was that the NHS had not given it to me and
 4 therefore that I had contracted it by some other
 5 route. Did they think it was an intravenous drug
 6 user? That really annoyed me.
 7 **MS FRASER BUTLIN:** Robert, I think that's what you were
 8 saying as well?
 9 **MR ROBERT BAMFORTH:** That's what I said, yeah, yeah. If
 10 they're saying you haven't got it there, and they
 11 reject you, they're saying that you've got it through
 12 sex or drugs or sharing needles, which -- and everyone
 13 else would think that of you because you've been
 14 rejected.
 15 **MS FRASER BUTLIN:** In terms of those records not being
 16 available, and lack of documents, what are your
 17 thoughts, collectively, individually, about how the
 18 system should operate if there are no records?
 19 **MR GARY MCKELVEY:** Well, clearly the system doesn't
 20 operate. That's a fact. I was really impressed with
 21 Andy providing records from Norway going back to 1986,
 22 yeah, and if he can do that, you know, with Norwegian
 23 health authorities, it makes ours look pretty poor
 24 relative to that. We should be doing much better.
 25 And it is just a total -- not a cop out, but I know

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1 **MS FRASER BUTLIN:** Because you'd provided that very
 2 lengthy statement and had it all sworn.
 3 **MS RACHAEL TERSTEEG:** Yes.
 4 **MS FRASER BUTLIN:** So when the rejection letter came in,
 5 how did that make you feel?
 6 **MS RACHAEL TERSTEEG:** I think the word that you used, was
 7 it -- you know, devastated. You put so much -- it's
 8 all true. You put your whole self into the statement
 9 and then for it to be rejected, not believed, just
 10 really, really hard.
 11 **MR PETER FRITH:** There is a bit of hope, isn't there?
 12 **MS RACHAEL TERSTEEG:** Yes.
 13 **MR PETER FRITH:** You hope and then that's taken away from
 14 you, that you are going to get some help, and it's
 15 taken -- the carpet is taken out from under your feet
 16 about that and you've got to go back to square one.
 17 **MS RACHAEL TERSTEEG:** Yes.
 18 **MS FRASER BUTLIN:** Andrew, do you have anything you want
 19 to add?
 20 **MR ANDREW BRAGG:** It didn't really impact my mental
 21 health. I was outraged because it was so difficult
 22 to -- you know, when the system destroys my medical
 23 records, how do you expect me to prove -- and what
 24 it -- is it not surely that it was for the Skipton
 25 Fund to disprove that the NHS gave it to me, not for

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1 everyone is following process and it is not the
 2 individuals that are -- at whatever sort of
 3 organisation you are speaking with, but they just
 4 repeat. And I can see it also in the documentation
 5 that you showed for everyone pretty much. It was
 6 a standard text. Yeah? It is like, "Okay, we will
 7 just churn it out again". And we will maybe -- but
 8 nothing was -- they didn't make you feel that, you
 9 know, there was anything personal involved or there
 10 was any care. It was just standard, put it out there
 11 and -- okay, in Peter's case, he, you know,
 12 demonstrated it is possible with a lot of effort, but
 13 I don't think everyone has the time or maybe the
 14 desire that he had, yeah, to make that happen. And,
 15 you know, at the end, as Robert said to me earlier, he
 16 has other issues, if it is okay to mention, yeah, with
 17 dyslexia, so it makes things very, very difficult. We
 18 are not all the same. And they should be making it
 19 easier not more difficult, and it appears that the
 20 barriers are constantly put in front of you. It
 21 shouldn't be that way.
 22 **MR PETER FRITH:** Very impressed with the -- by what the
 23 Norwegians were able to provide. Not only that they
 24 had the blood, they could identify the people it came
 25 from. Compared to the brief notes and the scratchy

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1 scrawl on some of the stuff I managed to retrieve
2 is -- then why we ever choose to destroy -- I know
3 they are paper and they take a lot of space, but it is
4 so critical for people to be able to track their
5 health records for this very purpose.

6 **MR ANDREW BRAGG:** What is the purpose of medical records?
7 You know, it appears to me that here is a system
8 which, at best, is ill defined. It doesn't appear to
9 be auditable, because when you look at the
10 documentation, it is so badly filled in and so
11 perfunctory filled in, you get the feeling that people
12 are just going through the motions of ticking boxes
13 and throwing a piece of paper in the file, and there's
14 never any follow-up. You know, has the NHS ever
15 audited its medicals? I know there are better
16 procedures now in terms of what they are supposed to
17 do, but it is a bit late now, isn't it?

18 **MS FRASER BUTLIN:** Andrew, you come at this from
19 a particular regulatory perspective, as a chemical
20 engineer. Do you want to add any reflections from
21 your own professional life in terms of audit and
22 records?

23 **MR ANDREW BRAGG:** I work in an industry which is high
24 hazard. So, you know, as part of our routine
25 operations, we put our people at risk and we put our

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1 and I haven't worked on an aeroplane for years but
2 everything I made, every rivet I used, every piece of
3 metal I used, is registered, written down, and they
4 could find out -- if a plane came out of the sky
5 tomorrow and I'd made a part for it, they would know
6 I made that part for it, and I haven't made parts for
7 years. Well, if they can do that on a rivet -- I
8 mean, I think I'm a bit more important than a rivet!
9 Do you know what I mean? It is every nut and bolt on
10 a plane is registered, right down, and forever. It is
11 never -- you know, a window come out of a plane a few
12 years back and they knew where the screws come from.
13 They could trace every -- and they pulled every
14 aeroplane that had screws from that batch in to be
15 re-checked. Well, if they can do that, why can't they
16 do it with -- for our health? You know ...

17 **MR GARY MCKELVEY:** More of a question from my side, in
18 most of the responses here we talk about records
19 destroyed after eight years, after ten years; is that
20 still the policy?

21 **MS FRASER BUTLIN:** The Inquiry heard a fairly lengthy
22 presentation a couple of weeks ago about medical
23 records retention. The answer is, it depends when and
24 where. But I can provide that to you after today.

25 Just thinking a little bit more about the

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1 neighbours at risk and -- we transport chemicals round
2 the world and we have to make sure we do it safely.
3 And we have systems and procedures to make sure we do
4 just that. But if we ever get it wrong, then we will
5 be audited by regulatory authorities and it will not
6 be a gentle process. It will be very ruthless and it
7 would be determined to find the facts. So I use as
8 an example in work that, in terms of record keeping,
9 you must always think that you were -- if something
10 goes wrong, somebody who is very, very rigorous, who
11 is very well trained is going to go through this and
12 pick out where you are at fault, so you always have to
13 follow your procedures through with the thought that
14 you would be audited. Now clearly some of that is
15 internal, we have to make sure we do it, but it
16 appears to me the NHS does not have that regulatory
17 oversight. And that is amazing, that something
18 which -- you know, they have a very difficult job to
19 do in terms of managing people's health, but equally
20 they have the ability to be detrimental to people's
21 health if they don't do it right. You know, they are
22 not a learning organisation. Nothing I have seen in
23 my encounters with the NHS would encourage me to think
24 that they learn from their mistakes.

