

Thursday, 4 July 2019

(10.00 am)

SIR BRIAN LANGSTAFF: Good morning.

MS FRASER BUTLIN: Good morning, sir.

SIR BRIAN LANGSTAFF: Our first witness is Pamela.

MS FRASER BUTLIN: That's correct.

**PAMELA PENNYCOOK, affirmed**

**Questioned by MS FRASER BUTLIN**

Q. Pamela, you're here to talk about your infection with hepatitis C?

A. That's right.

Q. You have spina bifida?

A. Yes.

Q. When you were 11 years old you underwent spinal fusion surgery?

A. That's correct, yes.

Q. What is your recollection of what happened?

A. Well, I remember waking up in the recovery room and I noticed that there was the drip set up with the saline and also the blood. I'd never had a blood transfusion before so it was a bit of a shock seeing that for the first time, and then by the time I went back on the ward, the blood drip had been taken down and it was just the other drip that was up.

Q. Before the operation, are you aware of whether your

1 parents were warned that you might need a transfusion?

2 A. Not at all. They weren't told.

3 Q. After the operation, were your parents told that you

4 had had a blood transfusion?

5 A. No, they weren't told.

6 Q. Please can we have document 2242002, please, Paul. If

7 we look at the top, we can see requirements and that

8 four were being delivered, four were held on reserve

9 and total of eight units of whole blood were ready for

10 the operation.

11 A. Mm-hm.

12 Q. Then if we go to the bottom of the page, part C, we

13 can see serial number in order for a transfusion and

14 there are three numbers.

15 A. That's right.

16 Q. The bottle numbers of the blood that you were

17 transfused with.

18 A. Yes.

19 Q. Can you tell us how you came to receive this document.

20 A. When I was going through my treatment at the Western

21 General, my consultant --

22 Q. For the hepatitis C?

23 A. For the hepatitis C, yes, so it was many years later,

24 my consultant gave me a copy of this form and said to

25 me, "Keep it safe. You're going to need this in the

1 future."

2 Q. Are there any other records of you having had  
3 a transfusion?

4 A. No, no. Just this one.

5 Q. On the same day that the consultant gave you this  
6 letter, she also wrote to your GP.

7 A. Yes, that is right.

8 Q. What did that letter say about your transfusion?

9 A. That there was no record that I'd had a transfusion.

10 Q. So the day you were given this, there was also  
11 a letter to the GP saying there was no record?

12 A. No record.

13 Q. As part of your spina bifida you had sensory loss in  
14 your right leg and right foot?

15 A. That's correct, yes.

16 Q. You had repeated infections and ulceration of the leg  
17 and the foot?

18 A. That's correct.

19 Q. And ultimately you underwent a below knee amputation?

20 A. That's right, when I was 19.

21 Q. Recently you've wondered whether your infection with  
22 hepatitis C contributed to those difficulties as  
23 a teenager.

24 A. Yes.

25 Q. Can you tell us why.

1 A. It was the fact my amputation, on the form it was due  
2 to recurring infections and ulcers so I asked the  
3 question because I thought it could have contributed  
4 to me losing my leg, the fact that I wasn't able to  
5 fight infections. So my consultant -- I took all my  
6 medical records because she couldn't get access to  
7 them and she went through them and she said, "Although  
8 it's not the sole reason, it may be a contributing  
9 factor that you lost your leg". But she said, "I'm  
10 not an immunologist so, you know, I can't make  
11 a definite decision on that", but she said it may have  
12 been a contributing factor.

13 Q. Nobody is very sure what impact the hepatitis C had on  
14 those infections but they may have had an impact and  
15 you're concerned that they did have?

16 A. Yes, that's right.

17 Q. In 2005 you were diagnosed with osteoporosis?

18 A. That's correct.

19 Q. Your GP decided to do some blood tests?

20 A. Yes.

21 Q. Can you tell us what those first tests showed.

22 A. They showed that I had an issue with my liver function  
23 so I was asked to keep a drink diary and then I would  
24 be retested again to see, you know, if there was any  
25 change to that, so -- which I did, I went back and got

1 the second lot of blood tests.

2 Q. So you've had the second lot of blood tests and what  
3 happened then?

4 A. Well, I was sitting at work one day and I worked at  
5 that time in a telephony role. So I just thought, oh,  
6 in my break I'll phone the GP to get the results and  
7 the receptionist said, "Yes, you're hep C positive",  
8 and I said, "What do you mean?" There was a pause and  
9 she said, "Oh, I don't think I was meant to tell you",  
10 and I said, "Well, I need to speak to somebody.  
11 I need to see a doctor", because previously I'd worked  
12 in drug and alcohol team, HIV/AIDS team, so I had an  
13 understanding of what hepatitis C was. She couldn't  
14 give me an appointment with the doctor, so finally my  
15 GP came on the phone and said, "You know, you  
16 shouldn't have been told this information over the  
17 phone. Come in and see me tomorrow."

18 So I just broke down in tears in the middle of  
19 the office space. My manager took me away.

20 I explained, you know, the telephone conversation and  
21 then I just had to go home. So my manager had to go  
22 and get my bag, you know, colleagues were looking  
23 around thinking, "What's going on here", then I just  
24 went home and went on the internet basically to see,  
25 to get as much information as I could about it.

