

Thursday, 11 July 2019

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(10.03 am)

**SIR BRIAN LANGSTAFF:** Our first witness this morning, indeed all our witnesses today are anonymous, as I told you yesterday, and so let me make the familiar order, at least I imagine it is familiar to most of you if not all of you by now, in the case of our witness, Mr AB.

I order that the name and address of witness W2239, that's Mr AB to you and me, the names of his wife and children, including his son who died, and the name of any other member of the witness's family and any other identifying information, such as the witness's image or a description of their appearance, cannot be disclosed or published in any form, unless express permission is given by me or by the solicitor to the Inquiry acting on my behalf.

Witness W2239 must be referred to only as Mr AB. The order remains in force for the duration of the Inquiry and at all times thereafter, unless otherwise ordered, and I may vary or revoke the order by making a further order during the course of the Inquiry.

As I've asked those of you who have been here on previous occasions when I've made these orders and it will apply to the other orders I make today, please be

1 very, very careful if you're taking photographs in and  
2 around the conference centre on your mobile phones or  
3 however that you don't inadvertently take a photograph  
4 of Mr AB or, which will follow, either of the other  
5 two witnesses that you hear from today.

6 Mr AB, please.

7 **MR AB, sworn**

8 **Questioned by MS RICHARDS**

9 **Q.** You're here to talk about your son and because it  
10 would be difficult for you to talk about him without  
11 naming him, we're going to use his name [redacted] in  
12 the course of your evidence.

13 **A.** Thank you.

14 **Q.** But his name is not to be published or disclosed, it's  
15 covered by the order that you've made, sir, and your  
16 evidence won't be live-streamed for that reason.

17 You and your wife had four children, two daughters  
18 and then twin boys born in 1975.

19 **A.** That's correct.

20 **Q.** And [redacted] was one of those twins?

21 **A.** That's correct.

22 **Q.** It was the age of about 11 months that they were  
23 diagnosed with severe haemophilia A.

24 **A.** Correct.

25 **Q.** And you'd had no previous experience of haemophilia in

1 the family.

2 **A.** None at all.

3 **Q.** That diagnosis was made at Yorkhill Hospital.

4 **A.** Correct.

5 **Q.** And you've described in your statement a brief meeting  
6 with Dr Willoughby on the day of the diagnosis. What  
7 can you recall about that and what you were told?

8 **A.** It was actually my wife who was in attendance on that  
9 day and explained it was [redacted] who had the  
10 injury, I think it was his tongue, he had put his  
11 tooth through his tongue and had a bleed in his mouth  
12 and it -- difficulty stopping it bleeding, couldn't  
13 understand it, and we decided to take him to hospital  
14 and it was after these further tests that it was  
15 proven that [redacted] had haemophilia, in fact.

16 The doctors then realised then or discovered then  
17 through conversation through [redacted] that in fact  
18 [redacted] was a twin and they asked for his twin  
19 brother [redacted] to be brought to hospital and he  
20 was also tested and proven to have haemophilia, yes,  
21 severe haemophilia, yeah.

22 **Q.** And can you recall what, if any, information either  
23 your wife was given that she told you about or that  
24 you were both given about haemophilia itself or the  
25 treatment that they'd require?

1   **A.** On that particular day, whatever day that might have  
2       been, not an awful lot. It was just such a shock.  
3       But after that we obviously be invited, we'd be going  
4       back for the boys to be treated if they had a bump.  
5       Very, very little information other than if the boys  
6       bumped themselves, cut themselves, we'd take them to  
7       A&E, yeah, at Yorkhill Hospital.

8   **Q.** And you've described that you were told they would be  
9       treated with Factor VIII concentrates.

10   **A.** Correct, yeah.

11   **Q.** Were you given at that stage, when you would take them  
12       into hospital for treatment if they needed it, were  
13       you given any information or warnings or advice about  
14       any risks of infection associated with the use of that  
15       treatment?

16   **A.** 100% not.

17   **Q.** And was there ever any discussion with you or your  
18       wife about different options for treatment?

19   **A.** I think -- I think the only option that may have been  
20       available Factor VIII and cryoprecipitate would be the  
21       only other option and I believe that the boys did in  
22       fact receive both.

23   **Q.** You've said in your statement that it was until the  
24       age of about three that the boys would be taken to  
25       Yorkhill and usually given Factor VIII but

1 occasionally cryoprecipitate when they needed -- when  
2 they had more severe bleeds?

3 **A.** Correct. If it would have been a more severe bleed  
4 I would have expected the boys to be kept in, one or  
5 the two of them to be kept in overnight, whether it be  
6 a head injury or whatever, and if it was  
7 cryoprecipitate, cryoprecipitate from my memory was  
8 given through an intravenous drip, okay, so that would  
9 be the difference. Factor VIII, for instance, been  
10 hospital, kids in cots, they were kind of easier to  
11 keep under control and hands tied to the side of the  
12 cots with bandages and stuff to make sure they're not  
13 climbing out, yeah.

14 **Q.** It was when they were about three years old in 1978 or  
15 so that you were told by Dr Willoughby that a home  
16 treatment regime could be commenced. What can you  
17 recall about the home treatment starting?

18 **A.** Yeah, that would have been my wife again attending the  
19 clinic, suggesting to my wife that this would be  
20 an advancement on -- for the care of the boys, because  
21 we were very, very frequently, if it wasn't one, it  
22 was the other, and it could have been any time of day,  
23 4 o'clock in the afternoon, 10 o'clock in the morning,  
24 I was out working that would have been my wife. In  
25 the evening it would be myself. So the suggestion of

1 home therapy treatment was quite a considerable --  
2 would have made a huge difference to our lives, yeah,  
3 yeah.

4 **Q.** And regime that they were put on was twice-weekly  
5 treatment on a prophylactic basis for each boy.

6 **A.** That's correct and then more as required.

7 **Q.** Then if they required more because of bumps or  
8 particular injuries --

9 **A.** That's correct.

10 **Q.** -- they would be given more?

11 **A.** Yeah.

12 **Q.** At this point when you moved from them always going to  
13 the hospital for treatment to a home treatment  
14 programme were there any further discussions at that  
15 stage as far, as you know, about any risks of  
16 infection?

17 **A.** No, there wasn't, no.

18 **Q.** And you've described in your statement how they were  
19 very active boys, swimming, cycling, [redacted] like  
20 to play golf.

21 **A.** Younger days, cycling and swimming, eventually about  
22 12 years old [redacted] and I would play golf. Yes,  
23 they were active boys.

24 **Q.** What can you recall about the process of collecting  
25 the products from the hospital?

1   **A.** Yeah. Collecting the product, it could have either  
2       been myself or the wife. It would have been my wife  
3       if she'd been attending the clinic with the boys for  
4       a check-up for whatever, teeth, all that kind of  
5       stuff, they were quite regular. Myself, because I had  
6       the transport to go and do so.

7           The procedure was you would attend the daycare  
8       unit at Yorkhill Hospital, you'd pick up the slip, the  
9       prescription, go over to haematology, you would be  
10      given your factor, Scottish Factor VIII came in  
11      a polystyrene box with I think it was ten bottles  
12      inside each one of them, so we would have double being  
13      twins.

14           If you were getting -- if they were receiving  
15      Scottish Factor VIII, you would then give a different  
16      slip to go to the pharmacy, to collect the syringes,  
17      the draw-up needles, the butterfly needles, the cotton  
18      reel, the plasters, all that stuff, your yellow bins,  
19      et cetera, for the disposal.

20           If you were receiving Armour factor which came in  
21      a nice -- something like a cake box I would describe  
22      it, everything was inside, it was so convenient, but  
23      I have to say, that convenience, that box contained in  
24      my opinion -- not my opinion, I'm telling facts  
25      here -- it contained Factor VIII, it contained

1 everything else you needed, so it contained Mr Men  
2 plasters, the butterfly 23 needle, which would be  
3 specific for a child.

4 These boxes were delivered specifically for  
5 administration to children, the factor -- the needle  
6 size 23 was for a child, for the vein size. For you  
7 or I, it would be much larger, so they were testing  
8 for Yorkhill for children.

9 **Q.** And you can recall this very different physical look  
10 of the two products, the Scottish on the one hand, the  
11 armour Factor VIII on the other for the reasons you've  
12 given and also because the process was different,  
13 because with the Armour product everything you needed  
14 was in the box. With the others you had to go through  
15 a process of getting the related equipment separately?

16 **A.** That's correct. Swabs and all that kind of stuff,  
17 yeah, were in the box, yeah.

18 **Q.** And what can you recall being told about the  
19 availability of either Scottish or American products  
20 by the staff when you were making the collection?

21 **A.** Yeah, that was -- that would have been discussed.  
22 We'd never specifically asked, myself or [redacted],  
23 because there was no risk known to us, to either one,  
24 but I do recall arriving at the haematology department  
25 and the person administering or handing over that



1 factor saying, "Sorry, Mr AB, we only have the  
2 American. If you want to get the Scottish you can  
3 come back later". We didn't have time to go back  
4 later. We needed that product to keep our children  
5 safe.

6 There was an apology made, yeah, the apology was,  
7 "Yeah, we only we have this available to you".

8 **Q.** So the sense that you got from the staff who were  
9 providing it was that if they could give you Scottish  
10 product, they'd like to.

11 **A.** Yeah.

12 **Q.** But often they couldn't, they have to give you  
13 American because that's all they had?

14 **A.** Correct, that's what I would have taken from that,  
15 yeah.

16 **Q.** But you hadn't been told and your wife hadn't been  
17 told anything in terms of any difference between the  
18 products or different risks associated with them?

19 **A.** No, none.

20 **Q.** And had you -- did you see any kind of package or  
21 product inserts with any information about risks?

22 **A.** No, no, definitely not, no. Neither for Scottish or  
23 Armour, no definitely not.

24 **Q.** I'm just going to ask for one document to be put on  
25 the screen. It will come up in front of you.

1           It's document 2239011, please, Paul.

2           We can see here, where we've got surname and  
3           forename, these are [redacted]'s records that follow  
4           beneath that, and we can see here a list of products  
5           and dates from July 1979.

6           This list goes on until late 1987 and if we look  
7           down this first page, we can see the vast majority of  
8           the products there recorded are Factor VIII SNBTS, so  
9           the Scottish-produced product, and we see on that  
10          first page only three examples of the Armour product  
11          Factor VIII in 1979 and 1980.

12          Then if we go to the second page, please, Paul.

13          We can see -- thank you -- only two instances of  
14          the American product Factor VIII there listed and the  
15          remainder being Factor VIII SNBTS.

16          Now, these are documents recently provided, very  
17          recently provided from the Glasgow Royal Infirmary to  
18          your solicitors, as I understand it, and you have some  
19          observations about the reliability or accuracy of  
20          what's here recorded?

21         **A.** Correct, yeah.

22         **Q.** Can you tell us what those are?

23         **A.** Yes, I can, it's completely inaccurate. 400%  
24          inaccurate. I've explained to you that the boys were  
25          on home treatment therapy, which would require the

1 boys to receive Factor VIII twice weekly as a minimum.  
2 That equates to eight per week, eight per month. This  
3 is suggesting they were getting treatment once  
4 monthly, it's just impossible. It's just nonsense.

5 **Q.** So my understanding is from your perspective this  
6 doesn't show nearly enough treatment?

7 **A.** No, it doesn't, no.

8 **Q.** But also it doesn't show or reflect correctly the  
9 balance between the American and the Scottish, because  
10 you were getting American products --

11 **A.** Yeah.

12 **Q.** -- a lot of the time?

13 **A.** Yes.

14 **Q.** Now, the boys continued under the care of  
15 Dr Willoughby at Yorkhill until he left the employ of  
16 the hospital in about 1982.

17 You've made some observations in your witness  
18 statement about your understanding that  
19 Dr Willoughby's departure was somehow associated with  
20 the use of products, commercial products or Scottish  
21 products.

22 What is it that you understand?

23 **A.** Okay. I have submitted a -- a newspaper article to  
24 Thompson Inquiry and it is something, I remember  
25 reading this back is 1982, and it was the Sunday Mail,

1 1982, December 1982, and I think that's close to when  
2 Dr Willoughby's leaving, and in that newspaper article  
3 it was "Doctor leaving NHS", okay, and it's a full --  
4 a centre page, complete with Dr Willoughby and with  
5 some children but I believe these children were all  
6 leukaemia children, unfortunately, and it was a very,  
7 very sad article because he was leaving and going to  
8 work in Australia.

9 The reason that Dr Willoughby gives in that  
10 newspaper article, it was unions. He was battling  
11 with unions within the hospital, working to rule,  
12 et cetera, et cetera, you know, and he was complaining  
13 about this, bitterly complaining about this, how can  
14 he possibly look after sick children, children with  
15 haemophilia, leukaemia, many, many serious illnesses  
16 of children when he's not getting the support of the  
17 staff. He had a massive dispute about that.

18 But the follow-up to that newspaper, and this is  
19 the one I cannot get my hands -- there was a follow-up  
20 to that, if that was December 1982, it would have  
21 probably been in 1983 there was a follow-up. Somebody  
22 had gone written back to Dr Willoughby, saying, "No,  
23 no, that's not" -- I can't get my hands on that so it  
24 is difficult for me to comment on it, but what I do  
25 recall, and I can't remember how I found this out, but

1 I have provided newspaper evidence again on  
2 a Dr [redacted], [redacted]. My memory tells me that  
3 Dr [redacted] and Dr Willoughby had a fallout, I'll  
4 say, yeah, over this, yeah.

5 And I think my understanding of it, my belief is  
6 that Dr [redacted] was using Scottish blood to develop  
7 back in that time an earth-moving invention of  
8 interferon, he was using that Scottish blood, and  
9 I think this is why the American blood was getting  
10 bought, whether it was for budget or whatever, but  
11 there was a shortage, clearly a shortage.

12 I'm going to go on a wee bit. I've read a lot  
13 about this Dr [redacted]. I don't think I ever met  
14 the man, other than reading the newspaper. He wasn't  
15 involved with my children. If this is the right time  
16 to mention it but I uncovered three newspaper  
17 articles, two of them in the Glasgow Herald, very  
18 close to that time, and they report back that  
19 Dr [redacted] was in fact -- he committed fraud by  
20 obtaining a charity donation of something like  
21 £38,000.

22 It's quite clear in that newspaper, Thompsons have  
23 a copy of it, that he received that cheque, gave it to  
24 his accountant in hospital and instructed the  
25 accountant to write him a separate cheque for him,

1           okay. He was struck off for that. He was uncovered;  
2           he was struck off for that.

3   **Q.** And your understanding is that there was some --

4   **A.** Yeah.

5   **Q.** There was tension --

6   **A.** There was tension --

7   **Q.** -- in terms of the availability of Scottish versus  
8       American products --

9   **A.** Yes.

10 **Q.** -- that was somehow connected with the --

11 **A.** Yes.

12 **Q.** -- research that Dr [redacted] was doing?

13 **A.** Yes, and if I could get my hands on that second  
14       newspaper I would.

15 **Q.** I should say, sir, that Dr Willoughby will obviously  
16       be asked to comment. I think he's already been  
17       invited to comment on not dissimilar evidence from  
18       another witness in any event and a number of the  
19       matters referred to about Dr [redacted] are a matter  
20       of record, in terms of being struck off, and the  
21       witness has provided Thompsons Solicitors, and they  
22       have shown me, with various newspaper articles in that  
23       respect but we will obviously, if we can, invite  
24       Dr [redacted] to respond if he so wishes.

25 **A.** Dr [redacted] is (*unclear*).

1 Q. In that case we won't.

2 A. Okay. Can I just continue?

3 Q. Yes.

4 A. There's a third newspaper article involving  
5 Dr [redacted] and it's about interferon and believe it  
6 or not it was actually reported in the New York Times  
7 that [redacted] had been in contact with I think  
8 a Dr Calman or Coleman to obtain some Factor VIII --  
9 to obtain some interferon because he had a young  
10 patient, a leukaemia patient, who was suffering from  
11 cancer.

12 The report on the paper was that this was working  
13 fantastically, the young child was recovering,  
14 et cetera, showing improvement on facial cancers,  
15 et cetera. Sadly, that child died three months after  
16 receiving the interferon.

17 The comment by Dr Coleman in that same newspaper  
18 was that he didn't know how much interferon to  
19 administer to a patient, but it also tells the story  
20 about it required donations, blood donations, from 270  
21 blood donators to create enough interferon to treat  
22 one person for two weeks. 270 blood samples,  
23 270 pints of blood. Has that got something to do with  
24 the shortage of blood?

25 Q. Okay. Other than those treatment records that we've

1 looked at which you don't believe are comprehensive or  
2 accurate, I understand that you and your wife would  
3 keep your own treatment records but that you were  
4 asked to hand those back to Yorkhill and haven't seen  
5 them since.

6 **A.** Correct.

7 **Q.** What can you tell us about that?

8 **A.** Yeah, it was a small book probably about half the size  
9 of a A4, beige coloured book and I think it had "NHS"  
10 on the front of it, and each time my wife had to  
11 administer the home therapy treatment, you know, the  
12 batch number, the date, batch number, et cetera, the  
13 dosage would be entered into that, yeah.

14 **Q.** And what you've said in your statement is that the  
15 hospital record those books -- or that notebook around  
16 the time that they informed you of the boys being  
17 infected.

18 **A.** Yeah.

19 **Q.** They said they wanted to photocopy the notes but they  
20 were never returned to you?

21 **A.** Correct. That's correct, yeah.

22 **Q.** You've described in your witness statement there was  
23 a parents' group at Yorkhill.

24 **A.** Yeah.

25 **Q.** And indeed we've heard evidence about that from



1 another witness. Can you recall whether there were  
2 any -- there was any information provided by any of  
3 the staff at Yorkhill to the parents' group about any  
4 risks of infection with HIV?