25 **MR ROBERT BAMFORTH:** I have worked in the aircraft hanger

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1 Skipton Fund. In the context of the NHS and the
2 records challenges that there were, what do you think
3 that the Skipton Fund should have done when they were
4 facing applications from people who couldn't provide
5 those records because they had been destroyed?

6 **MR ANDREW BRAGG:** They should have made some allowance for
7 it. I mean, they'd be paid to use it as an excuse to
8 reject rather than something which they needed to
9 include in their deliberations, so it was
10 a convenience to allow them to reject people.

11 **MS RACHAEL TERSTEEG:** Yes, they didn't take any notice of
12 witness statements. And it was such an isolating
13 period to go through, of no contact with other people
14 who had got the hepatitis C virus, say, a feeling of
15 being sort of victimised and the stigma around having
16 the illness, it's -- yes, it was awful. I think the
17 Skipton Fund didn't seem to really be there to say --
18 for us; it was there to protect the government.

19 **MR ROBERT BAMFORTH:** Yes.

20 **MR PETER FRITH:** I felt it should have been more
21 proactive, and it should have undertaken -- I
22 understand it needed to have rigour and, I think,
23 a more friendly response whereby, "Yes, we've noted
24 you have been diagnosed with -- we need to sort this
25 information out, let us help you to try and sort this

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1 out. We may come to a conclusion that you are not
 2 entitled but let us help you", and undertake -- you
 3 know, the rigour I went through to demonstrate it,
 4 I shouldn't have to do that. And I think that all
 5 should have been support for me or point me in the
 6 direction where I need to go, or, "We will contact --
 7 you tell us the name of the hospital, we will contact
 8 the hospital".

9 **MR ANDREW BRAGG:** Where did the burden of proof lie? It
 10 felt to me that I had to prove myself innocent.
 11 Whereas, in the balance of probabilities, that should
 12 have been taken -- I felt almost like the victim in
 13 this. That, you know, I had contracted this disease
 14 and -- and yet there was no sympathetic reception to
 15 that. There was no trying to understand the balance
 16 of where I might have got it. I can understand the
 17 need to, you know, look at all the possibilities, but
 18 overwhelming for me the probability is that I know
 19 where I got it. And yet that didn't fall into the
 20 review.

21 **MS FRASER BUTLIN:** Within some of your answers there is
 22 a sort of mention of the attitudes and the
 23 communication within Skipton being a challenge, and
 24 Gary, you picked up the point about the standard
 25 letters. What are your reflections on the

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1 label on that she was a high risk case, and nobody
 2 told me anything, nobody -- I went there. No-one told
 3 me she was a high risk according to the notes and
 4 nobody said anything. And then some of the -- when
 5 they gave me the notes -- because I asked them for the
 6 history, the medical history after Skipton Fund keep
 7 rejecting the application, and I was amazed at the
 8 dates. You know, from the date she came in, all those
 9 dates were missing. The dates were missing.

10 She came in on the 5th of the 2nd and then all the
 11 way down to the, even the ICU, some of those notes
 12 were missing.

13 Then I saw in the same notes that they give me,
 14 one of the consultant have had -- sorry, to ask the
 15 registrar's one, what happened to some of the notes
 16 that he had given -- passed on to them. They were
 17 just missing notes. And even with the Skipton Fund,
 18 after, they keep telling me, "When you get the right
 19 information then you can come back to us". And I went
 20 to the register of the death -- you know, registering
 21 the death, and I told them what had happened and they
 22 said, "Well, you have this", they sent me a form and
 23 to fill out the form. But they said the form had to
 24 be -- go to the hospital. The hospital had to fill
 25 the form out.

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1 communication that you had with them and the style of
 2 the letters received?

3 **UNIDENTIFIED SPEAKER:** Impersonal.

4 **MR GARY MCKELVEY:** Mm.

5 **MR PETER FRITH:** Very coldly, so ...

6 **MS RACHAEL TERSTEEG:** And each of the four rejections
 7 there was the same couple of paragraphs at the end of
 8 the letter each time. I think it was just a standard
 9 letter that had -- they'd popped a little bit of
 10 information in beforehand and then that was it and off
 11 into the post.

12 **MS FRASER BUTLIN:** What effect did that have on you?
 13 We've talked about the effect of the rejection but if
 14 you can separate it out, what was the effect of those
 15 cold impersonal communications with standard form
 16 letters?

17 **MS RUBY GILKES:** In Anne's case, I mean, I visited
 18 a hospital just on three occasions, Monday, Tuesday,
 19 Wednesday, before I went back to London, but I find
 20 that, you know, she was complaining about certain
 21 things in the hospital and that she wasn't being
 22 attended to and she'd keep ring -- because she was in
 23 a room on her own when I got there, and she said she
 24 would ring the bell and people wouldn't turn up.

25 When I saw the notes, I saw they had, like, the

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1 **MS FRASER BUTLIN:** Just in terms of your interactions with
 2 Skipton, Ruby, when you were communicating with them,
 3 how did you find your communications with the Skipton
 4 Fund?

5 **MS RUBY GILKES:** Well, it was very vague, very vague, and
 6 I would have expected the Skipton Fund, seeing as it
 7 is in NHS and the hospital NHS, would collaborate
 8 together and say, "Well, Mrs Gilkes said that -- what
 9 about the death of her sister and, you know, could you
 10 look into it?" But nothing was done.

11 **MS FRASER BUTLIN:** I think we are hearing from all the
 12 panel that problem of the joined up or lack of joined
 13 up thinking between the Skipton Fund and the NHS in
 14 terms of records.

15 **MS RUBY GILKES:** I was amazed because the hospital
 16 consultant had already written to Skipton Fund
 17 regarding the same thing, hepatitis C. It was all
 18 there but they did nothing. I don't know.

19 **MR PETER FRITH:** I don't understand why the Skipton Fund
 20 didn't believe what professionals were telling them.
 21 I expect, as a professional, people to understand me
 22 and believe me. Like you, as a barrister, your
 23 advice, I believe you.

24 **MS FRASER BUTLIN:** By that you are meaning your treating
 25 clinicians were saying, "This was

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1 transfusion-acquired"?

2 **MR PETER FRITH:** Yes. And they have examined me, they

3 have taken -- looked at my history, "Yes, this is

4 definitely transfusion-related". Why wasn't that

5 believed? Why did it have to go through all the hoops

6 of having to provide the evidence. You know, it is

7 almost calling these clinicians liars.

8 **MR ANDREW BRAGG:** One thing I never understood was that,

9 why was it my responsibility to interact with the NHS

10 to get my medical records? Why was it not that when

11 I made an application to the Skipton Fund that they

12 then facilitated, using the systems that they would

13 know very well, to do that on my behalf and to help

14 them? So I was always conscious that perhaps I'm not

15 writing to the right people or I've missed people,

16 because I'm not aware of who I had to approach.