1 Q. What's been the impact on your mental health of the  
2 way you were told that you had hepatitis C?

3 A. There was -- there was no professionalism there, you  
4 know. It was just so matter of fact. I mean, I know  
5 that she realised she shouldn't have told me but to  
6 get a shock like that over the phone is unforgivable.  
7 It should never have happened.

8 Q. You have said you went straight on to the internet  
9 when you got home.

10 A. Yes.

11 Q. What did you find?

12 A. Well I was reading about things when I die my body  
13 wouldn't be dressed, it would go into a hazardous  
14 waste bag, it would be in lead lined coffins and  
15 I just thought ... this is my life.

16 Q. You saw your GP the next day?

17 A. Yes.

18 Q. On 22 December 2005?

19 A. Mm-hm.

20 Q. What did they tell you?

21 A. They told me that I would be referred to the Western  
22 to discuss treatments, you know, but that was a long  
23 process to get to that and then she said that I needed  
24 to get in touch with my previous sexual partners to  
25 make them aware that I had the hep C.

1 Q. Did she explain how you might have come to be  
2 infected?

3 A. I had said that I'd had a blood transfusion in the  
4 early '80s because I knew from my understanding in my  
5 previous job that the blood transfusions in the early  
6 '80s could have been a transmission route.

7 Q. You were referred to the Western General?

8 A. That's right.

9 Q. But there was no appointment available until  
10 February 2006?

11 A. That's right.

12 Q. What happened in that interim period for you?

13 A. I found it very difficult to come to terms with my  
14 diagnosis. My Mum and Dad found it difficult because  
15 they were saying, "Well, how do you get it", and I was  
16 saying, "Well, through blood transfusions", and they  
17 are saying, "But you've never had a blood transfusion?  
18 How else can you get it?" And I said, "Well,  
19 intravenous drug use, tattoos", and they said, "But  
20 you've never had a tattoo", but it was the unsaid  
21 thing, "Well, you know, have you taken drugs?"

22 So it was a year later that I got the proof that  
23 I'd had a blood transfusion so in that time my parents  
24 had this doubt as to how could I have received this  
25 infection.

1 Q. When you first attended the hospital, Western General,  
2 can you tell us what it was like attending the clinic.

3 A. I was just totally outwith my comfort zone and the  
4 fact it was called the Regional Infectious Diseases  
5 Unit, you know, it's not the most welcoming of places.  
6 The first time I went there I got lost but I was too  
7 embarrassed to ask for directions. There was  
8 prisoners there with their guards obviously getting  
9 their treatment and I just thought, "This is my world  
10 now". It was very, very frightening.

11 Q. When you got to the hospital you've said that you feel  
12 you were given the information you needed --

13 A. Yes.

14 Q. -- about hepatitis C?

15 A. Yes.

16 Q. And it came at the right time for you to understand  
17 the illness?

18 A. Yes.

19 Q. Can you tell us how you reacted to finding out that  
20 you had hepatitis C.

21 A. Well, to be honest, I went off the rails. I started  
22 drinking too much and ...

23 Q. You ended up pregnant?

24 A. That's right.

25 Q. In circumstances that weren't ideal?



1 A. That's right.

2 Q. You decided you had to terminate the pregnancy?

3 A. Yes, because I knew there was a risk of passing it on  
4 to the unborn child. I decided that was the only  
5 option for me at that time and plus I knew I was going  
6 to be going through treatment as well that I had to  
7 terminate the pregnancy.

8 Q. Can you tell us a little bit of what the impact of  
9 that decision has had on you in terms of your mental  
10 health.

11 A. Even now I've never been a Mum so things like Mother's  
12 Day is a trigger for me and I've just got this  
13 emptiness.

14 Q. You've only recently felt able to tell your family  
15 about the termination?

16 A. That's right.

17 Q. Can you tell us why.

18 A. I needed to tell them because I knew this was part of  
19 my story and it also had an impact, my sister had her  
20 baby at the time of my termination; so I went from  
21 having the termination to go and seeing her with her  
22 new son.

23 Q. She had her first child in the same place on the same  
24 day?

25 A. Mm-hm.

1 Q. And for you, that's been incredibly difficult --

2 A. Extremely difficult.

3 Q. -- to try and have any relationship with your nephew?

4 A. Yes and I didn't want to take away from, you know, the

5 family's joy of this baby and from taking it away from

6 my Mum and Dad because that was their first and only

7 grandchild so I just kept it secret.

8 Q. When you were diagnosed with hepatitis C, did you tell

9 any friends at that point about the diagnosis?

10 A. No. There was only six people that knew up until two

11 months ago when I felt able to tell friends and

12 family.

13 Q. Why didn't you feel able to tell friends?

14 A. I know that there's a stigma about hepatitis C and

15 I just -- you can't untell people if you don't get the

16 right reaction that you're looking for, so it was --

17 at the time I thought it was easier not to tell but

18 now that I've shared my secret, it's such a relief.

19 Q. You've told them because you knew you were coming to

20 give evidence?