5 **A.** I've listened to the Inquiry and other people's  
6 comments on this. I think, let me make it perfectly  
7 clear, there was two parents' groups, okay. The first  
8 parent group was what I would describe as being  
9 a gingerbread parents group, an information for if  
10 I had been living with my children for say ten years,  
11 there was mothers, young mothers, fathers, coming in  
12 who had much younger haemophiliac kids. So it was  
13 an information group for us to share our experiences  
14 for younger parents. Yes, and the topics would be we  
15 would invite some doctors along, a dentist may come  
16 along and tell us how important it was to -- and maybe  
17 some other doctor would come along and give us  
18 a speech about how things had gone, et cetera,  
19 et cetera, et cetera. Always a topic, always  
20 a subject. That was the parents' group.

21 There was a separate group for the unfortunate  
22 families who were living with HIV and had been --  
23 okay, these are a wee bit more secret. We would meet  
24 at different locations, maybe a conference room in  
25 a hotel or some other room. These were different

1 meetings. The parents' group meeting about my wife  
2 and a friend, she's here today, raising funds for us  
3 to take the children out on many occasions, carefully,  
4 accompanied.

5 **Q.** So is it right that, as far as you recall, in relation  
6 to the parents' group that you're describing that was  
7 set up by the parents themselves --

8 **A.** Yeah, yeah.

9 **Q.** -- information was not provided to that group by any  
10 medical staff about risks of infection?

11 **A.** No, no, that was not the purpose of the group.

12 **Q.** And then the second group that you've described was  
13 specifically for those who had learnt that their  
14 children had been infected?

15 **A.** Yeah. I think, you know, the purpose of that, if  
16 we're talking about an HIV group, yeah, okay, it was  
17 a social worker who attended that group and I think  
18 she was a liaison person between ourselves and the  
19 hospital. I'm not saying she was a spy, I'm not  
20 saying at all, but she was a liaison to find out how  
21 things were going on, how did that appointment go, how  
22 are the boys -- seeing how they're getting on, blah,  
23 blah blah, just general information, and I think she  
24 was maybe the person who was going back with an honest  
25 feedback to the doctors. I would think that would the

1 case.

2 Q. You've described in your statement a recollection,  
3 something your wife told you, of your wife perhaps in  
4 1980 being told something quite casually about  
5 hepatitis.

6 A. 1980?

7 Q. Yeah. The way you've put it in your statement is:  
8 "When the boys were about five years old" --

9 A. Yeah, okay.

10 Q. -- "1980, I recall my wife telling me she had been  
11 told the boys might have some kind of hepatitis."

12 A. Correct, non-A non-B was the description used, non-A  
13 non-B, not C.

14 Q. And you've said in your statement it was something  
15 that said quite casually and it was no big deal --

16 A. Yes.

17 Q. -- is how it was presented.

18 A. Yes, on both occasions.

19 Q. Now, it was in 1985 that your wife was told on a visit  
20 to the hospital that both the boys had been infected  
21 with HIV.

22 A. Yeah.

23 Q. You had said in your statement that you thought that  
24 the diagnosis of HIV and hepatitis C had been given at  
25 the same time, and I think you've -- you've looked at

1           your wife's statement --

2   **A.** Yeah.

3   **Q.** -- and the diagnosis of HIV was told first.

4   **A.** Yeah.

5   **Q.** And the diagnosis of hepatitis C came later.

6   **A.** Correct, that's correct. My wife was correct, yeah.

7   **Q.** And in terms of the diagnosis of HIV, what can you

8           recall about how you learnt it? You came home I think

9           and took to the home and your wife was at home?

10 **A.** Yeah.

11 **Q.** What did she tell you?

12 **A.** She obviously told me through this Factor VIII

13           treatment that our boys had been infected with

14           a dreadful, dreadful illness, HIV, yeah.

15           Back then, goodness, you know, living with it was

16           just -- just, you know, everyone knows what it was

17           like. The newspapers were just -- the television,

18           news, it was all over the place, it was just

19           a dreadful, a dreadful illness, tragedy.

20           We took it on the chin, a daughter, second

21           daughter, two boys to look after, what do you do?

22           It's done. The damage is done. We have to live with

23           it. We have to move on and do our best.

24 **Q.** You describe in your statement being angry and upset

25           that your wife had been given this information --

1   **A.** Yeah.

2   **Q.** -- without you being there --

3   **A.** Yeah.

4   **Q.** -- to support her and to receive the information at  
5       the same time.

6   **A.** Of course, yeah.

7   **Q.** In those early days, what advice or information, if  
8       any, were you given about HIV?

9   **A.** It would have been -- it would have been at Yorkhill,  
10       obviously, and I can only expect that it would have  
11       probably been Dr Willoughby or one of the other  
12       doctors or nurses who would be telling us about  
13       cross-infections and all this kind of stuff and be  
14       careful, and about blood spillages and things like  
15       that, making sure that the way the Factor VIII was  
16       being administered was disinfected, cleaned, we had  
17       the place mats, et cetera, to put in for all the  
18       syringes and needles to be on for anything like that  
19       to happen, but great care, great care.

20   **Q.** And you were told that the boys' CD4 counts would be  
21       measured?

22   **A.** Now, blood -- blood would be taken, early days.  
23       I refer to CD4 counts being taken once I think over  
24       the progression of [redacted]. That's when we started  
25       talking about CD4 counts, but also when [redacted] --

1 that was more important to the doctors to tell us  
2 about. What I'm trying to say is that if the boys  
3 were infected in '85, you know, it was a progression  
4 before they started, you know, informing us about CD4  
5 counts and how critical it was, a low CD4 count means  
6 you're more highly likely to pick up an infection.  
7 That's the definition of CD4, yeah.

8 **Q.** Had you known that the boys would were being tested  
9 for HIV?

10 **A.** No.

11 **Q.** You've said this in your statement about the diagnosis  
12 and about the boys:

13 "The boys were fun to be around. They were  
14 mischievous. As identical twins they would play  
15 pranks on their teachers as to who was who. They were  
16 typical young boys who wanted to be like other  
17 children, play football, et cetera. They were both  
18 very artistic. Now they were infected with an unknown  
19 adult disease."

20 You were told, as I understand your statement, by  
21 the doctors not to tell the boys straightaway?

22 **A.** Yeah, and her sisters, and my daughters, yeah.

23 **Q.** And you've said it was in about 1987 when they were 12  
24 that you decided to tell them of their infection.

25 **A.** Yeah.

1 Q. What was their reaction?

2 A. As children, okay.

3 Q. Did they --

4 A. They had their parents' support. They knew that, you  
5 know, we would be there for them to look after them,  
6 you know. But there was no tears, if that's what  
7 you're referring, yeah, nothing like that at all. It  
8 was information to the boys, more information.  
9 They're more interested in what's actually on TV on  
10 a Saturday morning, you know, Swap Shop or something  
11 like that, you know.

12 Q. And you've said in your statement you don't think they  
13 fully understood what it meant then.

14 A. No.

15 Q. You yourselves still had limited information about the  
16 illness?

17 A. Yeah. [redacted] wouldn't have known about that then.

18 Q. I'm sorry?

19 A. [redacted] would not have known about that. She would  
20 not been part of that conversation.

21 Q. When you were later given the diagnosis of  
22 hepatitis C --

23 A. Yeah.

24 Q. -- again that was given to your wife.

25 A. Yep.

1 Q. You've described in your statement as the (unclear)  
2 she being given by Dr Hann and, again, when you  
3 weren't there when that diagnosis was given to her; is  
4 that right?

5 A. That's correct, yeah.

6 Q. And you and she both describe -- I think your  
7 information is based upon hers because she was the  
8 person who was having the conversation, Dr Hann saying  
9 something along the lines of, "Well, you already knew  
10 that", or, "You already knew about that."

11 A. Yeah, the story goes, obviously, the boys were at  
12 a Yorkhill clinic and Dr Hann decided on that day that  
13 he was going to inform my wife, and I believe he  
14 managed to get in a -- I think it was a corridor,  
15 certainly in a quiet space anyway, that he delivered  
16 the news and the doctor, as I mentioned in the  
17 statement -- we, as a family, would have spoke about  
18 Dr Hann saying if he was giving you bad news he would  
19 give you it with a smile on his face and we perceived  
20 that to be a nervous thing about it. But his closing  
21 statement was exactly that, "Mrs [AB], you would have  
22 known that anyway".

23 How would she know that? My wife's not a medic.

24 Q. And other than that passing reference to hepatitis  
25 back in 1980 when the boys were five --



1   **A.** Yeah.

2   **Q.** -- had you been aware that there was any testing or  
3       assessment going on about hepatitis?

4   **A.** No, no.

5   **Q.** And do you recall whether the doctors gave you any  
6       information or advice about the hepatitis?

7   **A.** I think it was similar to HIV. HIV -- today I think  
8       hepatitis C has become the new HIV. Back then it was  
9       all about HIV, you know. HIV was much more serious,  
10      you know, than hep C would have been so no, no. There  
11      was a risk of both. If there'd been a needle stick  
12      injury, you were -- you were -- you were becoming HIV  
13      and hep C so, you know, I think do what you're doing,  
14      just keep doing what you're doing.

15   **Q.** You've said in your statement that bloods would be  
16      taken from the boys over the years as a matter of  
17      routine and you were never really told what the bloods  
18      were being tested for; is that right?

19   **A.** That's correct, yeah. Although can I just add to  
20      that, if I can?

21   **Q.** Absolutely?

22   **A.** My son [redacted] was recently in Glasgow staying with  
23      us and I was speaking to him about this obviously and  
24      what [redacted] remembers, [redacted] being  
25      [redacted]'s twin brother obviously, is it's a really,

1 really strange thing that happened. He remembers  
2 being at these clinics and having blood taken. It may  
3 have been six/seven different vials of blood being  
4 taken, you know, the red one, the green one, the  
5 purple one, the blue one, all for different liver  
6 functions, all this kind of stuff, but after that they  
7 were asked to go across to the haematology department  
8 to have Guthrie test, a thumb-prick test live in the  
9 haematology ward, and I could only assume -- no idea  
10 why that was. No idea. Never explained. Was it  
11 taken from there to a microscope? I've no idea but  
12 I just felt -- I was not aware of that until last  
13 week.

14 Q. And you've said in your statement that you just  
15 assumed they would be checking the boys' iron levels  
16 and Factor VIII levels. You were never told precisely  
17 that the blood was being taken or used for and you've  
18 expressed a concern now that there was -- you and your  
19 wife had a lack of control over what was happening and  
20 you feel the boys were being treated like lab rats is  
21 the phrase you've used in your statement. In  
22 particular a concern about whether, as identical  
23 twins, they were being treated differently for the  
24 purposes of some form of monitoring or research. Is  
25 that right?

1   **A.** I've got kind of lost with that question actually.  
2            You started your question asking about blood  
3    samples; is that correct?  
4   **Q.** Yes. What you've said in your statement, you've made  
5    two observations one is blood samples being taken  
6    without being told what they were being taken for.  
7   **A.** Yeah.  
8   **Q.** And then your understanding that they will -- those  
9    blood samples will have been used for the purposes of  
10   testing over the years --  
11   **A.** Of course.  
12   **Q.** -- and you not being told that.  
13   **A.** That's correct, yeah, absolutely, yeah.  
14   **Q.** And it's in that context you've used the phrase lab  
15    rats?  
16   **A.** Well, yes, eventually as the passage of time and  
17    realisation, having a realisation of what in fact was  
18    going on, that was my definition, that was my  
19    description, yeah.  
20   **Q.** And you've said in your statement you'd often wondered  
21    why identical twins were affected so differently and  
22    whether at some point they were given differing  
23    medications, were the doctors trying out different  
24    things on them both?  
25   **A.** We're obviously not talking about Factor VIII here,

1 but there was a time, I'm sure, when [redacted] was on  
2 medication for HIV treatment, I'm trying to think why  
3 I would have said that, what [redacted] would have  
4 been taking versus [redacted]. Yeah, there was  
5 differences in medication, yeah. I can't remember the  
6 name of the drugs, I just can't.

7 **Q.** Don't worry. Perhaps the point is this: were the  
8 differences of treatment --

9 **A.** Yeah.

10 **Q.** -- explained to you about why the boys were being  
11 treated differently?

12 **A.** Yeah, okay.

13 [redacted], when he started on his HIV treatment,  
14 was with AZT; [redacted] started on his treatment with  
15 DDI and it's knowing to the -- in my statement, that  
16 lots of reasons why, the complications, the problems  
17 with AZT.

18 **Q.** You've seen in [redacted]'s medical records some  
19 documents which suggest that there came a point when  
20 he was being given DDI as part of possibly some kind  
21 of trial, and we'll just look at those documents.  
22 It's 2239003. And if we go to the second page,  
23 please, this is a 1992-letter  
24 from Bristol-Myers Squibb Pharmaceuticals Ltd to  
25 Dr Lowe at the Glasgow Royal Infirmary, and the second

1 of the two patients there listed is [redacted], and it  
2 refers to treatment with DDI on a named patient basis.  
3 It asks the doctor to inform the pharmaceutical  
4 company if there is any serious adverse events, and  
5 the last paragraph refers to a document being  
6 provided:

7 "... jointly prepared by the MRC HIV clinical  
8 trials group and the principal investigator and trial  
9 physician for Alfa."

10 And then we can see at 2239004 even after  
11 [redacted]'s death, because this is a document from  
12 March 1994, notification being given to the  
13 pharmaceutical company of potential adverse reactions.

14 **A.** Yeah.

15 **Q.** Were you aware of any of that during the course of  
16 [redacted]'s treatment?

17 **A.** The adverse reactions?

18 **Q.** First of all, that there was some form of  
19 a named-patient basis for him being given a trial and  
20 there was discussion between the pharmaceutical  
21 company and the hospital?

22 **A.** No, no. But obviously we became aware of it when it  
23 was suggested that we should change, not, "We're  
24 looking into this. We're researching this to find out  
25 why [redacted] is having so many adverse effects to

1 the AZT".

2 **Q.** Do you recall being asked for any consent for  
3 [redacted] to be treated in this way?

4 **A.** No, we weren't, never.

5 **Q.** You've described in your statement, and we can see  
6 from a number of the letters from the hospital that  
7 you've exhibited to your statement that [redacted]'s  
8 health began to deteriorate.

9 He started on the AZT treatment that you've  
10 referred to in September 1988, and in 1989 you were  
11 told by Dr Pettigrew that his CD4 count was a cause of  
12 concern and that he had AIDS.

13 **A.** That's correct, yeah, I remember it clearly. It was  
14 myself who became very concerned and I took myself up  
15 to Yorkhill Hospital to the daybed unit and I asked to  
16 speak to -- no appointment -- to speak to the doctor  
17 who was on duty that day, which turned out to be  
18 Dr Anna Pettigrew and she took me aside and  
19 I expressed my concern about [redacted]'s physique,  
20 his weight loss, he was fragile, he was being sick, he  
21 was being very, very -- losing hair, all that kind of  
22 stuff, falling out, and she sat and she listened to me  
23 for three or four minutes while I explained my  
24 concerns and she told me, "Yeah, we have also become  
25 very concerned about [redacted]. We have been

1 monitoring his CD4 count and it's a very -- it's  
2 become a dangerous level and it's time for him to  
3 start on HIV treatment, AZT, due to his CD4 count  
4 being so low".

5 **Q.** How did he take the AZT? How did he respond to it?

6 **A.** Again, I've said many times that -- my firm belief  
7 that back then, these doctors and the hospitals were  
8 not -- were not geared up for dealing with children,  
9 okay.

10 What I mean -- I'll explain what I mean by that is  
11 that AZT -- due to [redacted]'s body mass, his  
12 physique, lost so much weight, okay, the AZT had to be  
13 diluted, okay. He couldn't receive it in pill form  
14 like I would have done or any other adult would have  
15 done. He was a child. He had the body of a child,  
16 okay. It was diluted and they still managed to  
17 overdose it. That's what I remember.

18 **Q.** You've also identified in your statement he was the  
19 first boy at Yorkhill to be given AZT.

20 **A.** Yeah.

21 **Q.** He hated taking it; it made him very sick.

22 **A.** Yeah.

23 **Q.** And you've explained, as you've just told us, you  
24 believe he was given too high a dose.

25 **A.** Correct.

1 Q. His physical condition, as you've described in your  
2 statement, continued to get worse. He would develop  
3 headaches, mouth infections and ulcers?  
4 A. Many, yeah, endless.  
5 Q. Rashes all over his body?  
6 A. Correct.  
7 Q. Terrible diarrhoea?  
8 A. Yeah.  
9 Q. Whooping cough?  
10 A. Yeah.  
11 Q. And your wife became his carer at home?  
12 A. She did, yeah.  
13 Q. And you've said this in your statement:  
14 "She nursed him from hope as much possible. This  
15 involved preparing his medication to give him via  
16 a nebuliser. This was always a fight as he hated to  
17 take it and very distressing for us as parents having  
18 to force him to take it. He was still a little boy  
19 being treated for an adult disease. My wife was  
20 becoming a house doctor and providing home treatment  
21 when the doctor should have intervened more. She was  
22 effectively taking the burden off the doctors. Of  
23 course this required her to continue to inject  
24 [redacted] with the products which had caused his  
25 infections in the first place."



1           Then you say this:

2            "In amongst all this we were also still required to  
3           give our other three children the very best lives we  
4           could."

5   **A.** Correct, yeah. The nebuliser for the treatment for  
6           the lung infection. I can't remember, pneumocystis,  
7           yeah, was a fear, lung infections, and so we were  
8           given this nebuliser. If everyone knows what a  
9           nebuliser is, it's a small pump with the drug put into  
10          it and [redacted] has to inhale it and it has  
11          a exhaust which had to go out of a window, you know.

12           We were fortunate enough we had a back room, we  
13          had a dining room with a couch in it and this is where  
14          [redacted] would take that away from, you know, the  
15          presence of his brothers and sisters, and that was all  
16          left to [redacted]. "There you go. Take that home  
17          and just give that to [redacted]. Try it, try it.  
18          Try it with a 13/14-year-old. You need to take this.  
19          You need to take this to save your life, otherwise,  
20          you know, the lung infection will get much worse".