17 I went to the people I thought I needed to do but

18 there were probably more that I missed. So, for me,

19 it would have been far more effective if that, once

20 you made application to the Skipton Fund that they

21 then coordinated the search for medical records. That

22 would be a very -- relatively simply move that would

23 make sure the most effective sweep of the medical

24 records were made available.

25 **MS FRASER BUTLIN:** Gary, I think you had the same

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1 in that hospital. They were never passed on to my GP.

2 In some way you have to bring all this together. You

3 have to integrate it. They are my medical records, my

4 medical history, and yet the system does not look to

5 integrate it to bring it all into one place.

6 So it isn't standardised, it isn't ordered, and it

7 is not brought together, no wonder you fail.

8 **MR ROBERT BAMFORTH:** It all should be -- we've got an

9 NHS number, so when we have a vaccine for the thing,

10 we just give them our NHS number. And when I go

11 abroad and that, it comes up. I can see that I've had

12 this vaccine and that vaccine. Why isn't it all done

13 like that? We've all got an NHS number. It should

14 all just go on a computer under that number and

15 everything we've ever had done should be -- come up on

16 the screen. It is not that hard nowadays, is it? It

17 is not like they have to post a letter. It is on

18 a screen.

19 **MS FRASER BUTLIN:** Does anyone else have any thoughts on

20 records?

21 **MR PETER FRITH:** I'd give them 1 out of 10.

22 **SIR BRIAN LANGSTAFF:** What would you give them 1 for?

23 **UNIDENTIFIED SPEAKER:** Nothing!

24 **MR PETER FRITH:** Should we not have been given the

25 option -- before someone destroys the records, should

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1 experience of going round in circles.

2 **MR GARY MCKELVEY:** Yes, I'm just nodding as Andy's

3 speaking because I agree totally, because you don't

4 know where you are going and I have just got two

5 documents in front of me, so -- one from the Northern

6 Health and Social Care Trust, the other from the

7 Belfast Health and Social Care Trust. In terms of how

8 they make you feel, so it ends in both cases with:

9 "If you require any further help please do not

10 hesitate to contact me."

11 In other words, don't bother because, you know,

12 they can't -- if I go back then they send me somewhere

13 else, yeah? So they are closing the door with that

14 last sentence effectively.

15 **MS FRASER BUTLIN:** Along those lines, a number of you have

16 had to try to obtain patient records from a multitude

17 of hospitals and GP surgeries and the complexities of

18 a different GP where someone has died.

19 Do you have any thoughts on how much the fact that

20 records are dispersed have added to the difficulties?

21 **MR ANDREW BRAGG:** Absolutely. It seemed to me absurd that

22 wherever you get treated, so if you move around the

23 country, or even -- in my case I was visiting my

24 father and I got sepsis, so in Chesterfield Hospital

25 they have medical records for me for that period I was

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1 we not be given the option to actually receive them

2 ourselves and look after them ourselves? I understand

3 prior to digitalisation -- digitisation there had been

4 masses of paperwork and masses of records. Surely

5 before an option is taken to destroy, they should try

6 to locate that person and say, "Do you want these --

7 we'll pass these over to you or your current GP",

8 rather than just blanketly destroy -- I know it's

9 probably not -- but they would have -- they don't --

10 send them out to last addresses, no feedback, fair

11 enough. But a process should be in place where the

12 option to keep those records should be in place

13 because it's -- you know, somebody who was in hospital

14 when they were a child, it may be important that that

15 information is kept on record and not destroyed.

16 **MR ANDREW BRAGG:** I think the clue is in the name

17 "history". History goes back quite a long way.

18 **MR ROBERT BAMFORTH:** I had a car crash in France, and when

19 they finished with me in the hospital I got a folder

20 with the x-rays they'd taken, all what they'd done to

21 me, all in a folder, given to me, and I said, "Why are

22 you giving them to me?" And they basically said,

23 "Well, what good is it to us?" And they just gave it

24 to me. And I've still have it at home now, for what

25 reason I don't know, I mean. But I have just kept it

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1 because I was quite badly hurt and it's quite
 2 interesting to get the x-rays out and show them.
 3 **MR ANDREW BRAGG:** Oh, I wish I'd done that. When I came
 4 back from Norway I came back with a folder this size
 5 (*indicated*). Not only did it have all my medical
 6 records, I had every x-ray that had been taken while
 7 I was in the hospital. I made the mistake of taking
 8 that with me when I went to Broadgreen Hospital for
 9 the first time, and I never saw it again.
 10 **MS FRASER BUTLIN:** For those of you who have been bereaved
 11 and speaking about loved ones who have died, I have
 12 been asked to ask what your thoughts are on the
 13 support that should have been available to you from
 14 the funds in the particular context of applying in
 15 relation to someone who had died?
 16 **MS RACHAEL TERSTEEG:** I don't think the Skipton Fund even
 17 know that my husband passed away. Perhaps if
 18 something had been in place whereby there was, as you
 19 said, more communication between the applicants and
 20 the Skipton Fund, they would perhaps have some
 21 counselling in place to offer bereaved partners,
 22 parents. That would probably have been really
 23 helpful.
 24 **MS FRASER BUTLIN:** Gary, do you have any thoughts on that?
 25 **MR GARY MCKELVEY:** Again, it is a long time ago but it

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1 **MS FRASER BUTLIN:** Can I just check with the legal
 2 representative?
 3 In which case, sir, I wonder if we might take
 4 a short break --
 5 **SIR BRIAN LANGSTAFF:** Well, no, I think let us do this
 6 first. Shouldn't each of our panelists have the
 7 opportunity that everyone else has had to say anything
 8 that they may wish to say.
 9 **MS FRASER BUTLIN:** Sir, absolutely they should.
 10 Apologies. I missed that part. Indeed.
 11 Shall we go along the line.
 12 Andrew, would you like to start. Is there
 13 anything --
 14 **SIR BRIAN LANGSTAFF:** The only question which occurs to
 15 me -- I'm sorry to interrupt -- is we do have our
 16 anonymous witness, who will come after the break, and
 17 they will be given the same opportunity, but plainly
 18 they won't have the opportunity to engage in the panel
 19 discussion. I think that's something which is
 20 probably inevitable. I don't think there is any way
 21 we can sensibly accommodate that but if there is, now
 22 is your chance to tell me.
 23 **MS FRASER BUTLIN:** Indeed, sir, no. We have thought quite
 24 hard about this and discussed it with our anonymous
 25 witness. What I plan to do with Mr BD is take him

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1 would have been -- and again retrospectively -- it
 2 would have been useful for my mother at the time to
 3 have had some sort of, I don't know, psychological or
 4 counselling support, and some guidance maybe as to
 5 whether there are any remedies or routes for her to
 6 get some level of assistance because suddenly she is
 7 left on her own. I have two brothers but none of us
 8 live at home so she is a little bit isolated. It
 9 would have been very useful to have something, but we
 10 had nothing. No support.
 11 Just one comment regarding the records, in the
 12 record recording process, I thought actually it was
 13 only after death that they destroyed records but, as
 14 I have listened, it appears that you don't have to
 15 have died. They can still lose the records or destroy
 16 them. It is just an observation.
 17 **MR PETER FRITH:** In line with hospital policy.
 18 **MR ROBERT BAMFORTH:** I think they lose the records they
 19 want to lose.
 20 **MS FRASER BUTLIN:** Sir, do you have any questions you want
 21 to ask the panel in terms of themes before we invite
 22 Mr BD to give evidence?
 23 **SIR BRIAN LANGSTAFF:** No. I don't think I do. I have
 24 listened very carefully to what you have all been
 25 saying.