21 A. Yes, that's right.

22 Q. What was their reaction?

23 A. Totally supportive, you know. They're behind me

24 100 per cent.

25 Q. You started treatment for the hepatitis in

1 August 2006?

2 A. That's right.

3 Q. And that was with interferon and ribavirin?

4 A. That's right.

5 Q. What side effects did you have?

6 A. They were horrendous. Mood swings which led to me not  
7 being able to -- I wasn't allowed to then be alone  
8 with my new nephew because my sister didn't want to  
9 risk ... and I totally understand that. Lack of  
10 sleep, insomnia, loss of appetite, depression, and  
11 then really dark moods. You know, didn't want to be  
12 with anybody. So it was very hard. And I'd met John  
13 just six weeks before I started my treatment so that  
14 came out the blue.

15 So it was hard to start a new relationship while  
16 I was going through the treatment. Luckily, John's  
17 been so supportive, didn't judge me in any way and has  
18 always been there for me.

19 He had two young sons at the time so it was hard  
20 to start the relationship with them because there  
21 would be days where I wouldn't want to get out of bed  
22 so we couldn't go swimming or go for days out, so  
23 I was letting them down as well; so it was hard to  
24 maintain relationships.

25 Q. You were off work for about five months?

1 A. Five months, that's right.

2 Q. As you say, you met John and you and he decided that  
3 he should have a vasectomy?

4 A. Yes.

5 Q. Why was that?

6 A. John knew the trauma that I'd gone through with having  
7 my termination and the impact on my mental health. So  
8 we decided, you know, that was the decision for us and  
9 plus with being on the treatment I couldn't get  
10 pregnant while I was on the treatment or six months  
11 after, so that was the decision that was made.

12 Q. You've said in your statement that that closed the  
13 door on you having children of your own.

14 A. Yes.

15 Q. And that, combined with the termination, has impacted  
16 your mental health very significantly.

17 A. Yes, extremely so.

18 Q. Can you tell us a little bit more about that or would  
19 you rather I read that part of your statement?

20 A. No, it's okay.

21 On mother's day, I think it was about three  
22 years ago, I just thought I can't go on with my life.  
23 I'm never going to achieve what I really want, so  
24 I took off my wedding rings and left my little dog and  
25 just disappeared. John ended up phoning my Mum and my

1 Mum left me messages because I was going to take my  
2 own life. So my Mum kept phoning and saying, "Please  
3 don't do anything silly. We love you. Please come  
4 home."

5 So the next day the GP told me to go to the  
6 local psychiatric hospital for an emergency  
7 assessment, which I did.

8 Q. Since then you've had long periods of counselling?

9 A. Yes, because alcohol's been an issue for me, so the  
10 alcohol counselling has taken months and months at  
11 a time to complete.

12 Q. But you've described in your statement it's an ongoing  
13 battle with excessive drinking and depression?

14 A. Yes, although I must say since this process, I feel  
15 I'm able to control it because I've got a purpose  
16 which is today and there's no secrecy now because even  
17 a friend said to me last night that I was glowing and  
18 I looked so relaxed. He hadn't seen me like that for  
19 a long time.

20 Q. You underwent the treatment for the hepatitis C and  
21 successfully cleared the virus.

22 A. That's right.

23 Q. And after that you returned to work.

24 A. Yes.

25 Q. Your colleagues, other than your boss, weren't aware

1 of why you'd been off?

2 A. That's right.

3 Q. What was their reaction when you returned?

4 A. Well, they actually thought I'd either had cancer or  
5 I'd been in alcohol rehab and that was hard because  
6 I'm normally quite an open person. So having to keep  
7 that secret, they were obviously really concerned  
8 about me but I couldn't be honest with them as to what  
9 was going on because, again, due to the stigma, I just  
10 couldn't do it.

11 Q. Since your treatment, what's your physical health been  
12 like?

13 A. Well, I cleared the virus. I get tired, difficulty in  
14 picking up, you know, new tasks at work so I've cut  
15 back on my hours there, which has helped but it could  
16 be that I'm just getting older but, yes, touch wood.

17 Q. But thankfully there was very limited damage to your  
18 liver.

19 A. Yes, that's right.

20 Q. So in terms of your liver there's not been as much  
21 concern?

22 A. That's right, yes.

23 Q. Have you had any monitoring of your liver since  
24 completing your treatment?

25 A. No. And that's one of the things. You get so much

1 medical support when you're going through the  
2 treatment. I think I had a six months test and an  
3 annual test and then that's it. It's like, "There you  
4 go, you're fine" and I think it would be useful to  
5 have some sort of follow up, you know, even annual  
6 tests just to make sure everything's as it should be.

7 Q. You have received payments from The Skipton Fund?

8 A. That's right.

9 Q. And from the Scottish Infected Blood Support Scheme?

10 A. Yes.

11 Q. How did you find the process of applying for that?

12 A. I found it relatively easy but then I'm used to  
13 filling out forms with work and things like that, so  
14 I found it an easy process and then obviously the  
15 consultant had to complete part of the form and that's  
16 where the copy of the blood transfusion report came  
17 in, so it was a straightforward process for myself.