21           I feel sometimes when people, you know, are going  
22          through these -- whether it be cancer or something  
23          like that, you've got a choice, do you take that  
24          medication or do you not take it? It's your choice.  
25          You don't have many other choices left. It's

1 life-saving and I think that was a big part of  
2 [redacted]. If he didn't, I just don't think he would  
3 have been a normal wee boy, if he didn't put up the  
4 fight, the battle with me, with his Mum. I think it's  
5 just a normal reaction but he took it eventually.

6 **Q.** [redacted] never reached puberty?

7 **A.** Correct.

8 **Q.** He stopped growing, effectively?

9 **A.** Correct.

10 **Q.** That upset him greatly?

11 **A.** Yeah, brother, twins.

12 **Q.** He had to take testosterone?

13 **A.** Yeah.

14 **Q.** His muscles and bones were wasting. He didn't want to  
15 eat.

16 **A.** Yeah.

17 **Q.** Through all that he continued to try to go to school  
18 as much as he could.

19 **A.** Yeah.

20 **Q.** And you have described in your statement how he loved  
21 school.

22 **A.** Yeah.

23 **Q.** He was frustrated at having to miss it?

24 **A.** Yeah.

25 **Q.** He continued to study. He passed a number of his

1 exams?

2 **A.** He did.

3 **Q.** He was a very bright boy.

4 **A.** Yeah.

5 **Q.** With a zest for life that was frustrated by his  
6 illness?

7 **A.** Yeah.

8 **Q.** And you said in his statement he wanted to help people  
9 and perhaps become a paramedic?

10 **A.** Yeah, yeah.

11 **Q.** [redacted]'s HIV care transferred from Yorkhill to  
12 an adult hospital where he was treated in the  
13 infectious diseases department, is that right?

14 **A.** Okay, he transferred from Yorkhill to the Glasgow  
15 Royal Infirmary for the haemophilia part.

16 It became very, very difficult at that stage for  
17 GRI to deal with the HIV. Why, I don't know, but it  
18 seemed to be a better place and that was Ruchill  
19 Hospital, yeah.

20 **Q.** But the problem with [redacted] being cared for  
21 there --

22 **A.** For his HIV treatment.

23 **Q.** For his HIV treatment. But one of the problems for  
24 [redacted] being cared for there was he was being  
25 treated amongst adults who were drug users and you've

1 described in his final weeks there being prison  
2 wardens across the corridor guarding a patient who was  
3 a prisoner; is that right?

4 **A.** Yeah. It was just -- just a dreadful place to be.

5 **Q.** And you've also explained in your statement that the  
6 doctors there weren't used to caring for children,  
7 still less children who had haemophilia, and your wife  
8 effectively became his -- the person treating his  
9 haemophilia whilst he was in that hospital.

10 **A.** Correct, because he was having internal bleeding,  
11 which will come up later. It's a melena.

12 **Q.** In 1992, April 1992, [redacted] was admitted to  
13 hospital with a range of problems, fever, chest  
14 infections, conjunctivitis, rashes. What can you  
15 recall about his hospital stay at that point?

16 **A.** April 1992?

17 **Q.** Yeah. *(Pause)*

18 We can take it from your statement.

19 **A.** What I've noted there Ruchill Hospital, August 1992,  
20 I have here -- sorry, in April 1992.

21 **Q.** It is paragraph 31 of your statement?

22 **A.** Okay, got it here:

23 "Admitted to Ruchill for a variety of medical  
24 problems, including fever, chest infection, right  
25 hypochondrial pain, conjunctivitis, rash over limbs

1 and body, doctors didn't know the cause.

2 Infection/reaction to medication."

3 Yeah, it was a reaction to the medication.

4 **Q.** But there was an uncertainty that you recall the  
5 doctors just didn't know what in particular was  
6 causing a number of the medical problems he was  
7 experiencing.

8 **A.** Yeah.

9 **Q.** Was it an allergic reaction or was it the illness  
10 itself?

11 **A.** Yeah, they've made reference to his pet dog, whether  
12 he'd picked up something from the dog, which was  
13 proven not to be the case either. The dog was taken  
14 to the vet and checked out, didn't have HIV.

15 **Q.** And then [redacted] was admitted back into the  
16 hospital in August 1992, his final admission.

17 **A.** Yeah.

18 **Q.** He was having seizures by that stage.

19 **A.** Yes, that was his purpose, yeah.

20 **Q.** He had headaches, he was drowsy. He developed  
21 bronchopneumonia and that was his last admission. You  
22 and your wife stayed with him whilst he was there in  
23 hospital.

24 **A.** Yeah.

25 **Q.** And he then died in September 1992.

1   **A.** Yeah, it was 14 August that [redacted] became unwell  
2       and he was -- normally [redacted] would have been up  
3       and I'm thinking -- I can't remember if it was  
4       a weekend, no, it wouldn't have been a weekend.  
5       Anyway, he was still in bed and my wife went in and he  
6       couldn't move, he couldn't move his right side and he  
7       was getting himself very upset, he couldn't get out of  
8       bed, so I think my wife described it as bundling him  
9       into the car and I'm certain he was taken to Glasgow  
10      Royal Infirmary at that time.

11            Yeah, they had a look at things, checked him over,  
12      and they said the best place for [redacted] would be  
13      Ruchill Hospital. That would have been 14 or  
14      15 August 1992. He was -- he was still conscious,  
15      obviously not very well. Myself, I stayed there for  
16      17 nights, the whole time, every single day.

17            For the first couple of days I would help him to  
18      the bathroom, for example, and then the doctors  
19      intervened and said, "You shouldn't be doing this,  
20      blah, blah, blah. It's infectious disease ward. You  
21      need to take a step back and allow us to take over the  
22      care". That was all fine.

23            I think it was about after the fifth day,  
24      [redacted] was losing consciousness. Doctors were  
25      struggling to find out -- he was taken over to --

1 because he was having these fits and seizures, they  
2 couldn't identify what it was. They treated him with  
3 all sorts of antibiotics, different ones, old  
4 fashioned ones, ones for treating TB, all that kind of  
5 stuff but he was eventually -- I'm sure it was  
6 a Dr Petty from the Neurosurgical Hospital in Southern  
7 General was invited over.

8 He did an observation with [redacted] and he  
9 couldn't identify it and he suggested taking  
10 [redacted] over to the neurosurgical. He was taken by  
11 ambulance by myself and he was put through an MRI scan  
12 on his brain, uncovered nothing, nothing. Took him  
13 back to Ruchill. Kept him under sedation, antibiotics  
14 intravenous. No improvement.

15 **Q.** [redacted] was 17 when he died.

16 **A.** Yeah.

17 **Q.** He'd not long passed his driving test and had a car  
18 which he loved. You've described in your statement  
19 a conversation that you recall with Dr Kennedy and  
20 Dr McMenamin that you wanted talk about. What can you  
21 tell us about that?

22 **A.** This was about 6.30/6.15 in the evening and during the  
23 day he would have visitors, my wife would have been up  
24 and maybe some of her friends, went up to visit  
25 [redacted] to comfort us because [redacted] was

1 unconscious, so it was a more family-orientated thing.  
2 But this particular evening, like I say, it was about  
3 [redacted] hours before [redacted] died, so that would  
4 have been 31 August. I remember these doctors came  
5 in, McMenamin and Kennedy came through the door of the  
6 ward and I was sitting this side of [redacted]'s bed.  
7 [redacted] was -- he was under sedation. These two  
8 doctors, Kennedy and McMenamin sat there and before  
9 they spoke to me I says to them, "Please do not ask me  
10 what I think you're going to ask me", and I was  
11 correct in what they word were going to ask me. While  
12 my son was still alive in bed, unconscious through  
13 HIV, hep C, all that kind of stuff, they asked me if  
14 I would give them permission to carry out a PM --

15 **Q.** A post-mortem.

16 **A.** -- a post-mortem, and I says no. I says, "Don't" --  
17 "I do not want to. He's suffered enough, and please  
18 do not ask me that question after [redacted]'s passing  
19 in front of my wife."

20 They asked me -- they informed me, "When  
21 [redacted] does pass, what's your thoughts about  
22 a funeral?" I said, "I haven't thought about it." He  
23 says, "Well, there will be no burial. It will be  
24 a cremation. His body will be placed in a body bag,  
25 taken to a mortuary because his body could still be



1 infectious for some time after the death. They  
2 recommended a funeral undertaker to me, these two  
3 doctors. They told me, "Mr AB, really, you have to be  
4 thinking about [redacted]", which I was. He said,  
5 "It's not that we want to remove his skull, we want to  
6 take some samples from his lumbar puncture and his  
7 spine, take some fluid from his brain." That's what  
8 they told me. That's not what happened.

9 **Q.** What did happen?

10 **A.** They removed his brain -- removed his scalp and  
11 removed his brain. I was lied to. It's in the  
12 medical records.

13 **Q.** And you learnt that through an accidental encounter  
14 some months later?

15 **A.** Yeah. I learnt that from the medical records. Six  
16 months after [redacted]'s passing we still have  
17 [redacted] to worry about. [redacted] required the  
18 same medication. It was myself who would go up to  
19 Ruchill to collect up this medication for [redacted]  
20 and by chance the same Dr McMenammin was on the ward  
21 that day and he saw me. He said, "Oh, Mr [AB], I've  
22 been trying to contact you". He hadn't been trying to  
23 contact me. "Could I have a word?" Okay, we went  
24 into the side room, took me into his office. He says,  
25 "I have the PM report on [redacted] and [redacted]"

1 died of measles. He didn't have the spots, measles  
2 got into his brain and killed him. If only we had  
3 known that, Mr [AB], we could have probably done  
4 more."

5 **Q.** You talked in your statement about how after  
6 [redacted] died, other boys -- and we won't mention  
7 any names -- but other boys died and you recall  
8 attending the funerals of other Yorkhill boys.

9 **A.** Yeah.

10 **Q.** And you've said in your statement that the loss of  
11 [redacted] was utterly devastating for you as  
12 a family. You said:

13 "As a parent you never expect your child to die  
14 before you and it is never something you come to terms  
15 with. We also did not know what the future held for  
16 his twin brother who felt guilt at outliving his  
17 brother. It is horrifying to watch your child die of  
18 AIDS."

19 I just wanted to ask you a very little about the  
20 impact of [redacted] death on his brother. I'm not  
21 going to ask you, for reasons you know --

22 **A.** Yeah.

23 **Q.** -- to go into details about [redacted]'s brother and  
24 his health.

25 **A.** Okay.

1 Q. You've said in your statement that he suffered the  
2 loss of his twin as well as the fear that he himself  
3 would die.

4 A. Anger.

5 Q. And anger.

6 A. Yeah, frustration, fear, all these things. Quite  
7 explosive as a young boy, a 17-year-old. He lost his  
8 brother. He knows fine well what he has. He has the  
9 same infections. He's on the same medications that  
10 didn't work for his brother.

11 Through that duration, maybe a year, I think it's  
12 mentioned in my statement again [redacted] having  
13 to -- his well-being went down. We were identifying  
14 the same issues that [redacted] were -- what  
15 [redacted] had with the neuropathy. It was all  
16 happening again. Fortunately enough there may have  
17 been drugs -- there was a drug available which was not  
18 available to [redacted] which I guess has fortunately  
19 got through.

20 Q. What had been -- in the years following the boys'  
21 diagnosis in 1985 what had been the effect on your  
22 family and social lives? Had you felt able to tell  
23 people about the boys' condition?

24 A. Very few, very few people. I think, you know,  
25 an unfortunate circumstance, [redacted] would never

1 have known. She would have known after [redacted]  
2 passing and eventually. One of the most disappointing  
3 things is your family -- obviously, we were -- I think  
4 we were very fortunate to have friends who we met  
5 through Yorkhill Group, there's some here today, that  
6 was a great support, a great support to be able to  
7 chat about it, like most things, there's leukaemia,  
8 and there's parents' group, diabetes there's parents'  
9 groups, so that was a great -- but the one thing  
10 I found most disappointing was that family, and we  
11 mentioned brothers and sisters, but it was, and you  
12 would divulge and you would go to a wedding or  
13 something and meet somebody and somebody comes up and  
14 says, "God, you know, I'm really sorry to hear about  
15 [redacted]".

16 "How did you know about that", and that's one of  
17 the reasons why it was -- it was such a horrible  
18 secret, because other people -- it was okay for other  
19 people to talk about it but I couldn't, and people  
20 that you confide in let you down.

21 **Q.** You've described it in your statement as it was the  
22 family's dirty little secret.

23 **A.** Yeah.

24 **Q.** And that caused -- having that secret in the house was  
25 a source of friction for you and your wife.

1           As you said you felt unable to tell the girls, and  
2           you've said in your statement you essentially isolated  
3           yourselves?

4   **A.** Yes, I'm going to go back to the time I was speaking  
5           to Dr McMenammin and he took me into the side room to  
6           tell me the results of the PM. I kept that  
7           information to myself for 12 months. No one, no one,  
8           not my wife, no one, I couldn't speak about it.

9           So, yeah, would anyone not expect there to be  
10          tension, to be falling out of love with someone that  
11          you've lived with for 25 years and yet it happened  
12          over a very, very short period of time.

13   **Q.** And what was the impact on the family and on your wife  
14          of [redacted]'s death?

15   **A.** Where we stayed at that particular time, we had  
16          a train track at the back and my wife wanted to walk  
17          in front of a train. She'd had enough, yeah. She's  
18          really quite ill today with all this, depressions,  
19          anxieties all that kind of stuff, and she does take  
20          alcohol, as I do. I do enjoy a glass of wine in the  
21          evening but it has become a dependency for [redacted].

22   **Q.** And you've described in your statement you both  
23          experiencing depression and stress.

24   **A.** Yeah.

25   **Q.** But one particular comment made by a doctor to your

1 wife --

2 **A.** Oh, yeah, Dr Gibson. Dr Gibson. I think it was the  
3 same house, came to a home visit because we were  
4 struggling so badly, I think, struggling so much with  
5 all these pressures with the nebuliser and she came  
6 along with the ward sister, Chris Murphy, to speak to  
7 [redacted] and [redacted] was expressing -- I was home  
8 that day, fortunately, because I knew by the timing of  
9 it that my youngest daughter [redacted] would be  
10 coming out of school so I was making myself available  
11 so that [redacted] didn't walk into this.

12 But the statement made by Dr Gibson was -- and  
13 maybe this is what she thinks is a criticism, it would  
14 be sad if it was, but, you know, [redacted] you don't  
15 like a person suffering from depression. People with  
16 depression, women with depression will normally walk  
17 about with their underskirts hanging down from below  
18 their skirt and stuff like that, bedraggled,  
19 et cetera, look at you." My wife would look good in  
20 a bin bag.

21 **Q.** You've also talked in your statements, both you and  
22 your wife, of the lack of trust that you now have in  
23 doctors --

24 **A.** Yeah.

25 **Q.** -- and hospitals.

1   **A.** Yeah.

2   **Q.** And that's been something that hasn't improved over  
3       the years.

4   **A.** Certainly not, more so for [redacted] and I think it's  
5       one of the reasons she's suffering so badly just now,  
6       because there's definitely white coat syndrome, no  
7       doubt about it.

8   **Q.** In 1988 [redacted] received a payment from  
9       The Macfarlane Trust and that was used to buy  
10      a caravan.

11  **A.** Yeah.

12  **Q.** That's what he wanted.

13  **A.** Mmm-hmm.

14  **Q.** And that was to try and give him and his brother and  
15      indeed the family a degree of normal life and to have  
16      some fun experiences?

17  **A.** Yeah, it was good, it was a good time, yeah.

18  **Q.** You sold that after his death because you couldn't  
19      bear to go there.

20  **A.** Yeah, instantly.

21  **Q.** You've described in your statement the processes of  
22      making applications to The Macfarlane Trust as being  
23      a long and laborious process.

24  **A.** Yeah, yeah, I'm not quite sure if we're at that stage  
25      yet we're talking about The Macfarlane Trust or we're

1 talking about SIBBS.

2 **Q.** The observation you make in your statement about  
3 a long laborious process was in relation to  
4 The Macfarlane Trust but I wanted to ask you  
5 specifically about what you say in your statement with  
6 your experiences more recently --

7 **A.** Yeah.

8 **Q.** -- in applying to the Skipton and then dealing with  
9 SIBBS, what can you tell us about that?

10 **A.** That was a very by very tough experience. I think it  
11 lasted for probably over two years. Something we were  
12 never made aware of. We were made aware of this  
13 application through my son [redacted], the twin.  
14 Obviously [redacted] was receiving something from  
15 SIBSS. However, we were put in touch with the  
16 Skipton Fund at that time through I think two years  
17 ago approximately. It was transferred to Scotland  
18 under SIBSS, Scottish Infected Blood Support Scheme,  
19 however, we got the application form in 1995 -- sorry,  
20 2015, and it took us two years to get the application  
21 completed.

22 On the first application it was a refusal. We  
23 were then challenged again to provide more information  
24 on -- to provide information on [redacted]'s levels  
25 of -- was he in secondary stage hepatitis C, that's



1        what I had to do, ALT levels and all that. I took  
2        that application and I struggled for a long, long time  
3        to find a medic -- because it had to be a medic to  
4        make that application on our behalf, and I spoke to  
5        [redacted] about it and he had pointed me in the  
6        direction of a Dr Emma Thompson who was looking after  
7        [redacted] at Gartnavel Hospital HIV treatment.

8                She kept the application for several months.  
9        I think it was six or eight months it took her to --  
10       but she did manage to obtain a lot of information that  
11       I had no access to. She gave me a letter. She wrote  
12       to me a lovely, a lovely letter which I have as -- and  
13       what she uncovered was the limited amount of  
14       information, medical information, on records and  
15       [redacted]'s medical records, PM record, had been  
16       instructed to be destroyed by the Procurator Fiscal.  
17       I have that -- you have that letter, NHS headed paper,  
18       signed by a doctor.