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1 through his own evidence and then ask him to reflect
 2 on some of the discussions we have had this afternoon
 3 and he has been listening to those. So hopefully we
 4 will be able to have a shorter or different thematic
 5 conversation picking up some of the discussions we
 6 have already had this afternoon.
 7 **SIR BRIAN LANGSTAFF:** That way his voice will be heard
 8 too.
 9 **MS FRASER BUTLIN:** His voice will be heard too, both in
 10 relation to his own story and in relation to the
 11 thematic points this panel have very helpfully
 12 discussed.
 13 **SIR BRIAN LANGSTAFF:** Thank you.
 14 **MS FRASER BUTLIN:** Andrew, if we start with you, is there
 15 anything else you would like to say?
 16 **MR ANDREW BRAGG:** No, I would like to thank everyone for
 17 the opportunity to be here and say this. It has been
 18 quite an isolated experience and certainly a strong
 19 theme about not being listened to, not being
 20 supported. So my hope is that from this Inquiry that
 21 things change, that what went wrong is recognised and
 22 accepted and how the NHS as an organisation operates
 23 in future learns from this, and adopts it. And it is
 24 the adoption which is very important because there is
 25 a history in government of having inquiries and then

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1 not following through on it.
 2 But absolutely crucial that we have this, and I'm
 3 more than happy to have been involved.
 4 **SIR BRIAN LANGSTAFF:** Thank you.
 5 **MS FRASER BUTLIN:** Gary?
 6 **MR GARY MCKELVEY:** Right, from a personal point of view
 7 I wasn't looking forward to coming here today, so that
 8 is the first thing. However, I would like really to
 9 thank all of the people involved in the Infected Blood
 10 Inquiry team because right from the beginning -- and
 11 I met a lady this morning because I was trying to sort
 12 of set the history for this when I was sat last night
 13 on my own and she was the first person to contact me,
 14 almost four years ago. And those people who visited
 15 me at home and provided information and support, you
 16 know, I would like to thank them also. And all of the
 17 people here on this panel, it has been really quite
 18 cathartic to listen to the experience of others
 19 because I think, as Andy said, sometimes you feel
 20 isolated, a little bit remote from what's happening,
 21 and the one thing above and beyond anything else is
 22 you don't feel believed. And that's all we want, or
 23 I want and hope for the rest, is to be believed.
 24 Nothing more. Thank you.
 25 **MS FRASER BUTLIN:** Ruby, is there anything you would like

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1 signed and this hospital that is shut down, they
 2 completely shut down. They tell me they don't have
 3 nothing else to say. So I don't know really what to
 4 do. So I'm in a limbo with family and with the
 5 hospital and I want that cleared up and I will not
 6 cease until something is done about it. That is my
 7 determination, because whatever has been done, nobody,
 8 you know, come out to say anything, nobody -- she has
 9 family. Nobody knows. And the hospital to behave
 10 like that, I have never seen it in my lifetime, in my
 11 working time. I have never seen this. For a hospital
 12 to shut down and say they don't have nothing to say.
 13 **MS FRASER BUTLIN:** Thank you.
 14 **MS RUBY GILKES:** That's what I want to see happen.
 15 **MS FRASER BUTLIN:** Peter, is there anything you would like
 16 to say?
 17 **MR PETER FRITH:** Yes, like Andy, at the end -- I think
 18 hopefully at the end of this Inquiry the NHS can learn
 19 from this and put things in place, such as record
 20 keeping, and things don't happen again in the future.
 21 I would like to thank everybody here for listening
 22 to us. Like others, I was very nervous about coming
 23 and doing this. Hopefully doing so helps other people
 24 who have suffered. Last of all, I wanted to thank the
 25 lady I mentioned before, Sandra Taylor, because

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1 to say?
 2 **MS RUBY GILKES:** I just want to say thank you very much
 3 for listening and, sir, very much for the work that he
 4 is doing, and what I would like to really see happen
 5 in my sister's situation at the moment is with the
 6 document of the death certificate, which has not been
 7 correctly done, I have family at the moment that we
 8 cannot say what Anne has died of.
 9 I don't know what else to do. I went everywhere,
 10 lawyers, everybody. I don't know what else to do, and
 11 I would just like that cleared up because my family is
 12 not happy not knowing, not seeing what happened during
 13 the death of my sister, and I am the one that is being
 14 crushed because I had the power of attorney and they
 15 say I did not use it correctly as -- even to let them
 16 see the body, even despite. And I don't know really
 17 what to do. I don't know who to go to. There is
 18 nobody out there. Everyone I go to, everywhere is
 19 just like it is dead. I don't know.
 20 But with the Skipton Fund up to now, they ask me
 21 to say that I should go to this advice bureau, which
 22 in my area there is none, and there is nobody to go to
 23 and that I should take it to court, which I'm trying
 24 now to get a solicitor or a lawyer or whatever to take
 25 the matter to court to get this death certificate

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1 without her I wouldn't be here.
 2 **MS FRASER BUTLIN:** Rachael, is there anything you would
 3 like to say?
 4 **MS RACHAEL TERSTEEG:** Well, I managed half an hour's sleep
 5 last night and that was all before coming here. I was
 6 also very anxious even though we had had a Zoom call
 7 previously last week. The support from yourselves,
 8 from Collins(?) and here this morning today has just
 9 been, just the opposite end of the scale to the
 10 Skipton Fund. You have just all been so kind and not
 11 only sensitive but understanding, and it just feels
 12 like we are on the same side instead of having to go
 13 into battle.
 14 I came here just on the off chance that Rio phoned
 15 me and said, "Would you like to consider coming?"
 16 Although I had read some of the articles, I didn't
 17 think I would be able to manage coming. But here I am
 18 and so pleased to have heard others and shared
 19 stories. Again, just so that you don't feel the
 20 isolation and to just try and go forward for my
 21 husband who had put so much hard work and time into
 22 fighting this, so really carrying on the baton.
 23 Thank you, everyone.
 24 **MS FRASER BUTLIN:** And Robert?
 25 **MR ROBERT BAMFORTH:** I would just like to thank everyone.

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1 You have all been really good because I have not got
2 a lot of faith in this sort of thing. It's never done
3 me any good before. And you have all been so helpful
4 and -- everyone I spoke to has been just so helpful,
5 put me at ease and sorted out things I can't do
6 myself. And it is good to be able to -- because
7 I have kept it to myself for years, to be able to tell
8 people -- and I can actually tell people out in the
9 street now about it, where I have never told anyone
10 about it because you have made it, like, official, if
11 you get what I mean. It's not our fault and -- so,
12 yeah, it's been good to be able to come out with it
13 all. And to hear these other people with exactly the
14 same stories.