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

20 A. I'd just like to thank John for all his support.  
21 Without him I wouldn't be here today at all and also  
22 my step-son, Duncan. They've both been a tower of  
23 strength.

24 I'd also like to thank my family for their love  
25 and support throughout the years. I know it's not

1           been easy for them. I've got an amazing group of  
2           friends who have just rallied round me superbly in the  
3           last couple of months.

4                    I'd also like to thank my employer Lloyds  
5           Banking Group because from the day I was diagnosed  
6           through my treatment and to support me here today  
7           they've been amazing. I know that a lot of people  
8           don't have that support with their employers, so  
9           I really do support them.

10                   I'd like to thank Thompsons the solicitors for  
11           all their help and guidance. It's been invaluable and  
12           I'd like to wish the Inquiry well as you go round the  
13           other cities to hear other people's stories.

14    Q.   I am just going to turn and ask Mr O'Neill and  
15           Mr Dawson if there's anything they want me to raise.

16                    (Pause)

17                    Just one point that they'd like me to raise with  
18           you. You found out about something called C Plus  
19           Counselling?

20    A.   Yes.

21    Q.   Can you tell us how you found out about that and what  
22           it is?

23    A.   Yes. I went online to look for local support groups  
24           and they were based in Leith at the time and they were  
25           amazing. I got to see them almost straight away and





1 SIR BRIAN LANGSTAFF: Alice, please.

2 **ALICE MACKIE, sworn**

3 **Questioned by MS RICHARDS**

4 MS RICHARDS: Sir, before we start I should say that Alice  
5 is not anonymous but at her request she's not being  
6 filmed, so there will be a live audio transmission of  
7 her evidence but not her image.

8 SIR BRIAN LANGSTAFF: It must follow I think that to pay  
9 respect to Alice's wishes no-one should take  
10 a photograph of her attending this hearing of the  
11 Inquiry. Please make sure that if you are taking  
12 photographs in or around the building you don't  
13 inadvertently catch her on your photograph.  
14 Obviously, if she gives you her specific permission,  
15 that's a different story but please respect her  
16 wishes.

17 MS RICHARDS: Alice, you're here to give evidence about  
18 the circumstances in which your husband Robert became  
19 infected with HIV.

20 A. Yes.

21 Q. But it is important we make clear, and you wanted this  
22 to be made clear, Robert is still alive.

23 A. Yes.

24 Q. You are giving evidence essentially on behalf of both  
25 of you and Robert, like you, has given a detailed

1 written statement to the Inquiry.

2 A. Yes.

3 Q. Robert is one of what we'll here hear as we go through  
4 your evidence has been termed the Edinburgh cohort,  
5 and I will be asking you a little bit about how you  
6 came to find that out.

7 It is right to understand at the outset you have  
8 undertaken a very significant amount of research and  
9 investigation over the last two decades or so.

10 A. Yes.

11 Q. You have given that material to the Inquiry and you  
12 know that many of the issues that it raises and the  
13 documentation you have been provided are going to be  
14 examined at later stages of the Inquiry.

15 A. Yes.

16 Q. Robert has severe haemophilia A, diagnosed at a young  
17 age?

18 A. Yes.

19 Q. But his statement tells us that despite that  
20 haemophilia, he led a very active and sporty life?

21 A. Definitely.

22 Q. He would run, play golf, play tennis?

23 A. Yes.

24 Q. What was the particular sporting passion he developed?

25 A. Fishing.

1 Q. That involved a lot of walking?

2 A. Definitely. He could walk for miles and I'm talking  
3 about 30/40 miles in a day.

4 Q. If he had a bleed when he was growing up, he would  
5 largely treat it with bed rest?

6 A. Yes.

7 Q. As a child, if he had serious bleeds but serious  
8 bleeds only he might have fresh frozen plasma and then  
9 at a later stage cryoprecipitate?

10 A. Yes.

11 Q. Until he was about 13 he attended the Royal Hospital  
12 for Sick Children in Edinburgh?

13 A. Yes.

14 Q. But then his care switched to the Royal Infirmary of  
15 Edinburgh?

16 A. Yes.

17 Q. That's where it remained for the period of time with  
18 which we are primarily concerned?

19 A. Yes.

20 Q. You started attending the Haemophilia Centre which was  
21 located, as I understand it, on ward 23 at the Royal  
22 Infirmary in 1979 with Robert?

23 A. Yes.

24 Q. What can you tell us about the facilities that were  
25 there at that time?

1       A.   Basic.  I was really quite shocked at where patients  
2       were treated.  It was just a side ward off the main  
3       surgical ward -- it wasn't a surgical ward, it was  
4       a medical ward and they were treated, there was two  
5       seats, a trolley with syringes and everything on it  
6       and it was a mess.  I have to say it wasnae very clean  
7       and the treatment to be examined by a doctor, it  
8       wasn't the first time Robert was actually examined in  
9       a corridor when visitors to the main ward were passing  
10      or you could be examined in front of other haemophilia  
11      patients that was there.

12                When patients did take their treatment nobody  
13      come in to clear up a mess after them.  If they didnae  
14      clear it, it was left lying for however long.  It was  
15      not a very clean environment to be taking medication  
16      anyway.