19                The man from (*unclear*), he accompanied me to the  
20       SIBSS meeting. It was on 11 August, this is 11 July  
21       so next month it is exactly two years to the day.  
22       I had prepared a speech. It was an eight-page I did,  
23       submitted that, and the first thing they said to me  
24       was, "Mr AB, you only have 20 minutes", thinking I was  
25       going to be reading through this. I said, "Well,

1       that's okay", I says, "I've got you copies here",  
2       I says, "But it won't take me 20 minutes even to read  
3       this", but I think they thought I was going to be  
4       going for hours. I wasn't. I read out the whole  
5       speech to them. After that, it was questions. And  
6       all these people, these eight persons were all  
7       professionals, there was Professor Mills, who is  
8       an expert on hepatitis C. There was a haematologist,  
9       Dr (*unclear*), from Aberdeen. There were some other  
10      experts in hepatitis C and I was asked all sorts of  
11      strange questions about what date did [redacted]  
12      receive his first Factor VIII medication? Strange  
13      questions. At the time I just couldn't work out why  
14      they were asking these things, but I do now. I do  
15      now.

16             It was a challenging time, a really challenging  
17      time, and I left there and I was absolutely exhausted  
18      and I thought that was a complete waste of time. It's  
19      a shocking disgrace and scandal. Before I had gone  
20      along, I had read the application information prepared  
21      by the SIBSS and it includes -- they tell you in  
22      there, it includes -- they tell you in there that  
23      a person with haemophilia-contracted HIV, hepatitis C,  
24      is an automatic approval. Why was I put through that?  
25      Why was I put through that again?

1 Q. And one of the particular difficulties that you had  
2 had and Dr Thompson in trying to assist you had had  
3 was trying to access and find [redacted]'s medical  
4 records sufficiently to put forward information about  
5 his hepatitis C.

6 A. Hmm.

7 Q. What's the position in relation to [redacted]'s  
8 medical records? What have you been able to obtain  
9 and what have you been told is lost or destroyed?

10 A. In my own efforts to obtain, before Dr Thompson was  
11 involved, I was only given -- I managed to obtain them  
12 from Gartnavel Hospital Medical Records Department.  
13 I was only allowed to have [redacted]'s final year,  
14 that's all, '91 to '92. Under law, you are not  
15 allowed, permitted to issue any further back than  
16 that. That's what I was told.

17 Q. That's what you were told by the hospital?

18 A. That's what I was told and that's what I was given.

19 Q. And in terms of the efforts that have been made by  
20 your solicitors, they have been able to obtain those  
21 treatment sheets we looked at from Glasgow Royal  
22 Infirmary.

23 A. Yeah, yeah.

24 Q. There's some further letters and so on but they're  
25 really all from the 1991 to 1992 period?

1   **A.** Yeah.

2   **Q.** Have you been able to get hold of anything from any  
3       earlier period?

4   **A.** No.

5   **Q.** Those are the questions I had for you. Is there any  
6       more you would like to say, whether about [redacted]  
7       or any of the other matters that your evidence has  
8       touched on?

9   **A.** Yeah, there is actually. These are just some of my  
10       beliefs, yeah, okay.

11           I think you mentioned -- maybe you didn't mention  
12       but within -- in my statement to Thompsons Solicitors  
13       a few weeks past, I received an email from Lynn Fraser  
14       at Thompsons Solicitors two weeks past, advising me  
15       that the Inquiry team considered parts of my statement  
16       to be criticism towards six doctors mentioned in my  
17       statement.

18           You'll recall at the very start of the day I took  
19       an oath in this very room speaking about the comments  
20       I made in my statement and they still stand. These  
21       things were not imaginary. They actually happened.  
22       Which has scarred my wife, myself and my family.

23           The term of criticism in the sense that lawyers  
24       are referring to is quite wide and rightly so. In our  
25       minds, the criticism is reference to the ways that my

1 wife and I were treated and our sons were treated in  
2 every sense. I was expecting the doctors mentioned to  
3 close ranks on this issue as they have done for many  
4 years to deny everything and trying to rewrite  
5 history.

6 My closing remarks for today. What I have done is  
7 put on record exactly how we and many other  
8 patients/families were treated. I would hope that  
9 this Inquiry will make some impact on the shameful  
10 history of this heartbreaking nightmare that my family  
11 and others have been put through.

12 I do feel that the more the doctors and the  
13 Government deny, the more obvious it will become to  
14 the Inquiry and to onlookers that this is dishonest  
15 and uncaring. My sons and many others are unable to  
16 be here today, so I am speaking on their behalf and  
17 for the children and families still living through  
18 this nightmare, years of uncertainty of any sort of  
19 a future and fear of whether or not we would -- we, as  
20 a family, would be put through a second demise, and  
21 I'm talking about [redacted], due to this horrendous  
22 disease caused by careless by the NHS.

23 Thank you. I would just like to say a thank you  
24 to the lawyers and persons at Thompsons Solicitors, in  
25 particular Lynn and for Jamie and also Steve McTaggart

1           who have kept me reliably informed over the past weeks  
2           and I would just like to thank them for that.

3   **Q.** I'm just going to turn my back and ask them if there's  
4           anything further they want me to ask you.

5           No, there's nothing further. Thank you.

6           Sir?

7   **SIR BRIAN LANGSTAFF:** Mr AB, you've told us how you shut  
8           yourself off for a while and couldn't talk about what  
9           had happened and I can well understand why, the  
10          devastating impact that you have described to us of  
11          the infection of your twin boys. Thank you for having  
12          the courage to come and tell us, difficult as it was,  
13          what happened. You have our gratitude. Thank you.

14   **A.** Thank you.

15          Thank you.

16   **SIR BRIAN LANGSTAFF:** We'll take a break until 11.40 am.  
17          11.40 am.

18   **(11.13 am)**

19   **(A short break)**

20   **(11.47 am)**

21   **SIR BRIAN LANGSTAFF:** Our next witness, who is numerically  
22          witness W0196, will be known as Mr AC. So I make the  
23          order as follows: the name and address of witness  
24          W0196, that's Mr AC to you and me, and any other  
25          identifying information, such as the witness's image

1 or a description of their appearance, cannot be  
2 disclosed or published in any form unless express  
3 permission is given by me or by the Secretary to the  
4 Inquiry -- the Solicitor to the Inquiry, I'm sorry,  
5 acting on my behalf. Witness 0196 must be referred to  
6 only as Mr AC.

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

11 Mr AC, please.

12 **MR AC, sworn**

13 **Questioned by MS RICHARDS**

14 **Q.** You were diagnosed with severe haemophilia A when you  
15 were a baby.

16 **A.** Yes.

17 **Q.** And you've described in your statement your memory of  
18 having cryoprecipitate when you just a few years old  
19 in hospital on a drip?

20 **A.** Yeah.

21 **Q.** And were then given cryoprecipitate when you needed  
22 treatment until you were about 14 years old?

23 **A.** 13/14.

24 **Q.** And you've told us in your statement you'd be taken to  
25 hospital by ambulance when you had a bleed?

1   **A.** Yes, that's correct.

2   **Q.** It would take two to three hours to get the treatment.

3   **A.** Yes.

4   **Q.** And sometimes you might be in hospital for two to  
5       three days.

6   **A.** Yes.

7   **Q.** Now, when you were about 14 years old, 13/14 years  
8       old, your treatment changed from cryoprecipitate to  
9       Factor VIII.

10  **A.** Yes.

11  **Q.** And that was self-administered by you, given your age?

12  **A.** It was.

13  **Q.** And to start with, it was stored at the GP's?

14  **A.** Yes.

15  **Q.** But then you went quite quickly on to home treatment.

16  **A.** Yes.

17  **Q.** What can you recall about the home treatment  
18       programme?

19  **A.** I just remember being told that this was a new product  
20       that was gonna make life safer, believe it or not, and  
21       better and, to me, it did work to that extent because  
22       you knew when you were taking a bleed and it was  
23       getting straight into you. As I said, instead of  
24       phoning an ambulance, going to hospital, ten doctors  
25       came in. It made a huge difference.



1           It made a difference between being able to walk  
2           that night or not being able to walk at all and keep  
3           me out of hospital, and it gave you more freedom to do  
4           stuff as well.

5   **Q.** But you weren't told anything, your statement says,  
6           about any risks of infection?

7   **A.** I was told there was -- when it came out, I was --  
8           there was nothing, there was nothing. The first time  
9           I knew about a problem was what I was told on  
10          a holiday by a different doctor.

11   **Q.** Well, what you've described in your witness statement  
12          is in early the 1980s, perhaps '81/'82 --

13   **A.** Yes.

14   **Q.** -- Dr Ludlam -- you were going on holiday with your  
15          family --

16   **A.** Yes.

17   **Q.** -- to Chichester and Dr Ludlam told you not to take  
18          English Factor VIII.

19   **A.** Yes.

20   **Q.** And he used the word "poison".

21   **A.** Yes, he did.

22   **Q.** But when you went to the doctor in England what did  
23          they say?

24   **A.** Well, what happened is, being there, doing the holiday  
25          stuff, I took a bleed and we went and seen this guy.

1 It was -- I can't remember the name of the hospital  
2 but it was in Chichester and the guy sat me and my Dad  
3 down. My Dad explained what we'd been told and the  
4 guy turned round and he looked my Dad straight in the  
5 eye and he goes -- he goes, "Mr -- believe me when  
6 I tell you this, my treatment that I'm going to give  
7 your son is safer than the treatment he would get in  
8 Edinburgh just now", and we were astounded.

9 My Dad was white. That was the first warning  
10 signs was what we had been given off us this doctor.  
11 Sadly, I don't know his name, because I was just  
12 a youngster but he sat us down and he said look -- and  
13 the guy came in, he goes, "Look, if you didnae believe  
14 me, I'll give you consent forms saying if there's  
15 anything you catch of my treatment, it comes back to  
16 me". That's how confident this guy was about his  
17 treatment in Chichester at that time was safer than  
18 the ones in Edinburgh.

19 **Q.** And did you or your Dad repeat that discussion to  
20 Dr Ludlam?

21 **A.** Yes.

22 **Q.** And what can you tell us about that?

23 **A.** He just denied all knowledge or said it wasnae true,  
24 basically, because probably my Dad would be dealing  
25 with it more than me, and what I was -- I'm a year old

1 or something like that, because (*unclear*). He just  
2 told us not to worry, everything was fine. It was  
3 Scottish stuff.

4 **Q.** Now, do you know what particular Factor VIII products  
5 you were receiving?

6 **A.** Probably Scottish at the time, I think. Yeah, it was  
7 Scottish, yeah.

8 **Q.** You've described in your statement a meeting that was  
9 organised by Dr Ludlam in Edinburgh Royal Infirmary  
10 and I think you've said in your statement it was when  
11 you were about 14 but I think you think it is now  
12 a bit later?

13 **A.** A bit later, 15 going on 16. I'm not that great with  
14 dates, unfortunately.

15 **Q.** Don't worry about the dates. But you've described  
16 your parents receiving a call and you and your parents  
17 went to this meeting?

18 **A.** Yeah, me and my Dad and went to a meeting, yeah.

19 **Q.** And were there other people at the meeting?

20 **A.** Yeah, there was other haemophiliacs at the meeting,  
21 yeah.

22 **Q.** And what was said at the meeting by Dr Ludlam that you  
23 can recall?

24 **A.** As far as I can remember he said that therefore was  
25 something coming out and HIV or something or find

1 out -- came out and the statement what came out in  
2 this meeting it was stuff had been infected, patients  
3 had been infected with treatment but he didnae --  
4 obviously at that time he didnae say who and who  
5 wasn't.

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

7 "We arrived at the meeting. There were 100-odd  
8 people there. They were all haemophiliacs. We were  
9 told there was a chance we had contracted HIV from one  
10 rogue batch of Factor VIII. They said they didn't know  
11 who did and didn't have it."

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

13 **Q.** And then it was about a week later that you were told  
14 you didn't have HIV?

15 **A.** Yeah, we got a letter from Col to say to come in to  
16 speak him. And the way it went, it wasnae even in the  
17 Haemophilia Centre. It was done in annex, if you  
18 called it like, a schoolroom or something, it was in  
19 the car park and we got in and didnae even get into  
20 his room, and he turned round and said to my Dad,  
21 I was behind my Dad at the time, he said, "Just go  
22 away. Your son's got nothing. Your son's not  
23 infected".

24 **Q.** And here you're talking about the doctor, was that  
25 Dr Ludlam?

1   **A.** Yeah, it was.

2   **Q.** You've also recalled being told at some later stage  
3       that you had something else, another infection, but  
4       they didn't know what it was?

5   **A.** Correct, yeah.

6   **Q.** And --

7   **A.** It was described as non-A non-B infection, so ...

8   **Q.** And do you recall when that was that you were told you  
9       had something that was being described to you as non-A  
10      non-B?

11  **A.** Probably in the '80s, late '80s early '90s. Yeah, and  
12      then probably late '80s early '90s and then found out,  
13      what, in '93/'94 it was hep.

14  **Q.** And what you've said in your statement that when you  
15      were first told you had non-A non-B hepatitis, you  
16      were told there was no treatment and you had just get  
17      on with it?

18  **A.** Correct, yes.

19  **Q.** And then you've said it was sometime in the 1990s, you  
20      think between 1993 and 1996, that Dr Ludlam told you  
21      the infection you had was hepatitis C.

22  **A.** Hepatitis C, yes.

23  **Q.** What can you recall about the circumstances in which  
24      he told you that it was hepatitis C?

25  **A.** It was just a normal meeting. He just -- he had

1 a habit he'd just come out with stuff and dismissing  
2 stuff. He always done this, even from a young age  
3 going back and he didnae -- he didnae like other  
4 people's opinions on stuff. It was like his way or no  
5 way at all, and he just came out said and, "You've  
6 got -- you've got this, but dinnae worry about it, if  
7 it affects you it might not affect you for 25/30  
8 years", and there was no treatment and didnae worry  
9 about it, but don't -- but don't have kids, which was  
10 the main one at that time.

11 **Q.** So that was the main advice you remember being given  
12 by Dr Ludlam at the time was not to have children?

13 **A.** Yes.

14 **Q.** And you've said in your statement that there was  
15 little information provided about --

16 **A.** None at all, none at all.

17 **Q.** Did you know that you were being tested either for HIV  
18 or HTLV-III as it was then called?

19 **A.** They used to take blood and just tell it was for  
20 storage.

21 **Q.** That it was for storage?

22 **A.** That it's for storage, yeah, what I can remember, it  
23 was for storage or for research but definitely not for  
24 HIV or hep C, definitely.

25 **Q.** What -- you've said in your statement about being told

1           that you had hepatitis C. You said that you didn't  
2           leave the house for three to four weeks.

3   **A.** Yeah.

4   **Q.** You only left your room for dinner and that you  
5           started to feel depressed and had mood swings?

6   **A.** Obviously, you get stuff like that and then once --  
7           once it hits the mainstream, the media, and stuff like  
8           that before, even when the HIV thing came on and I was  
9           at school and that, everybody just deserted me. They  
10          all walked away and thought, "Oh, we'll keep away from  
11          that guy. We know one of his family's died of it".  
12          You were just put on the hang as everybody else and  
13          people were like -- used to cross the road, teachers  
14          didnae really want to deal with you and things like  
15          that. It was horrific, being 14/15 and having to deal  
16          with it all as well.

17                 And then once we hit C then came about obviously  
18                 I had to go back and tell an ex-partner, and she got  
19                 tested, as far as I know, and there was nothing picked  
20                 up, which was -- it would have been my ex-wife at the  
21                 time.

22   **Q.** And you've described in your statement that from  
23           about 1990, you'd experienced tiredness, lack of  
24           energy --

25   **A.** I was working then and we work five/six months into

1 a job, I just felt like I was -- from going full time  
2 I had to go part-time, I just felt more tired.  
3 I could go to my bed say 9 o'clock at night and I  
4 might not wake up until 4 o'clock the following  
5 afternoon. I thought, well, what's causing this?"  
6 And when you were asked about it you were just, "Oh,  
7 it's nothing, it's just you've just got haemophilia.  
8 It makes you tired and stuff like that as well", and  
9 there's no mention of viruses at all.

10 **Q.** And you've also described in your statement that you  
11 had poor concentration, you had trouble sleeping even  
12 though you were so tired.

13 **A.** I still have to this day.

14 **Q.** And you were getting panic attacks and anxiety?

15 **A.** Definitely and more -- and very angry, really, really  
16 angry.

17 **Q.** I'm going to ask you in a few minutes about the  
18 treatments you received for hepatitis C, but just in  
19 terms of the physical consequences for you, you've  
20 developed a number of bladder complications.

21 **A.** Yeah, yeah, it was -- yeah, it was -- what happened,  
22 maybe 2003 or something, I went to hospital with  
23 severe stomach pains and I was actually told I had  
24 cancer by one guy and after being told that I thought,  
25 "Well, what's going on?" And then they came back and



1       said, "You've got bladder complications", because when  
2       they put the catheter in, the bag that they put in  
3       just filled up straightaway, there was something like  
4       2 to 3 litres of urine held back and it's just been  
5       an ongoing problem.

6             It's got to the stage now it's that bad, the only  
7       time I can pass urine is in a catheter bag three or  
8       four times a day and, obviously, I'm quite happy with  
9       doing that because I had to stop doing that, they'd  
10      have to now go and take my bladder out. It's got that  
11      bad, and I was told by the one of the doctors that she  
12      reckoned it was the hep C treatment that caused this  
13      problem.

14   **Q.** That was what I was going to ask you. You've set out  
15      in your statement you understand there to be a link  
16      between --

17   **A.** Definitely.

18   **Q.** -- hepatitis C or the treatment for it --

19   **A.** Yes.

20   **Q.** -- and your bladder problems.

21   **A.** Yes, definitely.

22   **Q.** You've also been experiencing pain in the right side  
23      of your liver --

24   **A.** Yeah.