15 **MS FRASER BUTLIN:** Andrew?

16 **MR ANDREW BRAGG:** One final observation and it is about
17 regulations.

18 The Piper Alpha disaster lost 173 people and the
19 Cullen Report fundamentally changed my industry, oil
20 and gas and chemical. I hope this Inquiry can do the
21 same thing because what I see is fundamental failings
22 right across the NHS, not just in terms of how
23 specifically it dealt with this but, by implication,
24 how it, as an organisation, functions. And I hope
25 that that regulatory framework that applies to the

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1 most of you, how challenging it was to bring
2 yourselves to come to give evidence in this Inquiry,
3 and indeed that's underwritten by the fact that the
4 next witness will be anonymous and wishes to be
5 anonymous and you have chosen not to be. Can I,
6 without in any way taking away from him and his
7 anonymity, which is fully understandable, applaud your
8 courage in being prepared to come at all and being
9 prepared to sit here in front of everyone and to tell
10 your story to what is out there, the world. It has
11 been affirming.

12 Can I also say that one of the themes that I have
13 picked up, rightly or wrongly, and people can argue
14 about that later on in the Inquiry, is that there is
15 quite a contrast between the evidence that I heard
16 when we looked at Skipton -- you will remember the
17 evidence of Mr Fish and others -- which emphasised,
18 I think implied, a lack of appropriate or sufficient
19 resource to do what you have all suggested, to look at
20 the records, obtain them for people, help them to do
21 that because of the challenges of time and money.
22 What you have each I think given us is the patient
23 perspective.

24 It is all very well to look at institutions and
25 say, "Well, we can't do that because it will cost too

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1 chemical industry, something similar could actually
2 help shape the NHS to behave differently, because at
3 the moment it seems to me that they are a law unto
4 themselves. And that will not just, you know, reflect
5 on how it's dealt with on HCV but it reflects on
6 a number of other ways in which other unfortunate
7 incidents have occurred.

8 So I would hope that that regulatory approach can
9 form part of the report, about how we can get the NHS
10 as an organisation to shape up and respond
11 effectively. Because it has failed to do so here.

12 Fundamentally, for me, as an organisation, first
13 is do no harm and yet they have done harm to a large
14 number of people in this. And a lot more people than
15 173 people have died. So the magnitude of the issue,
16 the error, the problem, is far greater in respect of
17 this Inquiry than it was to what happened in my
18 industry.

19 **SIR BRIAN LANGSTAFF:** Can I for my part thank -- may
20 I apologise first for not thanking you individually.
21 It would be invidious to do so because you are here as
22 a panel but can I thank you all and pick up some of
23 the themes that you have mentioned, particularly in
24 the last few comments.

25 You have said, most of you, not all of you but

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1 much and because it will do this and do that", this is
2 what you have been saying to me I think, and I have to
3 decide how right or wrong that is. What you have said
4 is, "What about us? Look at the way we look at it,
5 look at the way we feel", and you have all told me
6 about how you have felt being disbelieved when really
7 what was the basis for that, is I think what you have
8 been asking.

9 So thank you very much for putting that different
10 perspective to us and through this Inquiry to others.
11 You deserve our appreciation and I'm very glad to give
12 it. Thank you.

13 We will take a break then for half an hour. You
14 are very welcome to stay or go. Your life is your own
15 entirely but you are welcome to stay should you wish.

16 We will take a break until shall we say 3.20 pm.

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

18 **SIR BRIAN LANGSTAFF:** 3.20 pm.

19 (2.49 pm)

(A short break)

20

21 (3.23 pm)

22 **SIR BRIAN LANGSTAFF:** Now Mr BD.

23 **MR BD:** Good afternoon.

24 **SIR BRIAN LANGSTAFF:** You are on screen to me and to
25 counsel. You are not on screen to anyone else in this

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1 room. I have told people this morning, you may have
2 heard, I don't know, that there is an anonymity order
3 which covers you and your evidence, and I am sure that
4 those here don't want to hear me repeat it again, just
5 to remind you of it.

6 Now, I will ask you to take the oath. You are
7 affirming, so would you repeat after me please.

8 **MR BD (affirmed)**

9 **Examined by MS FRASER BUTLIN**

10 **SIR BRIAN LANGSTAFF:** Thank you, Ms Fraser Butlin.

11 **MS FRASER BUTLIN:** Mr BD, can you see and hear me?

12 **MR BD:** I can, yes.

13 **MS FRASER BUTLIN:** When you were 8, you had an accident.
14 Can you tell us what happened?

15 **MR BD:** So I was playing in the front driveway of our
16 house and was climbing on the walls and slipped and
17 fell, and as I fell it turned out some of the chunks
18 of brick on the top of the wall were loose and
19 I pulled them down on top of my arm and broke my arm.

20 **MS FRASER BUTLIN:** And what was the nature of the break to
21 your arm?

22 **MR BD:** So I suffered a double compound fracture of both
23 radius and ulna.

24 **MS FRASER BUTLIN:** How much blood was involved in the
25 accident?

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1 further bleeding, which had soaked through the plaster
2 cast, but they decided not to replace it at the time
3 because it was too unstable.

4 Afterwards, I remember being laid up for some time
5 and feeling pretty awful, but I think that is to be
6 expected of an eight-year old having suffered that
7 trauma.

8 **MS FRASER BUTLIN:** You also remember getting some flu-like
9 symptoms not long after surgery; is that right?

10 **MR BD:** Yes, it is, yes. Again, I couldn't attest to
11 whether that was just -- I was probably on some fairly
12 hefty painkillers.

13 **MS FRASER BUTLIN:** How did you come to find you had
14 hepatitis C?

15 **MR BD:** So completely incidental findings. So I was
16 actually being investigated for a diagnosis of
17 vitiligo in 2013, which I realised I had, and went to
18 the hospital to get that diagnosis confirmed, and part
19 of the work up of that was to look at potential
20 auto-immune causes of the vitiligo, so they confirmed
21 the diagnosis and did a raft of blood tests. And at
22 the point, the SPR carrying out the blood tests
23 decided to do hepatitis.

24 Now, she's -- I have spoken to her since and she
25 still doesn't really know why she did it. She said

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1 **MR BD:** So there was significant bleeding to the point,
2 well, my father found me in the next door neighbour's
3 front yard with blood spurting out of my arm and spent
4 a lot of the next day cleaning the blood off their
5 path. So that's, you know, my memories of the blood
6 loss.

7 **MS FRASER BUTLIN:** You underwent surgery at Scarborough
8 General Hospital in September 1975.

9 Do you have any recollection of having a blood
10 transfusion?

11 **MR BD:** I don't, no.

12 **MS FRASER BUTLIN:** It is right, isn't it, that your father
13 has died and your mother is very elderly and doesn't
14 know you are infected with hepatitis C?

15 **MR BD:** That's right, yes. So my memory of the injury is
16 of seeing the bone sticking out of my arm in hospital,
17 seeing it bleeding excessively, and then being put
18 under and taken into surgery.