17      Q.   By 1980, your statement and Robert's statement tells  
18      us that he was being treated with both cryoprecipitate  
19      and Factor VIII products but from February 1981 it was  
20      Factor VIII only.

21      A.   February '81/beginning '82, I do note that he's got  
22      a notice in his medical records he has to be treated  
23      with Factor VIII only after a certain point, but it  
24      was factor and cryo for a while.

25      Q.   As well as the shift from both to it being at some

1 point exclusively Factor VIII, there was an increasing  
2 use of prophylactic treatment and home treatment as  
3 well?

4 A. Yes.

5 Q. Did Robert receive any information or advice or  
6 warnings about any risks of infection associated with  
7 the use of any of those products?

8 A. No, but maybe -- Robert started getting home  
9 treatment. When I was sitting fed up when he was  
10 taking his stuff I would read the packaging for  
11 inserts and on it I noticed hepatitis was mentioned.  
12 But before then Robert had approached Dr Ludlam to see  
13 if there was any risks to me or any future family  
14 members that we had from the Factor VIII and Dr Ludlam  
15 at that time says there's nothing, just the hepatitis,  
16 that Robert would go a bit yellow and that would be  
17 it.

18 So after I read it on the package inserts Robert  
19 went back to him again and specifically asked, package  
20 inserts, it states hepatitis and he was still told the  
21 same thing. Maybe go a bit yellow but there is no  
22 risk to any of your family members.

23 Q. That was as described in your statements and Robert's  
24 statement and you used to accompany Robert to all his  
25 appointments?

1 A. From April 1982, I attended every appointment Robert  
2 had.

3 Q. And a repeated refrain in your statements and Robert's  
4 statement is he would repeatedly ask Dr Ludlam and  
5 other doctors for reassurance or information, were  
6 there any risks, and he would press for an answer?

7 A. Yeah. You have to understand Robert is -- he's not  
8 scientifically minded if you understand but he always  
9 wants to know everything to do with his treatment. He  
10 always wanted to keep an eye on things.

11 He used to look after younger haemophiliacs. If  
12 they were in hospital he would always go in and check  
13 on them, check that they were being treated properly,  
14 check that they were looked after, that nothing was  
15 going wrong with them. If he thought they weren't  
16 being treated properly, he would go and tell the  
17 nurses or the staff that they have to do such and such  
18 for them.

19 Robert really was up upon all these virus  
20 things. He was always really careful. When I met him  
21 and he actually told me about all this and we started  
22 his home treatment, he always made sure I didn't touch  
23 anything, there was no blood or anything because he  
24 was always afraid that he could pass something on.

25 But the more he asked the more he trusted, which

1 is something he shouldn't have done but the more he  
2 asked the more he trusted these doctors and it wasnae  
3 just one doctor, it was every doctor that he saw and  
4 they would always come out with the same thing,  
5 "Nothing to worry about, Robert", and in the end he  
6 was actually told to stop asking, "You're just causing  
7 trouble".

8 Q. The Factor VIII products that Robert received were,  
9 with one exception, always the domestic SNBTS Protein  
10 Fractionation Centre-produced Factor VIII product?

11 A. Yes.

12 Q. The one exception was I think it was the day after you  
13 were married --

14 A. Yes.

15 Q. -- when you attended the hospital.

16 Paul, can we have up please document 2190011 it  
17 should be.

18 We can see here it's a record of treatment and  
19 if we go about -- thanks if you stop there, Paul -- we  
20 can see in the left-hand column about two-thirds of  
21 the way down, 7 June 1981, 3.45, left elbow, Armour,  
22 and then the batch number given.

23 A. Yes.

24 Q. So that was the one occasion that Robert received  
25 a commercial product.



1 A. Yes.

2 Q. What was Robert's response when being offered that  
3 product?

4 A. Well, when he was given it, the boxes anyway, he  
5 turning round and told the nursing staff that he  
6 didnae get commercial Factor VIII, that he only had  
7 Scottish Factor VIII or plasma, and they turned round  
8 and told him, "Well, that's all we've got, take it or  
9 leave it", but what we did discover was his uncles had  
10 went up the following day to get treatment and they  
11 had Scottish Factor VIII, so it wasn't all that was  
12 there.

13 There was also the fact that when you take a new  
14 treatment you're meant to have it as not an in-patient  
15 but you're meant to go in and take blood tests, blood  
16 levels and everything before and after you take it.  
17 There was none of that. It was just, "There's your  
18 treatment. Go mix it up. Take it", and that was it.

19 Q. Was there any particular reason at that point in the  
20 middle of 1981 why Robert was concerned about having  
21 a commercial product as opposed to a Scottish product?

22 A. Not in that -- Robert didnae like Factor VIII, full  
23 stop, all right. He had just got in his head using  
24 "our stuff" and then they turned up with this  
25 completely strange Factor VIII. One, he had nae been

1 tested for for a start and he just didnae like the  
2 idea of taking commercial Factor VIII because he was,  
3 as I say, he was always wary of what he got into his  
4 body and the commercial Factor VIII just was not what  
5 Robert wanted.