25   **Q.** -- and you've had fibroscans?

1   **A.** Yes.

2   **Q.** And you've been told, your statement says, that there  
3       are some abnormalities?

4   **A.** There were some abnormalities. I was -- last week  
5       I did another scan and it didnae work properly, but my  
6       fibrosan came up normal, my blood test came up  
7       normal, but when they repeated the blood test, my  
8       blood test came back normal and I've got another one  
9       next week to see if that's normal and I get the  
10      results.

11            They kept saying to me, "Didnae worry about the  
12      blood tests being abnormal because you've probably got  
13      an infection at the same time and that's what's made  
14      it abnormal". That's still the information I'm  
15      getting from the people that are treating me in  
16      Edinburgh.

17   **Q.** Now, I want to ask you next about the treatments that  
18      you've undergone for hepatitis C. You had your first  
19      course of treatment with interferon --

20   **A.** Yes.

21   **Q.** -- at some point in the 1990s.

22   **A.** Yeah, early to mid-'90s, yeah.

23   **Q.** And the way you've put it in your statement is that  
24      that treatment made you go off your head?

25   **A.** Totally. Not so much the first batch but the second

1 batch about '99 was, like, horrific. It was like --  
2 it was like you were in your body but it wasnae you  
3 who was in your body, it was absolutely horrendous,  
4 just like -- I flipped basically for 24/36 hours.

5 **Q.** And you've described having thoughts of suicide --

6 **A.** Yeah.

7 **Q.** -- in the course of one of the treatments that you  
8 received.

9 **A.** Yeah, in the second lot of treatment, definitely.

10 **Q.** You wanted to end it all and you became very angry.

11 **A.** What happened, I felt two days before it finally  
12 kicked in I had a routine appointment and I said to  
13 them I do the didnae feel well because we were told  
14 there was going to backup, right, from the hep C  
15 people. They were handing out the treatment and that  
16 to you and this turned out to be untrue, because  
17 I went up on the Thursday. By Friday, I didnae really  
18 feel that well and I went back, and I was told,  
19 "You've just got a cold or stuff from the treatment",  
20 and between the Friday afternoon and the Saturday  
21 morning I flipped, sort of thing.

22 To fair, if it hadnae been for my Dad I would be  
23 dead now, because I was sitting out the window on the  
24 roof swinging my legs, just ready for go for gold. It  
25 was just horrific. I couldnae sit down. I was

1 wandering about the house. I was smashing things up,  
2 basically smashed the house up, basically, I wasnae  
3 far off it, there was nothing really left in it, and  
4 that was it.

5 Then the GP was called in two or three times in  
6 the night and I was given diazepam which worked only  
7 for a couple of hours and then they came back in the  
8 morning and goes, "Would you be willing to go to the  
9 Royal Ed on your own accord", and we just looked -- me  
10 and my Dad looked at each other and went, "We have to  
11 do this". I went up there. I was wandering about and  
12 stuff and the guy sat us down and he goes -- and he  
13 goes, "Look, your son's not actually got -- his mental  
14 health as what we would call it, he's having a side  
15 effect".

16 But before that, the number we had been given we  
17 were told it was 24/7, so even on the Friday evening  
18 5 o'clock we phoned up and we couldnae get hold of  
19 anybody. Got hold of the chemo doctor on the Saturday  
20 morning and he just went, "I don't know what to do  
21 here", and the guy didnae know what to do and he tried  
22 to contact the nurse and she got back and said, "We're  
23 shut until Monday".

24 If I'd have knew that, I probably wouldnae went on  
25 treatment. We were told there were would be support

1 24/7 and anybody you need to speak to, because there  
2 wasnae any counselling or nothing at that time. It  
3 was just horrific.

4 **Q.** And the purpose you'd been told of the support, it was  
5 specifically to help you through the treatment.

6 **A.** Yes.

7 **Q.** And you'd been given what you'd been told was  
8 a telephone number for a 24-hour helpline.

9 **A.** Yes, definitely.

10 **Q.** But when you tried it you couldn't get through to  
11 anybody.

12 **A.** It wasnae just a helpline. It was meant to have been  
13 a nurse that was dealing with the side effects of  
14 patients that were on it, but what it turned out to be  
15 she was only there four hours a day, Monday to Friday,  
16 whereas we were told, even -- the stuff they had on  
17 the sheet, because even on the sheet it had like the  
18 hours they were going to be there, who to phone, and  
19 it turned out it they were there only between 10 and 2  
20 Monday to Friday, so there wasnae -- we probably  
21 wouldn't have been the only one. There was no help  
22 after that for anybody. They -- they must have known  
23 by now how interferon could affect people and how bad  
24 it could be.

25 **Q.** And it was your Dad who talked you down --

1 **A.** Yeah, it was my Dad.

2 **Q.** -- from throwing yourself off the roof?

3 **A.** We -- as obviously we stayed in different houses and  
4 he came down with my Mum and they went to me, "What  
5 was going on?" And to give me Dad his due, he did  
6 save my life. If it hadnae been for my Dad I would  
7 have been gone, because I had a big bedroom window  
8 that goes down on to like a shed thing, I was between  
9 that and the shed, and I was ready and he goes, "What  
10 are you doing?" I think his exact words were, what he  
11 came in with was, I was ready to just stand up and  
12 take a run and go for goal. And if hadnae, like,  
13 said, "Look, come on, we'll try and deal with this"  
14 and stuff like that -- because at that time he was  
15 probably the only person I would listen to, because  
16 obviously I had no confidence in medics after what's  
17 happened to me over the years, you didnae believe  
18 a word they said to you at all.

19 **Q.** So you had two courses of treatment. The precise  
20 dates don't matter to start with, I know you've had  
21 a third since.

22 **A.** Yes.

23 **Q.** The first was interferon. The second was interferon  
24 and ribavirin.

25 **A.** Yes, that's the one that sent me loopy.

1 Q. And you've described in your statement how the  
2 treatment has changed your personality, made you  
3 angrier.

4 A. It made me really angry.

5 Q. Made you less trusting.

6 A. Yeah.

7 Q. Taken your confidence away.

8 A. Aye.

9 Q. And you say it's really been a total nightmare since  
10 then.

11 A. I'm still having side effects with my bladder and  
12 that, and luckily there's now counselling in place for  
13 this and I'm seeing a counsellor still to deal with  
14 the mental stress. And anybody that tells you, I can  
15 just snap like that, whereas before maybe (*unclear*)  
16 a good person with my haemophilia and bleeds but  
17 I could deal with it, and now -- you end up cutting  
18 yourself off from anybody, like, even though a lot of  
19 myself cut theirselves off from me because of the HIV  
20 thing that's gone round and the AIDS and that it's  
21 different. I just didnae want to do nothing. It was  
22 like, oh, most people will go and want to meet  
23 partners and that. I was like, "woah". And it was  
24 like that as well because I thought, "Right, if this  
25 doesnae work I didnae want to be accused of passing

1 this on to somebody."

2 Even if maybe people work, they can be a bit  
3 strange. Even if somebody had got it before they'd  
4 met me, they're probably liable to come after me, and  
5 I did take a back step. Because I didnae at that --  
6 I didnae want to explain to people as well, even  
7 though I had a partner at that time as well, but, it  
8 turned out, told everybody about it anyway  
9 unfortunately.

10 **Q.** You then had a third course of treatment --

11 **A.** Yes.

12 **Q.** -- a number of years later.

13 **A.** Yes.

14 **Q.** Do you recall when the third course of treatment was?

15 Your statement says 2006.

16 **A.** It was something like that yeah, definitely.

17 **Q.** You've were told that there was a new drug. You

18 didn't want to take it to start because you were

19 worried about the side effects.

20 **A.** I was told -- I was told I had the choice, but I had

21 time to wait because my liver was absolutely fine.

22 But eventually I sat down and I spoke to people, and

23 if it's gonna do any good, let's get it done before it

24 all kicks in and dinnae leave til it's too late.

25 **Q.** You've described that course of treatment as much more



1           straightforward.

2   **A.**   Yes.

3   **Q.**   You sailed through, in your words in your statement.

4   **A.**   Yeah, totally different.  No side effects.  Nothing.

5           They brought -- they brought me the (*unclear*) nurse

6           with the second set of treatment, before it had all

7           kicked in, it had cleared the virus.  The second set

8           had worked, but obviously I had to get pulled off it

9           and I could never go back on it.

10  **Q.**   But that third course of treatment did clear the

11           virus?

12  **A.**   Yes.

13  **Q.**   But you've been left not only with the physical

14           problems you've described in relation to your bladder,

15           but also with the psychological problems that you

16           describe?

17  **A.**   I still have flashbacks.  I can wake up screaming, and

18           stuff like that, still thinking -- like the night it

19           actually all happened and stuff like that, and

20           obviously fearful as well I was dying with my bladder

21           condition.  And the people -- because even (*unclear*),

22           I don't know if that's what they call them, and I --

23           they kept saying, "Oh, no, nothing, nothing and

24           nothing."

25                    But there was one doctor did approach me in the

1 Western and she said, "I cannae put this on your  
2 records, unfortunately, but I believe that you've got  
3 this". And in recent years there's been research done  
4 and there was actually a professor came and spoke to  
5 us at one of the meetings, and he had done a study and  
6 connect -- put the final dots to it for me. But as  
7 far as I know, I was told, right, within six or seven  
8 months of having it that they reckon -- she reckoned  
9 this what has caused it because she had done studies  
10 in London and other cases had been turning up down  
11 South, but she couldnae, she was told -- probably told  
12 not to put it in my notes.

13 **Q.** I will just ask you about the effect that your  
14 infection and the treatment you've received for it had  
15 on your private and social life. You've told us  
16 already about the way it made you feel in terms of  
17 your attitude towards relationships, and you decided  
18 not to have children.

19 **A.** No. Go back to the first bit, where prof said not to  
20 have kids, right, and then a year or twos later he was  
21 saying it was safe to have kids. So what do you do?  
22 Do you say, right, it's safe and, like, get a partner  
23 or something like that, and then him to say, maybe six  
24 months, "Oh, your kids could be infected because it is  
25 no safe"? So you didnae know what to do, basically,

1           because it was just misinformation that was getting  
2           fired at you constantly.

3   **Q.** In terms of your work, you've described in your  
4           statement how your haemophilia had made it difficult  
5           for you in making job applications. You found it  
6           difficult to get work.

7   **A.** Nobody wanted -- nobody wanted to know us. I mean,  
8           like, the way I would describe people at my age and  
9           for ages 10 years to 11, we were like the forgotten  
10          generation. Nobody wanted to know us. We were  
11          treated differently at centres. They started  
12          splitting us up and employers -- as soon as you put  
13          "haemophilia" on something, employers -- employers  
14          will look at it and go, "Shush, shush", end of story,  
15          even though I was told two or three times I was the  
16          one that was qualified most for the job, and you could  
17          do the job with your eyes shut basically and stuff  
18          like that, but they just werenae going to take  
19          a chance. And then the job that I did get, I ended up  
20          losing it because of my haemophilia (*unclear*).

21   **Q.** You said in your statement that there was work that  
22          you undertook for Toys R Us, but your fatigue made it  
23          hard for you to continue.

24   **A.** Yeah.

25   **Q.** And at the time you didn't know that that was the

1           consequence of hepatitis C.

2   **A.** No, I didn't know what that was, no.

3   **Q.** Although your diagnosis is of hepatitis C --

4   **A.** Yes.

5   **Q.** -- and you had been told following that meeting you've

6       told us about in the 1980s that you didn't have HIV --

7   **A.** Yes.

8   **Q.** -- you've talked in your statement about the effect

9       that the stigma associated with HIV and haemophilia

10      has had on your life.

11   **A.** You could imagine being 14/15, living in an enclosed

12      village, sort of thing, right, where there's other

13      members of family and that are haemophiliacs,

14      unfortunately. Most of them have passed away now.

15      And then, you know what it's like, people pick up on

16      things and that. That was -- people used to point in

17      the street and goes, "Oh, go keep away from him. He's

18      the infected one, like." Because -- a plain example,

19      I remember being out with my wife-to-be in a social

20      club, and we were sitting and she knew about my

21      haemophilia but her parents didn't. And they were sat

22      and we was -- she would come back to me about

23      something, and her Dad come in like, "Wah, wah, shit",

24      and everything like that, because somebody has pulled

25      them up in the social club and said, "Keep him away

1 from your daughter, he's got HIV".

2 **Q.** And you've said you lived in a small community;  
3 because you had haemophilia, people assumed you were  
4 infected with HIV too.

5 **A.** Yeah, yeah. Two and two together and made six, hey.

6 **Q.** It was "they've all got it" attitude.

7 **A.** Yeah, it was, and it probably still is.

8 **Q.** And at school, when news broke about HIV --

9 **A.** Yeah.

10 **Q.** -- amongst haemophiliacs, friends disappeared and when  
11 you were out they wouldn't want to share glasses with  
12 you.

13 **A.** No, they didnae want to --

14 **Q.** You would be given different glasses and buckets to  
15 put them in.

16 **A.** It got -- I had one really good mate that stuck by,  
17 but everybody else disappeared. And even -- even when  
18 you went other places and that, obviously they started  
19 telling other people and people you didnae even know  
20 were like, "Keep him away from him". Even to the  
21 extent where people would come right up to me and my  
22 wife and say, "What are you's doing with him? He's  
23 got this and got that" and everything else. But my  
24 attitude was always, "Ask anything, and if you want to  
25 go and see my medical notes you're welcome to see

1           them. I've got nothing to hide." But obviously  
2           I didnae know about the second virus then.

3   **Q.** And you say in your statement:

4           "I was fighting off the stigma of HIV and I didn't  
5           even have it."

6   **A.** Yes.

7   **Q.** You did have an uncle. And without mentioning any  
8           names --

9   **A.** Yeah.

10 **Q.** -- you had an uncle who was a haemophiliac --

11 **A.** Yes.

12 **Q.** -- who died from AIDS --

13 **A.** Yes.

14 **Q.** -- through the route of infected blood.

15 **A.** He went the same way.

16 **Q.** And you've described in your statement --

17 **A.** It was horrific.

18 **Q.** -- it was a terrible death.

19 **A.** It was. Sitting and watching him going from what he  
20           used to be to what he'd been in hospices and at home  
21           and that, it was like naebody -- naebody should have  
22           to go through it. Kind of what made it even worse is  
23           to my -- you may not have seen this, but there was  
24           people used to come visit him who never even come and  
25           visit him before just to see him, and it was like

1 a bit of a freak show, unfortunately. And that's why  
2 I've always said to partners and everything that if  
3 I ever got that unwell and I knew I was on the way  
4 out, just to give me tablets so I could do it myself,  
5 because I didnae want to go through the freak show  
6 stuff.

7 **Q.** You've been having counselling --

8 **A.** Yes.

9 **Q.** -- for the last 18 months or so.

10 **A.** Yes.

11 **Q.** And you've described that in your statement as being  
12 very helpful?

13 **A.** Definitely.

14 **Q.** But that's the first time that you've had counselling?

15 **A.** I wouldn't even call it a counsellor. I would call it  
16 a busybody back in that '80s and '90s, and you  
17 realised after a couple of sessions that what you were  
18 telling him was going back to your consultants, which  
19 is meant to be private.

20 Now, the person I've got now is a totally  
21 different class. She understands people and I've seen  
22 one and then I got moved on to another one because the  
23 first one wanted to go down the antidepressant route  
24 and I thought I'm not doing that, no just because of  
25 that but because it could have damaged my liver and

1       stuff like that and bring different stuff on but I've  
2       never one for being a pill popper anyway unless I had  
3       to take painkillers, and then I managed to get moved  
4       on to the other one and she's just been a totally  
5       different class.

6             I can speak about anything to her and probably the  
7       first person I have confidence in in about 20 years in  
8       the medical profession, if not more.

9             You could tell anything and it does stay private,  
10       whereas before you knew if you say something to the  
11       other one, it would be on your notes for the next  
12       appointment, "Oh, why did you say this to so-and-so?"  
13       And you're like, "This is meant to be private", so  
14       obviously I just cut ties with the first one but she  
15       was not that good anyway.

16            It was actually done well away from the hospital,  
17       the first one as well, and there was like you had all  
18       these junkies and that sitting about you, taking drugs  
19       in front of you while you were waiting counselling and  
20       my attitude was like your self-inflicting -- your  
21       self-inflicting, you're so-and-so, expressing the  
22       thought, "I'm here for something that shouldnae have  
23       happened", because it was for everybody in Scotland,  
24       it should have been and could have been avoided. It's  
25       horrific.



1           If it was any other generation with a different  
2           disease it would be looked at different, but what that  
3           guy's done to haemophilia community has been mass  
4           murder. In my honest opinion, it's mass murder.

5   **Q.** You say in your statement that you've been told that  
6           your hospital records from the 1970s and 1980s have  
7           been shredded.

8   **A.** Yes.

9   **Q.** GP records exist, but not your hospital records?

10 **A.** What you may find out as well, we reckon that Prof  
11           Ludlam has got records in his house, which hopefully  
12           will come out when you get to question these people.

13           For one -- as far as we know he had two sets of  
14           records, one for your medical notes and one that he  
15           kept for his research or whatever he done and stuff  
16           like that as well. I'm adamant he's got two sets of  
17           records.

18 **Q.** Those are the questions I have for you, but is there  
19           anything further you would like to add about any of  
20           the issues your evidence has touched on or the effect  
21           of hepatitis C and the treatment on your life?

22 **A.** Well, it's no just trust. As I said before, guys my  
23           age and years younger, nobody wanted to know us. We  
24           were really the forgotten generation. Hospital  
25           appointments, what they started do was you could meet

1 people and then all of a sudden it is was split.  
2 There would be nobody about on the day you were going  
3 for your appointment. They made sure of this, and  
4 other things like that on as well.