19 **MS FRASER BUTLIN:** And after surgery, how well were you
20 post-surgery?

21 **MR BD:** So I was in surgery for a number of hours that
22 night and then allowed home that night, on condition
23 that they brought me back to fracture clinic the next
24 morning so they could check the alignment of the
25 bones. By which point there had been significant

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1 she would not normally be part of the work-up for
2 a vitiligo autoimmune raft of tests, but she did it
3 and it came back positive for hep C.

4 **MS FRASER BUTLIN:** You simply said in your statement that
5 she simply said, "Let's do the lot".

6 **MR BD:** Absolutely. I have spoken to her since, like
7 I say, and she's not sure what made her do it, but
8 thankfully she did.

9 **MS FRASER BUTLIN:** You had a follow-up appointment soon
10 after and also a FibroScan after diagnosis. What was
11 the state of your liver when you had that FibroScan?

12 **MR BD:** Bad. Full on cirrhotic. So my liver function
13 tests at that point were wildly deranged. And I had
14 MRI, CT, I had full radiological skeletal survey and,
15 as you say, FibroScan. The FibroScan came back with
16 a -- I can't remember the exact KPA figure but it was
17 around 20, which is -- anything over 10 is deemed
18 cirrhotic.

19 **MS FRASER BUTLIN:** What was your understanding of the
20 seriousness of cirrhotic liver disease? What were you
21 told about how serious things were?

22 **MR BD:** So I have some medical knowledge, so I knew
23 immediately it was a death sentence, incurable,
24 irreversible. So my immediate response was, "Tell me
25 how long I've got".

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1 **MS FRASER BUTLIN:** And what were you told?
 2 **MR BD:** I was told 10 to 15 years, and that's nine years
 3 ago.
 4 **MS FRASER BUTLIN:** Can you tell us anything of the impact
 5 that had on you, of that news?
 6 **MR BD:** Completely devastating. You go from worrying
 7 about have I got vitiligo and the vanity around how
 8 that might affect your appearance to suddenly that
 9 being so far from relevant it is unbelievable and your
 10 whole world is turned upside down and suddenly --
 11 I was 46 at the time -- you are told when you are
 12 going to die. So it was pretty devastating.
 13 **MS FRASER BUTLIN:** You were at that stage unable to have
 14 interferon. Why was that?
 15 **MR BD:** So I was profoundly thrombocytopenic, and still
 16 am.
 17 **MS FRASER BUTLIN:** That is a low platelet count?
 18 **MR BD:** Yes. And neutropenic, low neutrophils,
 19 lymphopenic, low lymphocytes, and so the feeling was
 20 that interferon would be -- it could probably be
 21 supported through haematology but it would be risky
 22 because it is likely to drop my counts even further.
 23 It would take an awful lot of support without
 24 a guarantee that it would clear the virus, and also,
 25 at this point, the new directly acting antivirals were

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1 June 2015.
 2 **MR BD:** Yes, I had.
 3 **MS FRASER BUTLIN:** And you were told you would receive
 4 Harvoni on the NHS shortly after.
 5 **MR BD:** Yes, absolutely.
 6 **MS FRASER BUTLIN:** And you started treatment in
 7 November 2015.
 8 **MR BD:** Yes. So unfortunately there were further delays
 9 and it was another six months before I was actually
 10 able to start the treatment. But got there in the
 11 end.
 12 **MS FRASER BUTLIN:** What was your situation when you
 13 received the treatment, how well or unwell were you
 14 with it?
 15 **MR BD:** So with the treatment or with the condition?
 16 **MS FRASER BUTLIN:** With the treatment.
 17 **MR BD:** So the treatment was -- compared to people who
 18 have been treated with interferon, it was a cake walk.
 19 So it is only three months. And the ribavirin does
 20 give you some issues with depression. It was -- there
 21 was insomnia but, to be honest, I worked through it.
 22 I was always -- I didn't have to take time off work
 23 through it and I still was able to exercise through
 24 it. Not very well but I was -- it was okay. To be
 25 honest, it was fine.

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1 on the horizon, so they were making their way through
 2 NICE approval. So the decision was made that it was
 3 better for me to hang on and hopefully be able to be
 4 treated with one of the new directly acting drugs.
 5 **MS FRASER BUTLIN:** In 2015 you became aware that the
 6 European Medicines Agency had licensed Harvoni.
 7 **MR BD:** Yes.
 8 **MS FRASER BUTLIN:** What did you then do in relation to
 9 that?
 10 **MR BD:** So, again, I have lots of close contact with my
 11 medical team, trying to track the NICE pathway to see
 12 how long it was going to be until it was available on
 13 the NHS, and then juggled with the idea of self
 14 funding, which was going to cost about 60,000. Each
 15 time I came to the conclusion that I wanted to self
 16 fund because I was fully aware that all the time I was
 17 still HCV positive it was causing further damage to my
 18 liver. I -- the NICE approval looked like it was only
 19 two months away each time, and so although knowing
 20 that NICE approvals constantly get kicked down the
 21 road then I still kept for a while thinking, no, I'm
 22 not going to self fund, then eventually made the
 23 decision I was going to self fund, and then a week
 24 later NICE approved it.
 25 **MS FRASER BUTLIN:** You had arranged to borrow the money in

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1 **MS FRASER BUTLIN:** You cleared the virus but continued to
 2 have six-monthly FibroScans.
 3 **MR BD:** No, so the -- so I continue to this day to have
 4 six-monthly ultrasounds to check for hepatocellular
 5 carcinoma, and I have six-monthly blood tests to check
 6 my liver function. FibroScan isn't part of routine
 7 surveillance. I've had I think two or so FibroScans
 8 in the nine years since.
 9 **MS FRASER BUTLIN:** Your infections had a huge impact on
 10 you. What do you want to tell us about that?
 11 **MR BD:** Well, it has had a massive -- you know at the
 12 time, myself and my partner had just decided we were
 13 going to have children, or try and have children, and
 14 that -- the diagnosis literally came weeks after, and
 15 at that point I couldn't cope with the concept of
 16 the risk of transmission to my partner, the risk of
 17 transmission to -- in utero to children if that
 18 happened.
 19 Also I couldn't cope with the idea of not being
 20 there to bring up my children and leaving them
 21 fatherless. So that went out of the window. The
 22 ongoing impact -- it affects every decision you make.
 23 Every time you are thinking, "Shall we go on that
 24 dream holiday next year?" half of you is thinking,
 25 "Yes, I need to do it now while I still can", but half

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1 of me is also debating internally whether I should do
 2 it because I'm trying to make sure that my partner
 3 will be financially secure when I'm gone. It affects
 4 every decision.

5 **MS FRASER BUTLIN:** In terms of the Skipton Fund, in
 6 March 2014, you were told about the fund by your
 7 treating doctor, is that right?

8 **MR BD:** Yes.

9 **MS FRASER BUTLIN:** And at that point you tried to obtain
 10 your records from Scarborough Hospital?

11 **MR BD:** Yes.