6 Q. We can see if we have up on screen please, Paul,  
7 2190009 that Robert, in fact, had a reaction to the  
8 commercial Factor VIII.

9 If we have the bottom half of the page, please,  
10 Paul, we can see the reference:

11 "Married this afternoon, severe bleed left elbow  
12 of one hour's duration."

13 And then we see at 4.30, which is probably about  
14 45 minutes after the treatment:

15 "Very uncomfortable reaction following  
16 commercial Factor VIII."

17 A. That's putting it mildly.

18 Q. What can you recall about the reaction?

19 A. Oh my goodness. His whole body, and I mean his whole  
20 body, come out in hives, spots, everything. He could  
21 hardly see in front of him. They actually gave us  
22 a -- they wanted to keep him in and he wouldnae stay  
23 in but what they did was they put us away in a wee  
24 place, a wee room, away where ward 45 ended up and we  
25 sat there for the rest of the night in a chair but he

1           couldn't move, he could hardly breath. They actually  
2           gave him cortisone I think at the time it was that  
3           bad, and we really thought he wasnae going to get home  
4           the following morning.

5       Q. Was it after that reaction that Dr Ludlam issued  
6       Robert with a letter that said she should be given the  
7       Scottish product only?

8       A. Yes.

9       Q. You've described in your witness statement that in  
10       1983 there were changes at the Haemophilia Centre.  
11       What can you recall about those changes?

12       A. We went up one day and it was spotless. Couldn't  
13       believe how clean it was. The cinbins -- there was  
14       big notices telling everybody to use the cinbins to  
15       put their used syringes in that. The trolley was all  
16       nice and neat but the difference was you had to ask  
17       the staff for syringes and needles and things and  
18       everybody was made to clear up after them.

19               Eventually, it was round about that time that we  
20       also got a small treatment room where a doctor could  
21       examine you, which is something they never had. New  
22       chairs come. The old ones that were covered in blood  
23       had all disappeared and a couple of new reclining  
24       chairs for them come. Everything just turned  
25       professional.

1           At that time as well what we did notice was, I'm  
2 not sure if it was '83/84, but the staff in the main  
3 ward had all changed as well. The people that Robert  
4 had -- the nurses and sisters and that that Robert had  
5 grew up treating him, they'd all disappeared and it  
6 was all new staff that was in. And the Haemophilia  
7 Centre themselves also got a nurse, which is  
8 something they'd never had in all these years, a nurse  
9 to themselves was something.

10    Q. Do you attach any particular significance to those  
11 changes?

12    A. Looking back now, right, at the time we just wondered  
13 what it was for but it was when the AIDS started, when  
14 America started getting AIDS-infected people and then  
15 people started talking about haemophiliacs in this  
16 country, and it was at that time, right at that time  
17 is when the centre changed and everything changed.

18           We did discover later on, which I probably  
19 should mention just now, is the AIDS studies and  
20 things like that, but at that time more blood was  
21 starting to be taken from Robert and all these  
22 different things. The whole treatment regime changed.  
23 They started weighing them. Robert had never been  
24 weighed that I could tell and they started taking his  
25 weight as well, which is something they'd never done

1 before. It was just wee things that you could pick up  
2 on.

3 I was friendly with one of the cleaners that  
4 used to clean the main wards and she always spoke to  
5 me, and this day the first time we turned up when this  
6 side ward was spotless, she walked right past me. She  
7 wouldn't even look me in the face and I said to myself  
8 now even the cleaners knew about the risks or why they  
9 were changing the wards like this before even the  
10 patients knew. The whole thing was completely  
11 different to what it was in '82 -- '81/82.

12 Q. As you have just said, it was at this point you  
13 noticed more and more tests being undertaken, blood  
14 being taken?

15 A. Not tests being undertaken, blood being taken for  
16 routine, just his normal routine bloods is what we  
17 were told.

18 Q. Were you told for the reasons of the weighing of  
19 Robert?

20 A. It was just something new that they were to do, new  
21 procedures.

22 Q. At some stage there were requests to Robert to donate  
23 blood. What can you recall about that?

24 A. Not just Robert, his uncle -- well, one of his uncles  
25 used to donate pints of blood. The last -- when

1 Robert donated this, he did ask, years ago he had  
2 asked why they were taking the blood, why specifically  
3 haemophiliac blood because it's not normal.

4 What he was told it was for heart operations to  
5 stop them using Warfarin for the clotting, and then it  
6 got to the stage he did ask, he kept asking but this  
7 time he asked and the person that was putting the  
8 needle into him says, "Well, what have you been told  
9 it's for?" And Robert says, "Well, heart operations",  
10 and the man actually laughed and walked away as if to  
11 say, "Ken, Robert's talking out the top of his head  
12 because it's not for heart operations", and we never  
13 did find out what it was for.

14 In '83 Robert gave -- Dr Ludlam requested plasma  
15 free -- Factor VIII-free for plasmapheresis and in '83  
16 I would have thought it was a bit risky because people  
17 had AIDS by then. Haemophiliacs were known to have  
18 AIDS, never mind hepatitis because everybody had  
19 hepatitis by then as well, but we didnae know that at  
20 the time so ...