5 We were just basically guinea pigs. The whole  
6 haemophilia community were basically guinea pigs and  
7 to an extent we probably all are, and that as well,  
8 all this all sadly for -- this should be as well for  
9 the people that didnae make this far. Because this  
10 has to be a big part of this, apart -- we were the  
11 lucky ones that have survived it, if you can call us  
12 lucky, but for different stuff and we didnae know,  
13 because even now I'm finding out that even the liver  
14 experts didnae know how it is going to affect people,  
15 because basically I didnae think -- we were told  
16 there's 25 years kicking in, it might kick in, so  
17 basically that tells me they thought we would have  
18 been gone after 20/25 years, and it's just  
19 unfortunate -- I do class myself as one of the  
20 forgotten generation.

21 **Q.** I'm just going to ask Mr O'Neill if there's anything  
22 further he would like me to ask you. *(Pause)*

23 Just a couple of points --

24 **A.** Yes.

25 **Q.** -- Mr O'Neill would like me to explore with you. The

1 first is your recollection of your interactions with  
2 Dr Ludlam when you had a knee operation --

3 **A.** Yes.

4 **Q.** -- in Edinburgh.

5 **A.** This goes back to the point I made, it was his either  
6 way or the other -- I was between 14 and 15 as well  
7 and I'd a synovectomy needed on my right knee and my  
8 Dad and me were told, we were very aware but we  
9 thought it was better -- it maybe needed to be done  
10 but we were told -- I was going, "I'm no going in.  
11 I'm no going in", even then I did not trust you.

12 He says, "You'll only be in for five/six weeks",  
13 so the way -- the way it was going to be treated was  
14 he was obviously going to be the haemophilia  
15 consultant but I was going to be treated at  
16 Princess Margaret Rose Hospital by a Malcolm MacNicol  
17 who was the surgeon and he was going to be in charge  
18 of the physio and things like that.

19 You could have confidence in this surgeon guy  
20 because his reputation went before him and he would  
21 always speak to you and what happened was I got the  
22 operation and then 12 hours after the operation I woke  
23 up in the middle of the night I was moved back to  
24 ward 23, which was never meant to happen. So what  
25 he's done then he's sneaked me back there, whatever

1 his plans were for me there, instead of -- well, the  
2 guy who done the operation was at home. So he came  
3 back and you could hear -- you could hear the  
4 arguments between my Dad, Professor MacNicol and Prof  
5 about my treatment. My Dad wasnae happy and  
6 Mr MacNicol was going absolutely mental.

7 **Q.** And your understanding is it was at Dr Ludlam's  
8 insistence you were transferred back to the care of  
9 Haemophilia Centre.

10 **A.** Because it wasnae the treatment plan that was agreed  
11 before we went in, because me and my Dad were  
12 sceptical this could happen, but Mr MacNicol had  
13 reassured us and he's got no fault in this at all  
14 because the guy -- after I got moved back, the guy  
15 would come in at 10 o'clock on a Saturday night, even  
16 after he had been out for dinners and that kind of  
17 thing, just to make sure you were okay and he was  
18 like, "I'm sorry about this", and stuff like that,  
19 hey, and that -- and that proceeded to be, instead of  
20 being in for six weeks, I went in the October and  
21 I was discharged the following May.

22 **Q.** Then the second point that Mr O'Neill has asked me to  
23 raise with you is again an interaction you had with,  
24 it may have been, I think, Dr Ludlam when you asked to  
25 sign a waiver when there was a discussion --

1   **A.** Yeah.

2   **Q.** -- about a transfer of products.

3   **A.** What happened was I was being -- I was being  
4   treated -- during the second treatment, I was being  
5   treated and I got a phone call, "Can you come up", and  
6   he goes, "Oh, we're running out of the factor you're  
7   on. Would you like to go back" -- and we called it  
8   "tartan Factor VIII", and to me this was the stuff  
9   that gave you the infection, and I'm looking at him  
10   going, "Are really you being serious? And he goes,  
11   "But if you can take it, but I want to sign this and  
12   you cannae come back", because it was whole blood  
13   basically, and he says, "If you pick up anything, you  
14   cannae come back" and I just looked at him -- I threw  
15   a chair at him. I was like, "This isnae happening.  
16   I've had enough of Your crap. I'm not having this".

17         So I went away, back straight away in the sitting  
18   room and you could hear them going on, and there was  
19   a young nurse, hadnae long -- well, she was there for  
20   her second stint. I knew her from her first sort of  
21   stint, and she's, "What's going on" and she come back  
22   and went, "I've sorted it, but you cannae get home  
23   treatment, but I will treat you myself personally  
24   during centre hours and we'll make sure there was  
25   treatment for you on the ward".

1           You can imagine, you've been told you've got hep  
2           and you've been treated for it right, and it's worked,  
3           and then this guy wants to put you back on the stuff  
4           that's caused it. How does that work? It's like he  
5           is trying to murder you all over again. He didnae do  
6           a good enough job the first time. Perhaps we'll catch  
7           him the second time.

8   **Q.** And that was around the 1990s?

9   **A.** Yeah, that would be about --

10 **Q.** And that was when you were told there was  
11       a shortage --

12 **A.** A shortage.

13 **Q.** -- of the new Factor VIII product.

14 **A.** Yes.

15 **Q.** And that's why they wanted you to go back on to using  
16       the earlier product.

17 **A.** What I was told was they would keep the stuff I was on  
18       for the kids.

19 **Q.** Right. Thank you.

20 **A.** Thank you.

21           I'd just like to say thank you to Sir Brian and  
22       everybody that's working on this. This has been  
23       a long time coming, not just for us but for people who  
24       are sadly no longer, this is for them as well.

25 **Q.** Thank you.

1 **SIR BRIAN LANGSTAFF:** You've thanked us. Can I thank you.  
2 You've raised quite a number of interesting points in  
3 what you've said. It's very valuable. Thank you.

4 **A.** Thank you.

5 **SIR BRIAN LANGSTAFF:** We'll take a break now, shall we,  
6 until just after 1.30 pm.

7 **MS RICHARDS:** Thank you, sir.

8 **SIR BRIAN LANGSTAFF:** 1.30 pm.

9 **(12.25 pm)**

10 **(The luncheon adjournment)**

11 **(1.38 pm)**

12 **SIR BRIAN LANGSTAFF:** Our third and final witness will be  
13 known as Mrs AD. The order in her case reads like  
14 this:

15 "The name and address of witness W2202, that's  
16 Mrs AD to you and me, the name of her husband who died  
17 and the names of any other member of the witness's  
18 family and any other identifying information, such as  
19 the witness's image or a description of their  
20 appearance, cannot be disclosed or published in any form  
21 unless express permission is given by me or by the  
22 Solicitor to the Inquiry acting on my behalf.

23 Witness W2202 must be referred to only as Mrs AD.  
24 This order remains in force for the duration of the  
25 Inquiry and at all times thereafter, unless otherwise

1 ordered, and I may vary or revoke the order by making  
2 a further order during the course of the Inquiry.

3 Mrs AD, please.

4 **MRS AD, sworn**

5 **Questioned by MS FRASER BUTLIN**

6 **Q.** Mrs AD, you're here to talk about your late husband.

7 **A.** Yes.

8 **Q.** And it's going to be too difficult for you to talk  
9 about him without using his name, and so we've turned  
10 off the live-stream, including the audio, so that  
11 while you give your evidence you can refer to him by  
12 name as [redacted].

13 That means the people in this room will hear his  
14 name, but it shouldn't be referred to outside of this  
15 room and the restriction order will apply. His name  
16 will also be removed from the audio and written  
17 transcript before it's published?

18 **A.** Thank you.

19 **Q.** [redacted] had severe haemophilia A.

20 **A.** Yes.

21 **Q.** And you met him in 1963 when you were 19.

22 **A.** Yes.

23 **Q.** How did you meet?

24 **A.** At the dancing.

25 **Q.** And what was [redacted] like?



1 **A.** He loved animals. He was an outdoor person. Hated  
2 being in the house, he was in the hospital that much,  
3 just loved animals and outside.

4 **Q.** And you married just a year after you met, when you  
5 were 20.

6 **A.** Yes.

7 **Q.** And [redacted] was one of four brothers?

8 **A.** That's right.

9 **Q.** Who were all severe haemophiliacs.

10 **A.** Correct.

11 **Q.** What did [redacted] tell you about how his haemophilia  
12 affected him when he was growing up.

13 **A.** They didn't try to affect him because -- because there  
14 were four of them, they couldn't all get mollycoddled,  
15 they just went and done their own thing.

16 **Q.** And once you were married, how did his haemophilia  
17 affect him?

18 **A.** Sorry?

19 **Q.** Once you were married, how much did his haemophilia  
20 affect him, on a day-to-day basis?

21 **A.** Well, just -- he just carried on the same as what he  
22 did. If it came a bleed at that time he had to go  
23 over to the hospital or bed rest for two to three  
24 weeks, in the sixties. It just carried on like that.  
25 When he was okay he was outside with his animals and

1           that was it.

2   **Q.** And what treatment did he usually require? What  
3           treatment did he have or need?

4   **A.** Well to begin it was just like the plasma and that and  
5           the cryo and ... to begin with, mmm-hmm.

6   **Q.** Then some point it changed from cryo, and what did it  
7           change to?

8   **A.** I think he went on to the Factor VIII. As I say, he  
9           would just go over hisself. I never, ever went over.  
10          We're quite a bit away from the hospital. He was just  
11          used to get the ambulance and come over hisself, get  
12          his treatment and come back home again.

13   **Q.** He usually had his treatment at the Royal Infirmary?

14   **A.** That's right.

15   **Q.** Apart from one occasion when you were at his nieces  
16          wedding and he needed treatment down in Coventry.

17   **A.** That's correct.

18   **Q.** And at some point you were aware that he moved on to  
19          home treatment?

20   **A.** Mmm-hmm.

21   **Q.** But you're not entirely sure when?

22   **A.** I just can't remember the date, no.

23   **Q.** And so [redacted] had treatment at home but if he ran  
24          out of his Factor VIII what did he do sometimes?

25   **A.** When he had the treatment?

1 Q. If he ran out of factors products.

2 A. Sometimes he would go down to his brother's, the one  
3 brother he still had beside him, if either ran out  
4 they just used to take each other's rather than come  
5 back over to the hospital and get more.

6 Q. Did [redacted] ever talk to you about having been  
7 warned of any risks of infection from the factor  
8 products?

9 A. No, no.

10 Q. Now, in 1980 Dr Ludlam took over [redacted]'s care --

11 A. Right.

12 Q. -- from a Dr Davis who had been treating him since he  
13 was very young.

14 A. Mmm-hmm.

15 Q. What did [redacted] think of that?

16 A. He didn't like him.

17 Q. Why not? What did he say?

18 A. He used to come home and speak about it and I actually  
19 I actually spoke up for Dr Ludlam to begin with.  
20 I said, "You're not giving the man a chance. You've  
21 been that used to have Dr Davis all these years", and  
22 he turned round and he says to me, "It's not that.  
23 It's not. You can't talk to him one to one". He  
24 said, "he's not a patient person". He says, "I'll  
25 tell you something else", he says, "All he's worried

1 about is his research".

2 Q. You've said in your statement that [redacted] didn't  
3 find Dr Ludlam very approachable?

4 A. He says you couldn't get through to him.

5 Q. How often did [redacted] need treatment, as far as  
6 you're aware?

7 A. Well, it depended, some weeks he would maybe --  
8 a couple of times a week he would have to get it,  
9 maybe next week, once. It just varied. There were  
10 hardly -- there were hardly two weeks went by he  
11 wouldn't have at least one bleed.

12 Q. And they were mostly bleeds in his knees?

13 A. In his knee, yes.

14 Q. Could we have document 2202006 please, Paul.

15 Mrs AD it is going to appear on your screen in  
16 front of you. It's a handwritten note that you found  
17 after [redacted] had died.

18 A. That's correct.

19 Q. And we can see that there's lots of treatment noted in  
20 1984, a little bit in '85, '87 there's a note "Returned  
21 unused", and then we can around about March 1984  
22 a little note of a batch number 2910090.

23 You've said that doesn't mean much to you --

24 A. No.

25 Q. -- but we've heard evidence from previous witnesses

1 about this particular batch, 2910090.

2 If we just look again at the full picture, we can  
3 see 1987 "returned unused". Is that your recollection  
4 as well, that if [redacted] hadn't used factor and it  
5 had got to its use-by-date --

6 **A.** He'd take it back again to the hospital, yes.

7 **Q.** Can we then have 2202004 please. It's a letter  
8 written in 2003 and a little bit later I'm going to be  
9 asking you about how you end up with this letter in  
10 2003 but for now can we just look at the middle  
11 paragraph. It's a letter from Dr Ludlam and it says:

12 "I've looked back at his records and find that he  
13 was negative for HIV antibody test on 31 January 1984  
14 and was found to be positive on 29 May 1984. During  
15 this five-month period, he was treated exclusively with  
16 Scottish National Blood Transfusion Factor VIII  
17 concentrate. It seems highly likely that he became  
18 infected from this concentrate."

19 Was [redacted] told during the entirety of 1984,  
20 at any point in 1984, was [redacted] told that he was  
21 HIV-positive?

22 **A.** No.

23 **Q.** In the summer of 1984, you were in Canada --

24 **A.** Mmm-hmm.

25 **Q.** -- visiting some family and you read something that

1 concerned you. Can you tell us what that was.

2 **A.** It was in a Canadian newspaper and it was about two  
3 haemophiliac brothers had been infected and developed  
4 AIDS, and I cut it out and I brought it home and  
5 I showed it him and his words to me was, "That can't  
6 happen here. Scotland, makes their own". He says,  
7 "We don't import stuff", he says, "I've no worries  
8 about that", he says, "Don't worry".

9 **Q.** [redacted] just said to you "Do not worry"?

10 **A.** Mmm-hmm.

11 **Q.** Then in December 1984 [redacted] went to a meeting in  
12 the hospital auditorium. You weren't there?

13 **A.** No.

14 **Q.** But when he came home what did he tell you about that  
15 meeting?

16 **A.** He said that they were talking about -- before that  
17 they started getting vague things through the  
18 Haemophiliac Society and one of the letters was about  
19 safe sex, use condoms and that, he was saying, "Use  
20 condoms, I've been married 20-odd year".

21 When he went to the meeting and there were two  
22 doctors there and they were talking about, "Oh, you've  
23 been hearing things about HIV and that. Don't worry  
24 now, don't worry. Nothing will happen to you. Just  
25 eat well, do this and do that", and [redacted] says he

1        stood up and he says, "But it can't happen anyway  
2        because we don't use imported from America", and one  
3        of the doctors says, "But yes you have".

4                "He says, "What do you mean?" He says, "Scotland  
5        was going low, so we had to give you it". He says,  
6        "Well, we weren't told. You never informed us". He  
7        said, "Well, we can do what we want because we'd grown  
8        low in stock".

9        **Q.** You've said in your statement that [redacted] felt  
10       that the doctors were being cagey with information of  
11       exactly what was going on.

12       **A.** Mmm-hmm.

13       **Q.** And what was the impression that [redacted] was left  
14       with when he left that meeting about his own status?

15       **A.** Between that going on and then hearing more and more  
16       stuff in the media, he started to -- things started to  
17       form in his mind and he started to wonder what was  
18       happening his self.

19       **Q.** So at the end of 1986 --

20       **A.** Mmm-hmm.

21       **Q.** -- what did [redacted] do?

22       **A.** He went over to the hospital and asked for his self,  
23       me and our son to be tested. He said, "I want an AIDS  
24       test for them", and he said -- first of all, he says,  
25       "Your son does not need to be tested, nothing could

1       happen to him", and he said, "I'm no caring, I still  
2       want my son to be tested as well", so he says, "Right  
3       then", so the three of us went over and got a test.

4       **Q.** And then he went back for the results.

5       **A.** And he went back the next week his self for the  
6       result, and the doctor says to him, "Your family's  
7       okay", and [redacted] says, "That's fine". He says --  
8       and I looked at him and he says, "But you're not  
9       asking about yourself". And he says, "Well, when you  
10      says 'family' I thought you meant me as well. I take  
11      it I'm not all right". He says, "No, you're  
12      HIV-positive", and [redacted] says, "Well, why wasn't  
13      I told then?" He says, "Oh, the doctors don't like to  
14      tell you that unless you ask yourself". That was the  
15      answer he got.

16     **Q.** For the record, I should note that Dr Ludlam's been  
17     invited to respond to this witness statement, and we  
18     understand that a response will be provided in due  
19     course.

20             You subsequently went to see a lawyer.

21     **A.** Uh-huh.

22     **Q.** And if we can have document 2202005, please, Paul.  
23     The second paragraph, it says:

24             "We've been awaiting a letter from Dr Ludlam  
25     confirming when you were informed of your diagnosis and



1           this has just come to hand. He informs us that your  
2           anti-HIV status was made known to you in approximately  
3           December 1986."

4   **A.** That's correct.

5   **Q.** What was [redacted]'s reaction to the fact that he'd  
6           not been told his HIV status until the end of '86?

7   **A.** He was horrified. Not for his self, for me and my  
8           son -- our son. He went off his head. In that two  
9           and a half years he could have been infected. That's  
10          what he was really angry about.

11   **Q.** At that stage, what information was [redacted] given  
12          about his HIV?

13   **A.** Not very much. Nothing. We hardly got told anything.

14   **Q.** At some point [redacted] was then referred to  
15          a psychologist.

16   **A.** Mmm-hmm.

17   **Q.** Can you tell us about what happened with that?

18   **A.** Well, as I say to begin with, when he first met  
19          Alison -- and our circumstances, and he heard she was  
20          with other people, hey, and he had a few words to say  
21          to her but it turned out she became solely for the  
22          haemophiliacs and in the end she was -- she was very,  
23          very good. She was the only one you could talk to.  
24          She would try and answer your questions, give you as  
25          much information as she could tell you.