12 **MS FRASER BUTLIN:** What were you told by them? What were
 13 you told had happened to your records?

14 **MR BD:** That they had been destroyed. So that everyone's
 15 records were destroyed upon or shortly after their
 16 25th birthday.

17 **MS FRASER BUTLIN:** Were you required -- you were provided
 18 with at least one page from Scarborough Hospital in
 19 terms of the accident and emergency department and we
 20 are going to look at that document in a moment. When
 21 they sent you that, were you required to pay for the
 22 limited records they were able to provide you with?

23 **MR BD:** No, I wasn't.

24 **MS FRASER BUTLIN:** Could we just turn to the document
 25 which is the A&E record.

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1 start with.

2 We can see here that your application has been
 3 declined. If we go down the page it says this:

4 "Our assessors acknowledge that you do have
 5 chronic hepatitis C however, there is no evidence to
 6 support a history of transfusion.

7 "The assessors stated that it is highly unlikely
 8 that a transfusion would have occurred, and would not
 9 usually be necessary at an operation to repair
 10 a broken wrist."

11 You appealed that decision and I just want to look
 12 at your email in response as your appeal and then ask
 13 you about it. If we go back to page 2 of the same
 14 document. It is the paragraph at the bottom.

15 You indicate you wish to appeal and then you wrote
 16 this:

17 "It seems clear from the wording of the
 18 explanation of the declined claim that the assessors
 19 have not read the application properly. They describe
 20 it as 'an operation to repair a broken wrist'. If the
 21 documentation provided had been read properly they
 22 would see that nowhere is the word 'wrist' mentioned,
 23 and to dismiss the injury as such is more than
 24 a little insulting. As clearly stated, the injury was
 25 a double compound fracture of the radius and ulna;

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1 SKIP0000072_006. And it is page 5 I would like,
 2 please, Lawrence.

3 What we can see here on the left is:
 4 "Compound [fracture] lower [left] end radius and
 5 ulna."

6 Then on the right:
 7 "Compound [fracture] of [left] radius and ulna."
 8 Something that's difficult to read and then
 9 a little further down there is a note that Pethidine
 10 had been given. Then:
 11 "However on call contacted for advice. Sutures to
 12 the closure to the wound. No vascular or tendon
 13 injury. Check x-ray in the morning."

14 That's what's on the A&E record. And that's the
 15 only document that you were able to obtain in relation
 16 to the entire incident, is that right?

17 **MR BD:** It is, yes.

18 **MS FRASER BUTLIN:** When you applied to the Skipton Fund
 19 the first time, you were rejected by them?

20 **MR BD:** That's right.

21 **MS FRASER BUTLIN:** You then re-applied to the EIBSS in
 22 2020, is that right?

23 **MR BD:** Yeah.

24 **MS FRASER BUTLIN:** And if we can turn to that document.
 25 WITN4211002, please. It is page 3 I would like to

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1 this means that both bones were fractured, and the
 2 fractures were in the middle of my forearm. Further,
 3 just to clarify, the word 'compound' means that this
 4 involved an open wound. This open double fracture led
 5 to large loss of blood (my father spent many hours the
 6 following day cleaning the blood off the neighbours
 7 path), and the surgery was long and involved; it is my
 8 strongly held opinion, and the equally strong
 9 assertion of my medical team, that it is highly likely
 10 that such a serious injury in a young child would have
 11 required blood transfusion, and that this is the cause
 12 of my infection with hepatitis C."

13 That was the email you sent in appeal and you have
 14 referred to the original refusal of your application
 15 as more than a little insulting. Can you explain to
 16 us how you felt about the original refusal?

17 **MR BD:** Yes. I mean, I think reading that email again you
 18 can almost -- my fury is tangible. I think for me it
 19 is not the rejection, it is the manner of the
 20 rejection. And to see the words, you know, "compound
 21 fracture of radius and ulna", and describe that as
 22 a broken wrist is either a panel misunderstanding what
 23 the words radius and ulna mean, in which case that
 24 panel is not fit for purpose, or it is a deliberate
 25 attempt to diminish the severity of the injury, to

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1 then subsequently justify a rejection of the appeal.
2 And either way I don't think that is a panel that's
3 fit for purpose. And I was very angry.

4 **MS FRASER BUTLIN:** And your appeal was rejected again.

5 **MR BD:** Yes. And it was rejected again without any
6 reference whatsoever to my description of -- you know,
7 or highlighting of them describing my injury as
8 a broken wrist.

9 Now, I would at the very least have expected them
10 to say, "Yes, you're right. It doesn't say 'wrist'.
11 Sorry about that. It says you had a broken radius and
12 ulna", but there was no acknowledgement of it
13 whatsoever.

14 **MS FRASER BUTLIN:** I think you were listening into the
15 earlier discussion with the panel this afternoon, and
16 one of the things we talked about was the effect of
17 the rejections on people's mental wellbeing. Can
18 you -- do you have any reflections on that for
19 yourself?

20 **MR BD:** Yes. I mean, I think the main responses I heard
21 earlier were both anger and devastation.

22 Now, I think mine was mainly anger because I was
23 fully expecting to be rejected, because I was aware
24 anecdotally that the Skipton Fund appeared to be set
25 up to require a level of proof that most people

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1 have any reflections on that part of our discussion?

2 **MR BD:** So, yes, I agree with what they said entirely. In
3 an ideal world, we wouldn't be expected to retrieve
4 the records ourselves, because, you know, you hunt
5 around and you don't know where those records are, you
6 don't know whether you've asked the right questions to
7 the right people, and it would be very good if you
8 knew that that was being done on your behalf.

9 Now, the -- in retrospect, knowing what I know now
10 about the way that they acted. I wouldn't trust them
11 to do it. So, that's the dichotomy, is that if the
12 Skipton Fund said, "Oh, we have tried and we couldn't
13 find your records", after the treatment of that and
14 the EIBSS support scheme, I'm not sure that I would
15 trust them to do it. That is my -- how low my opinion
16 of that Fund has got.

17 **MS FRASER BUTLIN:** In terms of records and the
18 difficulties in finding records, you were obviously
19 told that the majority had been destroyed.

20 What are your thoughts on record keeping and the
21 ability to access them?

22 **MR BD:** So the NHS's record keeping has for a long time
23 been shambolic and I think this demonstrates it very,
24 very amply.

25 We should have -- I was shocked when I found out

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1 couldn't provide because their records had been
2 destroyed. So I wasn't so much devastated by the
3 rejection, I was angered by the manner of the
4 rejection. It felt patronising and disrespectful to
5 my injury. I would have hoped that they would at
6 least try to understand what had happened and
7 understand the full extent of the injury and then make
8 an educated professional assessment of that.

9 Perhaps with, you know, recourse to appropriate
10 professionals -- you know, they say in their letter
11 that on their panel they have got a liver expert,
12 a haematology expert. Now, my injury was orthopaedic.
13 So to reject on the basis that -- I would hope that
14 a panel like this, to function properly, would perhaps
15 canvass the opinion of one or two paediatric
16 orthopaedic surgeons, preferably ones who had
17 experience of treatment protocols in the '70s and say
18 to them, "Do you think a transfusion is likely in that
19 circumstance, now we have all the details of that
20 injury?" And there is very little effort made, in my
21 opinion.