21 Q. You have explained in your statement that it was  
22 around this time, approximately 1983, Robert began to  
23 pick up, as others had, about the illness in America  
24 that was killing people and he started asking doctors  
25 about that.

1                   What did he ask and what response did he get?

2       A.   Robert -- we didnae have -- our lifestyle at the time  
3           was busy with one thing and another just doing things  
4           so we never bought papers we didnae really watch the  
5           television.  It was the radio that we listened to.

6                   Robert started hearing things.  He didnae know  
7           what to call this thing, right, he didnae know AIDS  
8           HTLV-III or anything like, but he knew it was killing  
9           people, not haemophiliacs specifically but people.  
10          But Robert's brain told him people that are getting  
11          this are blood donors, just the general public, so is  
12          blood going to be safe for Factor VIII, and he was in  
13          the hospital and he asked Ludlam, he asked every  
14          doctor he saw about this disease.

15                   As I say, he didnae know what to call it so he  
16          couldnae pin them down specifically to the name and  
17          every one of them told him, "Nothing to worry about.  
18          Our Factor VIII's safe.  It's always checked.  It's  
19          checked for every virus", and constantly -- and he  
20          asked that much that other patients were asking the  
21          doctors the same questions.  They didn't know why but  
22          they were asking the same questions and Robert got  
23          told if he didn't stop asking, he would be barred for  
24          the hospital.

25                   Patients, there's been a few but I can remember

1           one that's HIV positive come up to him and said,  
2           "I didn't know why you were asking the questions  
3           Robert", he says, "but I do know now", because he was  
4           infected. The hepatitis, somebody that had hepatitis  
5           said his Mum used to think Robert was a bit loud in  
6           telling them they shouldnae be taking this, they  
7           didnae need it, just don't play rugby and they wished  
8           they'd listen to him because he had hepatitis and  
9           ended up with cirrhosis.

10                        It's all these things but Robert was always told  
11           to shut up, to keep quiet, he would be barred for the  
12           hospital.

13       Q.   You've described it this way in your statement, he was  
14           essential branded a trouble maker and they thought he  
15           was frightening other patients with his questions and  
16           he was told he would be banned if he carried on.

17       A.   Yes.

18       Q.   Did that stop Robert?

19       A.   No. No, just makes him worse.

20       Q.   Robert had, in fact, as I understand your statements  
21           wanted if possible to stay receiving cryoprecipitate.  
22           What was he told when he asked about that?

23       A.   He was told that they'd stopped making cryo.

24       Q.   Who told him that?

25       A.   Dr Ludlam.



1 Q. Did he also have any discussions with Dr Ludlam about  
2 whether there was in the Scottish donor population any  
3 risk of AIDS that you can recall?

4 A. Robert asked about AIDS, he asked about -- when he  
5 spoke to doctors he wasnae speaking about American or  
6 commercial or whatever, he was always speaking about  
7 "our blood" because that's what he received, and  
8 whenever he spoke to Dr Ludlam or any other doctor,  
9 and it wasnae just Dr Ludlam that he asked about the  
10 risks, he was always told, "Our blood donors don't  
11 have AIDS. It's safe. We don't have the likes of  
12 that in this country". Where they got that  
13 information from I don't know but he was told it was  
14 safe, we didn't have AIDS in Scotland or HTLV-III in  
15 Scotland.

16 Q. As you have said, apart from that one episode when  
17 Robert was given an Armour product, he received the  
18 Scottish-produced product.

19 A. Yes.

20 Q. If we have up on screen, please, document 2190012,  
21 Paul.

22 We can see here some of Robert's treatment  
23 records from 1984 and we can see the top of the page  
24 there, 8 April, and we have under batch we have  
25 a batch number written out as follows:

1                   "023110090", and it appears from that entry he  
2                   is receiving that batch for a right shoulder bleed and  
3                   then over a number of subsequent days he's receiving  
4                   it prophylactically.

5           A.   Yes.

6           Q.   Then, Paul, there should be another page of similar  
7               records under the same reference. Do you have that?

8                   Well, there was another set of similar records  
9                   for March 1984 which again show, and the date is  
10                  I think 2 March, that full batch number, that same  
11                  batch number is written out and that's shown as being  
12                  for a left elbow bleed and then we see the full batch  
13                  number again in early April.

14                  We can see a contrast, Alice, that you have  
15                  raised in your statement, as has Robert, the full  
16                  batch number being written out there and then  
17                  abbreviated numbers being used for other batch  
18                  numbers.

19          A.   Yes.

20          Q.   It's yours and Robert's understanding that it was from  
21               that particular batch, the one the number of which is  
22               written out in full, that Robert became infected with  
23               HIV.

24          A.   Yes, we've actually been told that was the batch  
25               number.

1 Q. We can see some documents from Dr Ludlam that confirm  
2 that.

3 Paul, can we have 2189002, please.

4 A. I don't know if I should say this here but it's the  
5 only batch number ever in his medical records that is  
6 written out in full.

7 Q. I was absolutely going to ask that question, Alice.  
8 You and Robert, looking at his records, have  
9 identified that that is -- these are the only  
10 occasions when it is written in full.