1           As I says to you, [redacted], he was very  
2           inquisitive and he wanted to know what was going to  
3           happen to him, what symptoms he could look forward --  
4           I don't mean "look forward to" but what was going to  
5           happen to him, and she says, "I could only tell you  
6           what I've seen in other people". She said,  
7           "Everybody's different", she said, "It could be brain  
8           cancer." She said, "It could be pneumonia. I don't  
9           know", she says, "These are just some of the symptoms  
10          that could happen to you".

11   **Q.** [redacted] found her one of the most helpful people --

12   **A.** The only one.

13   **Q.** The only person who could give him any real  
14          information.

15   **A.** Because at one time he even told her he was going to  
16          commit suicide, and she got him through that as well.

17   **Q.** I was about to ask you how [redacted] coped with his  
18          diagnosis psychologically.

19   **A.** At one time he was going to commit suicide and Alison  
20          asked me as well about it. She says -- because  
21          sometimes we seen her separate. I seen her on my own  
22          as well, and she asked me what I felt about [redacted]  
23          saying that and I said, "Well, I don't condone it", I  
24          says, "but I don't blame him". I said, "The only  
25          thing I don't want is for him to ask me to help him",

1 and Alison says, "He'll not do that".

2 And then later on I says to her one day, I says,  
3 "He's never really mentioned it again". She says,  
4 "Sometimes they get to a point and they will get over  
5 it", she says, "and they come to their senses". She  
6 says, "He'll not do it now, [redacted]. You'll be all  
7 right".

8 **Q.** You've said in your statement as well, though, that he  
9 did become angry and aggressive at times.

10 **A.** Very.

11 **Q.** Can you tell us about that.

12 **A.** Just he was a person that never really drank. It was  
13 later on in life before we even went out at weekends.  
14 Still to the day, he hated bitter, he hated beer, he  
15 could never drink beer, it was only, like I say, at  
16 New Year he would take whisky, but there was a time he  
17 went more to drink as well and very, very angry. Very  
18 angry at times.

19 **Q.** Did you and [redacted] tell people about his HIV?

20 **A.** Not to begin with and then he must -- my sister, even  
21 our own family we hardly told. His mother and father  
22 were still living at the time and he didnae want to  
23 worry them. He told one brother he was really close  
24 to, and then, as the time went on, he decided to tell  
25 one person and then he got a very bad reaction for

1           that.

2   **Q.** Can you tell us about that reaction.

3   **A.** It was New Year and we'd been down to their house, and  
4       I didn't know at the time but I just wondered later on  
5       how he went very quiet. And after we'd been there we  
6       went home, and I says to him, "What's wrong with you?"  
7       And he says -- it turned out that this man told --  
8       well, New Year, you give everybody a kiss, hey, "Happy  
9       New Year", and the man's grandchildren had been there,  
10      a wee girl, and he turns and says to him, "Don't you  
11      ever kiss my grandchild again", and [redacted] was  
12      completely distraught.

13           He says, "For a start", he says, "I wouldnae harm  
14      anybody." He says, "If I thought I was infectious",  
15      he says, "I wouldn't have done that", he says, "plus  
16      it had been" -- he loved children. He said, "I would  
17      never harm a child in my life. He said, "If I thought  
18      I was going to infect anybody, I wouldnae have kissed  
19      anybody". He says, "Don't ever kiss my grandchild  
20      again".

21           It was a long, long time afore he told anybody  
22      else. And later on, I should say, when I seen  
23      photographs of him later on when he was ill, I used to  
24      say to myself: why did I no realise people would know  
25      just looking at him, the state that he had become

1 before the end?

2 **Q.** But at that point, just after the New Year's party,  
3 you've said in your statement that his confidence went  
4 down and he became scared of anyone knowing about his  
5 diagnosis.

6 **A.** We live in a small community, a small village, and  
7 Alison used to say that. She says, "I don't know if  
8 it's a good thing or a bad thing for you". She says,  
9 "People find out". She says, "They could either all  
10 rally to you or they would ignore you, and if they  
11 want to go against you they would ignore you right  
12 away", but everybody knew the haemophiliacs are a bit  
13 famous, everybody knew them. She said, "I don't  
14 know", she says, "When you're in a big town like  
15 Edinburgh or Glasgow", she said, "you could be sitting  
16 by the person next to you and nobody would bother",  
17 but she says, "When you're in a small community", she  
18 says, "I didnae ken how that would work, hey".

19 **Q.** And when did [redacted] start to become unwell  
20 physically?

21 **A.** It was maybe at least a couple of year after he was  
22 diagnosed, at least a couple of year after that, it  
23 was really -- really started to then.

24 **Q.** And can you tell us what the early symptoms were for  
25 him?

1   **A.** It started, he wouldnae eat. He started to lose his  
2       appetite. He was never a big person anyway, but he  
3       really started -- he wouldnae eat and for all he  
4       was -- he liked his food, but got tired, very tired,  
5       things like that to begin with.

6   **Q.** And then he started to get flu-like symptoms.

7   **A.** Mmm-hmm.

8   **Q.** And what else at that point?

9   **A.** And then he got mouth ulcers, things like that, and  
10      then the first time he was diagnosed with pneumonia.

11   **Q.** And that was about 1990 --

12   **A.** Mmm-hmm.

13   **Q.** -- he had his first bout of pneumonia. What happened  
14      with that?

15   **A.** Well, he was -- he was in the hospital, in the  
16      Edinburgh Royal Infirmary, and we were actually going  
17      to go on holiday. We'd got a -- we'd a caravan  
18      through the Haemophiliacs Society, we were going to  
19      Ireland. Some of his relatives come from Ireland  
20      years ago and he always wanted to go and we were gonna  
21      go, and he'd taken the pneumonia. Well, we didnae  
22      know at that time it was the pneumonia and he was in  
23      the hospital, and he was still adamant he was going to  
24      Ireland. And I think it was Dr Henry Watson says to  
25      him, "You can go", he said, "but you'll come home in

1 a box". And they'd taken a test off him, and I think  
2 they says to him, "We're looking to see what this is",  
3 and when I went over to visit him that night and he  
4 was standing at the top of the stairs. I says,  
5 "What's wrong with you?", and he broke down and he  
6 says, "I've just been told by a young doctor that  
7 I'm" -- he had walked into the room where he was lying  
8 and he says, "That's the results back. You've got the  
9 pneumonia. You've into your full-blown AIDS", and he  
10 walked back out the door again, and that's how he was  
11 told.

12 **Q.** And how [redacted] feel about the way he had been  
13 told?

14 **A.** He was very angry, and somebody must have said, but  
15 Dr Watson came down, and we were in a waiting room and  
16 he sent for -- because [redacted] was calling him for  
17 everything, and that's being polite, and he sent for  
18 Alison Richardson and Alison come down. But I must  
19 admit Henry Watson says to him, "[redacted], I don't  
20 blame you". He says, "You promised me", he says, "you  
21 would come and tell me when that result was in". He  
22 says, "I didn't even get the result". He says, "That  
23 should never have happened". He says, "You should  
24 never have been told that way".

25 **Q.** At around this time your GP tried to get you and

1 [redacted] the Disability Allowance?

2 **A.** Yes. Our own doctor, our own local doctor, mmm-hmm.

3 **Q.** And what happened there with that?

4 **A.** Well, it was in October, my husband had went up to --  
5 he had been up to doctors' for something and he  
6 explained it to him, and [redacted] says, "Okay. So  
7 I've been in that for that and it was refused", and  
8 the doctor says, "No", he says, "[redacted]", he said,  
9 "You know the circumstances, it is a fatal disease  
10 you've got". He says, "This -- you know medicals", he  
11 says, "I say what's on the letter", he says, "and you  
12 get it through within two or three weeks." "Go on  
13 ahead then." He says, "It'll help you financially",  
14 and -- because that day stuck in my mind is 6 October.

15 We was back again in December and the doctor says,  
16 "Did you get your money". He says, "I haven't heard  
17 any word". The next thing was Christmas.

18 The January, he got taken into hospital again.  
19 Pneumonia again. And he was talking to -- it was  
20 Geraldine Brown at that time, the social worker, and  
21 he told her, and she says, "That's funny, because you  
22 do get that right away." She says, "I'll enquire".  
23 She come back and she says, "They're saying they  
24 havenae got your doctor's letter". She's said, "But  
25 I've spoke to your doctor. He's going to put another



1 letter in". He says, "Fine".

2 It went to April. She enquired again. Then they  
3 say they never had the doctor's second letter through.  
4 The doctor says, "That's two letters, I cannae put any  
5 more in", so that -- Gordon Brown was our MP at that  
6 time and he came to hear about it. [redacted] went to  
7 him and explained to him. He says, "Right", and he's  
8 seen about it, and it was the next September I got  
9 a letter -- in fact, I'm glad -- ah, no, before that,  
10 sorry, it was long after that and Geraldine phoned me  
11 and [redacted] had been in the hospital again and we'd  
12 just come home, and it was late October that time, and  
13 I actually had him hooked up to the whole -- they  
14 never had the stand at that time to feed him, to keep  
15 him alive, and Geraldine phoned and she says, "I've  
16 got good news and I've got bad news".

17 She says, "They're finally admitting they've got  
18 the letters". He has to get a medical. I says, "I've  
19 got a man hooked up to a wall to keep him alive",  
20 I says, "I don't want their money". I says, "Keep  
21 it". She goes, "No, no, no", she says, "not after  
22 what you've went through". She says, "It is somebody  
23 from your own practice that will come out and give you  
24 the medical".

25 So I says, "Aye, fine". So it wasnae actually our

1 own doctor but it was another local doctor two or  
2 three days later. By this time [redacted] had been  
3 taken away again, and this doctor phoned me and says,  
4 "I have to come and give your husband a medical".  
5 I said, "My husband's away to the hospital again, and  
6 I don't know if he'll even come back again."

7 "Will you let me know?" I says, "Yes."

8 So I had to phone down the next day, and I says,  
9 "Look, my husband's been kept in again". He says,  
10 "I don't know what's going on here", he says.  
11 "I actually got told I had to tell him to reapply."  
12 He says, "I'm phoning them", and I actually sent  
13 a local Edinburgh doctor into Edinburgh Royal  
14 Infirmary to examine him in the hospital. And then it  
15 was the September -- I'm glad I read the letter first  
16 in the morning, because when he come down and read it,  
17 the paper went up in the air and I said, "Look, read  
18 it again", but I read, "We have refused you the  
19 special attendance allowance but, on reflection, we  
20 will give you the night and day one". It was exactly  
21 the same money, and he says, "They've been waiting on  
22 me dying. That's what they've been waiting on, so  
23 they no have to give me it." He died in February so  
24 it no longer mattered, so that was nearly a year we  
25 went through to try and get it.

1 Q. And during that year, as you've said, [redacted] had  
2 a second bout of pneumonia.

3 A. Mmm-hmm.

4 Q. And then in December 1991 a friend of his passed away  
5 from AIDS.

6 A. Mmm-hmm.

7 Q. How did [redacted] react to that? For obvious  
8 reasons, we're not going to mention the name.

9 A. That devastated him. He was -- he was a young man  
10 with three children. True he had, after he was  
11 diagnosed and they hadnae tell him either, and that  
12 completely, completely -- it just brought [redacted]  
13 down all the more.

14 The young boy died in the December and [redacted]  
15 died in the February, because he come home to me in  
16 the January. He'd been over to the hospital one of  
17 the times, I cannae mind what it was for, and as we --  
18 he never broke down much, it was the only time he  
19 broke. I said, "Look, what's wrong?" He says, "I've  
20 been told today I've only got six weeks." I says,  
21 "Who told you that?" And he kind of -- it turned out  
22 nobody had told him, he had deduced that himself. He  
23 says to one of the nurses, "I've only got about six  
24 weeks". She says, "Oh, come on [redacted], no, you  
25 haven't." She says, "You've got about a year". He

1 was right enough. He didn't even get his six weeks.  
2 And I says to him, "You promised me you wouldnae give  
3 in", and he says, "I'm no giving in", he says, "I'm  
4 tired".

5 **Q.** [redacted] contracted a third bout of pneumonia, and  
6 you've described with that third bout his body  
7 couldn't take any more and his health deteriorated  
8 significantly in January 1992 and, as you've said, he  
9 knew at that stage he was dying.

10 **A.** Mmm-hmm.

11 **Q.** And [redacted] died in February 1992 aged 47.

12 **A.** Mmm-hmm.

13 **Q.** What can you tell us about what happened after  
14 [redacted] died in relation to the funeral and the  
15 arrangements with the body.

16 **A.** Well, when my husband died, as I said before, we live  
17 in a small community and at that time, it was an old  
18 man undertaker, everyone in the place knew him, and he  
19 come that morning and he started to say, "I'll do this  
20 for him and I'll do that with him", and I says, I'll  
21 had to say to him, so I says to him, "Look, [redacted]  
22 had AIDS", and he just stopped. He says, "Look,  
23 I don't mean any harm, but I can't touch him." He  
24 says, "He has to be taken away", and he went away.  
25 And I don't know who it was he contacted. We're

1 sitting and my sister and my brother-in-law and that  
2 was in and -- because I can remember my son coming and  
3 throwing (*unclear*) in the kitchen and I can just hear  
4 my son saying, "Uncle [redacted] will you help me?"  
5 And he says, "Yes, son", and he says -- and the two of  
6 them put his Dad in a body bag.

7 **Q.** Your son was 24?

8 **A.** My son was 24 year old and he had to put his Dad in  
9 a body bag.

10 **Q.** Can you tell how that's affected your son?

11 **A.** My son for years -- it took my son a long time. My  
12 son is very, very deep. He struggled on many a year  
13 for to try to come to terms with his Dad's -- and the  
14 way he died. Very, very deep, my son, and he  
15 struggled, even yet -- you know, he is married and  
16 that now, but his wife had a good few hard months and  
17 years with them to begin with, just -- just, as I say,  
18 he's very -- didnae show his feelings easily, my son.

19 **Q.** You've said in your statement he wouldn't talk about  
20 things, he was keeping people at arm's length. You  
21 said he's better now, but for years he was really bad  
22 at coping emotionally about his father's death.

23 **A.** Mmm-hmm.

24 **Q.** Can you tell us a little of how [redacted]'s death has  
25 affected you?

1   **A.** As I said, at the time, I mean, I was just (*unclear*)  
2       feel on all my days where you're just getting on with  
3       stuff and you didnae -- you got on with it and that  
4       but ... it took a long time before it hits you as  
5       well. And you're no thinking about the implications,  
6       hey. I just can't describe it, to tell the truth.  
7       I mean, it's 27 year since my husband died and  
8       I never, ever will forget, never, what you went  
9       through and what they went through and what caused  
10      them, I mean.

11   **Q.** You've been diagnosed with depression.

12   **A.** Yes, I went through that, as say, myself before.

13   **Q.** You've needed antidepressant medication.

14   **A.** Mmm-hmm.

15   **Q.** And you say in your statement:

16            "It's now been 27 years since my husband died but  
17       I'll forget it and it will never leave me."

18   **A.** I'm still the same.

19   **Q.** When you received [redacted]'s death certificate --

20   **A.** Mmm-hmm.

21   **Q.** -- do you remember what was put on it?

22   **A.** Yes, it was because -- our local doctor, and before  
23       [redacted] died, it was only through fear for us, as  
24       usual, and I had -- we had a wee policy for my  
25       husband, hey. I shouldn't even have had him insured

1 with him being a haemophiliac, it was only a wee  
2 policy but we'd had it for years, hey, and he was  
3 terrified I wouldn't even get that, and he says,  
4 "Look, could you not put AIDS on it when I go. Will  
5 you please not put AIDS on it", he says, "just put on  
6 it what determines it". And it was -- pneumonia was  
7 first, then it was septicaemia and then he had  
8 haemophilia, and that was on the death certificate.

9 **Q.** And they hadn't put AIDS on the death certificate?

10 **A.** No, no. But they were maintaining it was pneumonia  
11 really and the septicaemia that really actually killed  
12 him, what he died with. It may not have killed him,  
13 but he died with that.

14 **Q.** And how do you feel about what's recorded on the death  
15 certificate?

16 **A.** Well, as I say, in one way he didnae want that on his  
17 certificate, and I don't know if he didnae realise the  
18 implications of not having it on it. He was only  
19 worried about if an insurance person seen that, we  
20 wouldnae get no money paid out. I think that was all  
21 just in his mind.

22 **Q.** In terms of the wider family, you believe that one of  
23 [redacted]'s brothers also died of AIDS because of  
24 infected blood products.

25 **A.** As far as I know.

1 Q. About a year after [redacted]'s death.

2 A. As far as I know, yes.

3 Q. And another brother who is still living has

4 hepatitis C.

5 A. It's supposed to be lying dormant with him.

6 Q. What impact has that had on the wider family?

7 A. Well, the brother that I know, the brother I'm in

8 contact with, he was for years and years as well, he

9 felt guilty that he never contracted AIDS and his

10 brother did, hey, and he's been going through a lot

11 and his wife died with cancer now and now they're

12 saying his is lying dormant, hey, and he's ill and

13 that now as well.

14 Q. Financially things haven't been very easy?

15 A. No.

16 Q. And after [redacted]'s death, you were told that your

17 Macfarlane Trust payments would stop.

18 A. Mmm-hmm.

19 Q. How did that make you feel?

20 A. Well, in fact it was the day of my -- when my husband

21 was there, he did get put in (*unclear*) The

22 Macfarlane Trust, and actually it was the day of my

23 husband's funeral and I got a letter from

24 The Macfarlane Trust saying that his payments would

25 continue for six months and because I'd no dependants,



1 my husband -- my son was over 16, I was classed as no  
2 dependant, that my husband's money would stop and  
3 I would get nothing.

4 **Q.** What did you do about that?

5 **A.** As I say, that was the day of my husband's funeral,  
6 hey, and it was six-monthly and I wasn't even thinking  
7 about it. My son had actually taken me away for  
8 a couple of days. I'd been feeling like that, hey.  
9 I come back and there was a letter to say that my next  
10 payment would be my last. That they'd informed me.