22 **MS FRASER BUTLIN:** That was something that the panel also
23 discussed earlier this afternoon, of the question of
24 the Skipton Fund being more proactive in terms of
25 obtaining information and obtaining records. Do you

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1 that all my records had been destroyed because I don't
2 know whether I was just naive, but I wasn't aware of
3 that as a policy, and I do think that an organisation
4 fit for purpose would probably have asked for consent
5 of the patients and said, "This is our plan. If you
6 wish to retain these records, you need to do it
7 yourself", but at least give you the opportunity, as
8 one of the panel said earlier, to keep the records
9 yourself. Because you don't know when you might need
10 them.

11 But, you know, all that being said, they have
12 probably been sitting in cardboard boxes at
13 six different hospitals for all sorts of years, so how
14 much use they would have been and how traceable they
15 would have been, I don't know anyway.

16 **MS FRASER BUTLIN:** With that dispersion of records in
17 multiple different locations, do you have any
18 recollections on what a different system might look
19 like?

20 **MR BD:** Obviously, digitation has made all that much
21 easier and hopefully now much better. NHS hospitals
22 have always worked in silos and they still, to quite
23 an extent, do, so the cross-fertilisation of data and
24 information is wanting, and it was very poor then.
25 You were going back to the '70s. It was appallingly

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1 bad. But one of the panel did make the point earlier
2 on that in a lot of industries their record keeping
3 has to be pristine.

4 The NHS seems to be able to get away with writing
5 very perfunctory notes in a completely illegible way
6 and only half-filled-in records and half-retained
7 records, which is pretty awful.

8 Now, it has all happened and we can't change that
9 now. One of the lessons that has to come out of
10 an inquiry like this has to be that they have got to
11 get better.

12 **MS FRASER BUTLIN:** Given the state of the records
13 historically, do you have any reflections on how the
14 Skipton Fund should have been operating within that
15 context?

16 **MR BD:** So the constant reference through the Skipton Fund
17 and the EIBSS to "There is sufficient evidence" is
18 really irksome when that evidence has been destroyed

19 You know, don't keep telling me there is no
20 evidence. I know there is no evidence. Don't then
21 use that for a reason for rejecting it. We need to
22 take it as read that there is no evidence because it
23 has been destroyed. Now, we need to look at the
24 injury and we need to look at it with due diligence.

25 You know, they should have come back to me when

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1 rejection. You know, when there isn't the evidence --
2 I don't know for a fact that I had a blood
3 transfusion. Nobody knows that. And so there has to
4 be a tolerance set somewhere or else anybody could
5 write in and say, "Give me compensation, I have HCV".
6 There has to be a tolerance set somewhere. But in
7 light of the fact that everybody's data has been
8 destroyed, everybody's records have been destroyed,
9 that tolerance doesn't seem to be -- and whether this
10 is down to what Sir Brian said earlier on about
11 Skipton's claim to lack of funding, whether it is down
12 to lack of funding or whatever, it doesn't feel to me
13 like there is due diligence around the process.
14 There's been no effort made to fully understand the
15 injuries or the conditions that some of the other
16 panel described earlier on.

17 I mean, I was quite frankly shocked by the level
18 of evidence that some of the panel earlier today had,
19 way in excess of mine, and they still got rejected.
20 I was listening to them thinking, well, how on earth
21 can they be rejected? It is obvious that they had
22 transfusions within that time frame. And I would
23 have -- if they had explored the injury, taken my
24 testimony about the severity of the injury, spoken to
25 paediatric orthopaedic surgeons and got testimony from

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1 I disputed them calling my break a broken wrist.
2 I could send them a photograph of the scar. It is in
3 the middle of my forearm, it is not my wrist, so they
4 could have done that, and they could have asked for my
5 testimony. And I think, and a number of the panel
6 earlier on made the same point, that the testimony of
7 the people themselves, us, is ignored. It is almost
8 that that is taken as, "Let's not believe that". We
9 were there. I was there. I know and I still carry
10 the scars so I know what the injury was better than
11 anybody. Better than anybody alive, actually, because
12 my father is the only other person who saw that
13 injury, because my mum never looked at it, so I saw it
14 and he saw it.

15 Now, they didn't even ask me any of those
16 questions. It is almost like -- this is why I used
17 the word "patronising" earlier on. It treats us like
18 they know best. It's almost like getting a pat on the
19 head, "No, you just had a broken wrist". Well,
20 actually no, I didn't just have a broken wrist.

21 **MS FRASER BUTLIN:** Having listened to the panel earlier,
22 do you have any other reflections on what was
23 discussed?

24 **MR BD:** I don't. I mean, I think the main points I wanted
25 to make through this were that it is not the

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1 them, and they'd come back and said, "No, you wouldn't
2 have had a transfusion", I would have said, "Okay,
3 maybe I didn't", and I would have felt like it had
4 been taken seriously, thoroughly examined and reached
5 a logical, professional conclusion.

6 That's what I would have expected from a fit for
7 purpose support scheme.

8 **MS FRASER BUTLIN:** Thank you.

9 Sir, do you have any questions for Mr BD?

10 **SIR BRIAN LANGSTAFF:** No, I don't think I do.

11 **MS FRASER BUTLIN:** Mr BD, is there anything else you would
12 like to add in relation to your evidence?

13 **MR BD:** No, there isn't. I just want to thank you for the
14 opportunity to tell my story and it has been very
15 interesting and illuminating listening to the rest of
16 the panel as well.

17 **SIR BRIAN LANGSTAFF:** Can I, for my part, thank you very
18 much for having made the courage to come and tell us
19 what has been powerful and I think still angry
20 testimony -- and you are agreeing with that I can see.

21 **MR BD:** Yes. The EIBSS rejection is quite recent so
22 that's probably why I'm still -- if I talk about it
23 I get passionate, shall I say.

24 **SIR BRIAN LANGSTAFF:** Yes, I have a feeling it is quite
25 raw still.

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1 **MR BD:** Yes.

2 **SIR BRIAN LANGSTAFF:** Well, thank you very much anyway for

3 telling us. You have covered not only the question of

4 rejection but also the recent knowledge of it and the

5 recent treatment, so thank you.

6 **MR BD:** Pleasure.

7 **SIR BRIAN LANGSTAFF:** Now, Ms Fraser Butlin, tomorrow?

8 **MS FRASER BUTLIN:** Tomorrow, sir, we will hear from

9 a panel of witnesses about the experiences of people

10 with hepatitis C who cleared the infection without

11 treatment.

12 The people who are giving evidence are

13 Wayne Gathercole, Marlene Neve, Kevin Roberts and

14 Steven Towsey.

15 **SIR BRIAN LANGSTAFF:** Very well. Tomorrow at 10.00.

16 **(3.54 pm)**

17 **(The Inquiry adjourned until 10.00 am on Tuesday,**

18 **27 September 2022)**

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