11 So I wrote down to them and I says, "Look, don't  
12 get me wrong", I says, "You were good when my husband  
13 was there", I said, "but I'm still here. I've still  
14 got the same bills coming in. I've still the same  
15 stuff coming here and here for all my husband's no  
16 here". And they wrote back and says, "Oh, sorry, we  
17 didn't know you were ill. If you get a doctor's  
18 letter, we'll see what we can do".

19 And I went to my own doctor and she said, "Yes,  
20 I will give you a line", and I got £80 a month for  
21 years and years and years. That's what I was given.  
22 And then they kind of upped it from The  
23 Macfarlane Trust. Then, was it two year ago, we went  
24 to the Scottish and that was more substantial then.

25 **Q.** And you found that process much more straightforward

1 with the Scottish process?

2 **A.** Yes, yes, mmm-hmm.

3 **Q.** About a year after [redacted] died, you had to go into  
4 hospital.

5 **A.** Yes.

6 **Q.** And you were worried about whether you might have  
7 contracted HIV?

8 **A.** I wasnae worried. As I said, my test was clear when  
9 I went with [redacted], but after [redacted] died, we  
10 had no real issues anyway, but when he went into  
11 hospital, I said, I'm no going down into hospital in  
12 case I still had it. I knew I didnae have it, but I  
13 wanted to make sure. I didnae want anybody to go  
14 through what I went through. And I went to my own  
15 doctor and asked to be tested for the AIDS again, and  
16 that come back clear.

17 **Q.** And it was just your fear that perhaps somehow you'd  
18 contracted it and you wanted to be absolutely sure?

19 **A.** I wanted to be absolutely sure for other people.

20 **Q.** And then in 2002, you read a series of things about  
21 hepatitis C. What did you do after that?

22 **A.** Well, I started -- the same (*unclear*), I said one of  
23 the letters I got said that in their opinion  
24 90-odd per cent of haemophiliacs that had AIDS would  
25 have hepatitis C as well, and I went to my own doctor

1 and said, "Look, I've had the test for the AIDS, will  
2 that cover hepatitis?" She said, "No, it's  
3 a completely different test", she says, "You'll have  
4 to be tested again". I says, "Well, I want it done".  
5 And I got the test done and it -- it come back  
6 negative again, and when I went up and she says to me,  
7 "Dr Ludlam's phoned me" and I'm saying -- and I wasnae  
8 thinking when I was up in the surgery and it was after  
9 I come home and I said, "What is Dr Ludlam phoning my  
10 surgery for?"

11 **Q.** Just before we get there, you'd had the test for the  
12 hepatitis C and then you'd phoned the infirmary,  
13 hadn't you --

14 **A.** Mmm-hmm.

15 **Q.** -- to ask about [redacted], just before we get to why  
16 Dr Ludlam rings your GP. So you've gone to your GP  
17 for a test, and then you phoned the infirmary.

18 **A.** I phoned -- my brother-in-law says, he says, "I tell  
19 you what to do", he says, "Phone the haematology  
20 department and ask for this nurse", he says, "and they  
21 should tell you". And I phoned this nurse, and I got  
22 to speak to her and she says, "I didn't actually know  
23 your husband. I know who you're talking about", and  
24 she says, "What is it you want to know?" I says,  
25 "I want to know if I he's had hepatitis C", and she

1       says, "Oh, well, I can find out for you. I'll let you  
2       know", and I never got any word back.

3       **Q.** And then you went to your own GP for your own  
4       hepatitis C results.

5       **A.** Mmm-hmm.

6       **Q.** And what did the GP tell you?

7       **A.** But she says, "Dr Ludlam phoned here", and after  
8       I went home I'm saying, "Why is Dr Ludlam phoning  
9       about my result for? He's not my doctor". So  
10      [redacted] must have had hepatitis C because he  
11      wouldnae be worried about me if [redacted] never.

12             And I phoned my brother-in-law and I says, "What  
13      do you think?" He says, "[redacted] never had  
14      hepatitis C then."

15             And I phoned -- later on I phoned the hospital  
16      again -- no, I got a letter off Dr Ludlam saying about  
17      his -- his records about hepatitis C, and then he  
18      says, "Would you like to come over," he said, "because  
19      I've got volumes here", he says, "and you may nae be  
20      able to understand them."

21             And I made an appointment, I went over -- was it  
22      2002 or 2003? My husband died in '92. I went over  
23      and I seen him in the hospital, and he says, "What is  
24      it you're actually wanting to know?" I said, "I want  
25      to know if my husband had hepatitis C." And he says,

1 "Well, actually, yes, he did." Went in such a state.  
2 He says, I don't know, "This is liver function and  
3 this and this". I didn't understand these figures he  
4 was giving me.

5 And I says, "That was 12 year ago when my husband  
6 died, and he was infected then?" Why was he -- why  
7 was I not even told?" I says, "That's 12 year ago".  
8 He says, "Hepatitis C is not passed through sex", he  
9 says, "it's only passed through dirty needles or blood  
10 transfusions." I told to him, "You told him to tell  
11 me that?" I says, and that's what he says to me.

12 Q. You referred there to a letter from Dr Ludlam  
13 indicating about [redacted]'s records. If we can have  
14 2202003. It's a letter from December 2002, and we can  
15 see in the middle paragraph:

16 "As his case notes comprise several volumes,  
17 I wonder whether you might find it easier to obtain the  
18 information you would particularly like if we were to  
19 meet and review his casenotes. This way I hope that you  
20 would be able to get access to the information you  
21 require. I am concerned that as the casenotes are very  
22 extensive, you might have some difficulty in obtaining  
23 the results."

24 And there's then an offer to phone and have  
25 a meeting with him, which is the meeting you've just

1 described.

2 When you got [redacted]'s records, how much did  
3 you receive?

4 **A.** About 40 pages or so was all I got.

5 **Q.** And when you reviewed them -- first of all, if we can  
6 have 2202002, please. Within it was a result of  
7 a positive hepatitis C result, and if we look in the  
8 top right corner we can see that it was reported --  
9 "Date Reported" -- in January 1992. But you're clear  
10 in your mind that [redacted] didn't know before he  
11 died that he was hepatitis C positive?

12 **A.** I know for -- I know 100%. I know for 1,000,000%,  
13 because [redacted] came right home that day, walked in  
14 my door and told me he was HIV-positive. If he knew  
15 he had hepatitis C, he'd have come home and told as  
16 well. Not for himself, as I've tried to say; for my  
17 sake. He wouldnae have been bothered about -- I'm not  
18 saying he wouldnae have been bothered about himself,  
19 but he would have worried about me. I know for a fact  
20 he didn't know he had hepatitis C.

21 **Q.** And when you received [redacted]'s records, you  
22 queried some missing years. There were no records  
23 between 1985 and 1987.

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

25 **Q.** And after you received that query, you received the

1 letter from Dr Ludlam that we looked at at 004,  
2 please, Paul.

3 And his response in relation to the records in the  
4 paragraph that starts:

5 "So far as I can ascertain, he didn't have any  
6 treatment in the years 1985/86/87 and therefore there  
7 would not be any transfusion records available."

8 But you don't think that's right.

9 **A.** Well, for a start, [redacted] was a haemophiliac. He  
10 hardly went two weeks without a bleed, and he said he  
11 went three year without being to the hospital. That's  
12 not -- that's not possible.

13 Does that mean he wasnae treated for the HIV or  
14 AIDS in the three years as well that he says he  
15 couldnae find any treatment?

16 **Q.** Since then, since you got [redacted]'s records, you've  
17 been told that [redacted] was probably part of some  
18 research undertaken by Dr Ludlam.

19 **A.** I've been told that, yes.

20 **Q.** And he was one of what's been called the Edinburgh  
21 cohort.

22 **A.** Mmm-hmm.

23 **Q.** Were you aware of whether [redacted] agreed to being  
24 the subject of any research work?

25 **A.** No, no.

1 Q. You're not aware or you don't know if he was?

2 A. No, sorry, I know for a fact -- sorry, I didn't know  
3 and he didn't know for a fact, no, that he was ever in  
4 research, no, no.

5 Q. Those are the questions I have for you. Is there  
6 anything you would like to say?

7 A. I have a statement, if you don't mind?

8 Q. Please do.

9 A. My husband and others put their bodies and trust in  
10 the people they thought would help them, care, and  
11 deliver them a better quality of life. So why instead  
12 did most of them die? Why was it that people were  
13 diagnosed with HIV, hepatitis C, they were never told?  
14 In my husband's case it was years. As for  
15 hepatitis C, he died without ever knowing he had it.  
16 They do not care what effect it put on families.  
17 Myself and son could have been infected. That would  
18 have totally destroyed my husband and he would never  
19 have been able to live with himself, even though it  
20 had never been his fault.

21 I know of one incident where a person with AIDS  
22 deliberately went out and infected other people and  
23 they were jailed; so why is it people, knowing full  
24 well that their patients were infected with a fatal  
25 deadly disease, highly infectious disease, and they



1 chose not to tell them, why is that not classed as  
2 a crime as well? Because in my eyes, that is a crime.

3 I would like to know why my husband and others  
4 died far too early. They never got to spend more time  
5 with myself, our son, never see him marry, have  
6 children. He would have loved that. Is that the last  
7 memory our son will have of his Dad, that he helped  
8 put him in a body bag and see him taken away? No son  
9 should ever see that.

10 It's no wonder that for years he struggled for  
11 years to cope with his Dad's illness and death. Why  
12 can't the people responsible not see the heartache on  
13 victims and families not telling us anything? All the  
14 secrets, they were hidden. Records mysteriously lost.  
15 Why can't they take some responsibility and at least  
16 give them a bit of justice? They didn't deserve to  
17 die like that, they didn't.

18 **Q.** Thank you. I'm just going to turn and ask Mr O'Neill  
19 and Mr Dawson if there's anything they would like me  
20 to raise with you.

21 **A.** Thank you. *(Pause)*

22 **Q.** I've just got a series of questions that Mr Dawson  
23 would like me to ask you.

24 **A.** Mmm-hmm.

25 **Q.** We went to the handwritten document with those numbers

1 of the dates and the batches. Was that [redacted]'s  
2 handwriting?

3 **A.** I'm not -- to be truthful, I'm not sure. I couldn't  
4 tell you for certain.

5 **Q.** But you found it amongst his --

6 **A.** It was definitely --

7 **Q.** -- after he died?

8 **A.** -- in my possession, yes, mmm-hmm.

9 **Q.** Did [redacted] know he was being tested for HIV before  
10 December 1986? Was he aware at all of being tested?

11 **A.** No, no.

12 **Q.** And did he know he was being tested for hepatitis C?

13 **A.** No, he didn't know.

14 **Q.** In amongst the 40 pages of documents that you received  
15 of his medical records, were those 40 pages all  
16 [redacted]'s?

17 **A.** Mmm-hmm -- no, there were two I got through -- there  
18 was [redacted]'s name and they were two different  
19 people, mmm-hmm, which I shouldn't have got either.

20 **Q.** We spoke earlier about a friend of [redacted]'s who  
21 died. Again we're not going to name anyone, but do  
22 you know what happened to the family after that person  
23 died?

24 **A.** This is -- his wife and family, as I said, she woke up  
25 one morning and they had AIDS graffiti all over her

1 wall, and she just upped -- upped and took her and her  
2 family, went down to the Borders where she come from  
3 to begin with.

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

5 **SIR BRIAN LANGSTAFF:** Well, thank you. You've given us  
6 an account of how you were met with silence rather  
7 than with information, and when it came to dealing  
8 with some of the authorities, such as when you applied  
9 for special hardship allowance, how you had insult  
10 added to injury. Thank you very much for that and  
11 for, again, shining some light on different aspects of  
12 what we've been hearing about. But, as I say,  
13 everyone's testimony says something a little  
14 different. Thank you very much.

15 **A.** Thank you.

16 **Closing remarks by the Chair**

17 **SIR BRIAN LANGSTAFF:** Well, let me just finish by saying  
18 a few words, since this is the last time we shall be  
19 meeting here in this room.

20 I reflected that the dates that have been chosen  
21 for the Edinburgh hearings, totally coincidentally,  
22 have a certain significance for the Inquiry. We began  
23 on the first anniversary, if you want to call it, of  
24 the acceptance by Parliament of the terms of  
25 reference, 2 July.

1           We finish on the second anniversary of the day on  
2           which our Prime Minister Theresa May announced that  
3           there would be an inquiry. That's two years to get  
4           where we have got to. We have begun -- we have by no  
5           means finished, as you well know -- the evidence which  
6           we have to hear. But I think it shows that  
7           anniversaries are not a cause for celebration in our  
8           case; they are a cause, rather, for reflection. There  
9           are a number of people here who might, had matters  
10          been quicker, have been here to see it.

11          We do not have the luxury of time, but I do think  
12          it has been right to start by spending the time that  
13          we have hearing the accounts of those who have been  
14          infected and those who, like our last witness, have  
15          been affected by the infection of others, people first  
16          in the Inquiry, and it is worth, to my mind, spending  
17          time. Now, I haven't got enough time to hear the  
18          accounts of everyone who would like to be heard, but  
19          let me just say this to those who have not yet come  
20          forward to give a witness statement or those who are  
21          left feeling unhappy, as I leave Edinburgh, that you  
22          haven't had the chance to give evidence orally as well  
23          as on paper as you would have wished.

24          At the end of the hearings in Leeds, I said  
25          something similar to what I'm about to say and

1 following that, that very day, somebody who had been  
2 in those hearings hearing what I was saying came to  
3 the solicitors acting for the Inquiry and offered  
4 a statement, because they hadn't felt that they had  
5 anything to offer beforehand. And it does not matter  
6 that you feel that other people may have more  
7 compelling stories or more distressing stories or more  
8 detailed stories or can talk about more people in  
9 their family who have been affected than you can, or  
10 that your story simply seems so repetitive of that  
11 which has been told by others, because every single  
12 story plays a part, even if it is a part which  
13 reinforces that which has already been said.

14 One pebble does not make a beach. A lot of  
15 pebbles do. A statement may be a pebble, it may be  
16 a rock, but all of them have value. And it is, to my  
17 mind, important to remember that we will still be  
18 hearing from those infected and affected even though  
19 we move on now. We will hear next in Cardiff, that is  
20 beginning on 23 July. Anyone who wants is very  
21 welcome to be there. That's a week in Cardiff. Wales  
22 is a little smaller than Scotland.

23 Then we will hear again in October in London, and  
24 we are adding a week to the amount of time we have  
25 there to hear people who have been infected and

1 affected, because the numbers who have come forward  
2 demand it, in my view. But at the end of the Inquiry  
3 there will be further opportunities and I expect to  
4 hear something like 150/200 people. The format will  
5 be slightly different from witnesses on their own or  
6 as a family telling their tale. There may be panels.  
7 But it allows people to say what they have to say and  
8 be heard orally if they wish.

9 But it is not necessary to be heard orally. You  
10 can be heard on paper. And it is, I think,  
11 particularly important perhaps that those who haven't  
12 yet had the courage, because it is difficult to come  
13 forward and give you statement, let alone to come into  
14 this room and talk, whether anonymised or not, but to  
15 talk on paper about what has happened.

16 If there is anyone, and it may be that there are  
17 cultural reasons or reasons of living in a small  
18 village or reasons of not having told friends,  
19 neighbours, even family, statements can be given and  
20 will be given confidentially. If anyone wishes, they  
21 may talk to one of the Inquiry's intermediaries and  
22 give them an account, which will not be attributable  
23 at all, so that what they have to say is captured.  
24 Because if we are to be faithful to my undertaking to  
25 honour the terms of reference and to answer them as

1 best I can, then I need as much information as can be  
2 given, and each of you who has been infected and  
3 affected has a degree of that information. Please  
4 don't undervalue the contribution you can make. If  
5 you have a contribution to make, please make it.

6 As I've been listening, I was asked earlier today  
7 whether it was different in each of the different  
8 centres we've been to. It has been. There is  
9 obviously much more in common than there is that  
10 separates, but in each individual centre that we've  
11 been to -- and, again, it has shown to me the value of  
12 coming out of London and not being London-centric, we  
13 are, after all, a UK-wide Inquiry and it is a matter  
14 of principle to me that we should be out and around  
15 the country as much as we can realistically be within  
16 the constraints of finance and time that we have --  
17 there have been similar stories in different centres,  
18 rather with a different emphasis.

19 But in each case those who have given evidence  
20 have shown, to my mind, impressive dignity, impressive  
21 courage and impressive resilience in most cases. And  
22 I would just like to thank those of who have given  
23 evidence, and those of you who have supported by  
24 listening, for giving that evidence and for being here  
25 to listen, because, as I have repeatedly said,

1 listening is what this Inquiry is and ought to be  
2 about.

3 And just on the listening theme, the processes we  
4 use in this Inquiry; I'm not, I hope, arrogant enough  
5 to think we have got it completely right. I'm sure  
6 there are matters that can be improved. If any of you  
7 think that there are aspects of what has happened to  
8 you in your experience of the last couple of weeks  
9 that could be done better, don't hesitate to mention  
10 that. If you're represented by one of the firms which  
11 represent core participants, tell them. If you are  
12 a direct witness of the Inquiry, don't hesitate to be  
13 in touch with one of the Inquiry's Secretariat,  
14 because if we do anything, we want to do it right.

15 So finally thank you. Thank you Edinburgh for  
16 being so hospitable. Thank you in a different way for  
17 the staff. They are different from you, because you  
18 choose to be here. You volunteered. You don't have  
19 to be here. The staff, it is their job, it is what  
20 they do so. In a sense, when I thank them, I thank  
21 them, rather, in a different way for being here and  
22 serving us as they have. But most of all I thank the  
23 witnesses for educating us, me, the Inquiry team, just  
24 that little bit more.

25 Those of you who are coming to London or Cardiff,



1 I look forward to seeing you again. Thank you very  
2 much.

3 **(2.38 pm)**

4 **(Inquiry adjourned until Tuesday, 23 July 2019)**

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