11 A. The only one that is written out in full, and I'm  
12 talking about for 30/40 years it's the only batch  
13 number, and it's not just in his treatment record  
14 sheets, it's the completion sheets that the nursing  
15 staff fill in at the end of the years or you're  
16 getting your medical -- as you're Factor VIII the  
17 nurses write in a separate form and it's in that  
18 written out in full as well and it's the only number.

19 Q. Thank you, that's the one.

20 If we look at this letter it's not terribly easy  
21 to read but we can see it is dated 17 September 1987.

22 It is from Dr Ludlam to Dr Wensley and we see point 3:

23 "In my opinion he [that's Robert] became  
24 infected with HIV as a result of transfusion of batch  
25 023110090 of SNBTS Factor VIII in the transfusion

1 records this is abbreviated to 0090", just pausing  
2 there, is that correct that it's abbreviated to 0090?

3 A. No, it's all written out in full.

4 Q. Then it tells us he was anti-HIV negative on 27 March  
5 1984 and positive on 29 May 1984 and I don't think we  
6 need to put them on screen but there are some clinical  
7 records which show Factor VIII being administered on  
8 particular dates in April which we've seen from the  
9 earlier documents.

10 So that is one of the sources of your  
11 understanding and Robert's understanding that it was  
12 that particular batch that infected him?

13 A. Yes.

14 Q. As I understand it, it's important for you to make  
15 clear and for Robert to make clear that that was  
16 a Scottish-produced batch that infected him?

17 A. Yes.

18 Q. Now, some years later, in March 2003, Robert wrote to  
19 Dr Ludlam asking similar questions about when he'd  
20 become infected.

21 If we have up on screen please, Paul, 219 --

22 A. I actually wrote the letter.

23 Q. -- 003. Sorry?

24 A. It was actually me that wrote the letter.

25 Q. We can see it is a letter 7 March 2003 sent by Robert

1 but drafted, as I understand it, by you to Professor  
2 Ludlam:

3 "I am writing to ask if you can give me written  
4 information on the following: the date when you  
5 started testing me for HIV/AIDS or any related  
6 illnesses, the date when I tested positive for  
7 HIV/AIDS or any related illnesses and the batch number  
8 I can contracted it from", and then similar questions  
9 in relation to hepatitis C which we will come back to.

10 The response from Professor Ludlam, Paul, should  
11 be at 2190004 and if we can have the first three  
12 paragraphs, please, highlighted.

13 So this is 14 March 2003. Professor Ludlam  
14 refers to what he says was the first reasonably  
15 reliable test for HTLV-III available in the second  
16 half of 1984:

17 "We first started testing individuals with  
18 haemophilia for anti-HTLV-III in the autumn of '84 and  
19 spring of '85. We tested earlier stored samples and  
20 we found that the last sample that was negative for  
21 anti-HTLV-III was 27 March 1984. The first positive  
22 result was 13 August 1984. I believe it was most  
23 likely you were infected by batch 023110090 of SNBTS  
24 Factor VIII concentrate which you received in March  
25 and April 1984."

1                    Now that confirms the source of the infection,  
2                    the batch, again?

3                    A. Yes.

4                    Q. There is a difference in terms of the date given for  
5                    first positive result, the earlier letter --

6                    A. Yes.

7                    Q. -- suggested it was the end of May. Here it is  
8                    suggested it is 13 August 1984.

9                    Do you know what the explanation or reason is  
10                    for those differences?

11                    A. No. Whenever we asked anything like that we just get  
12                    ignored so you just give up asking.

13                    Q. Robert's observation in his witness statement is, no  
14                    matter what the precise timing, he says that:

15                    "I was given an infected product at a time when  
16                    the risk of AIDS from Factor VIII was well known."

17                    That is his core point.

18                    A. Looking at it, Robert was actually ill at the dates  
19                    that they seroconverted and he was at the hospital  
20                    because he had attended the GP and then went to the  
21                    hospital about his sore throat and what not. So  
22                    personally I know that Ludlam knew that he was  
23                    infected because of what he went up to the hospital  
24                    with, the sore throat that wouldnae clear up and that  
25                    and when Wensley got the letter that confirms it about

1 the very sore throat and what not that he had, so  
2 Ludlam knew at the time that Robert was infected from  
3 that specific day, well date, and I feel that he  
4 should have said something then to Robert.

5 It's not as if AIDS was something in '84, the  
6 beginning of '84, that nobody knew about.

7 Q. When you say you believe that Dr Ludlam knew that  
8 Robert was infected because of the symptoms that he  
9 was displaying, you're talking about this period in  
10 around the middle of 1984, are you?

11 A. It's March -- about March '84, March/April '84, Robert  
12 actually had this sore throat and he went to the GP  
13 and it wouldnae clear up so he went up the hospital  
14 and that is seemingly when Ludlam says he thinks  
15 that's his sera conversion. But he must have known at  
16 the time. He knew what he was looking for, for  
17 patients that had HIV or AIDS or call it what you  
18 want. He knew what he was looking for and Robert had  
19 these symptoms. So if he didn't know definitely, he  
20 must have thought it and that is the time he should  
21 have stopped and said to us, "Well, perhaps you might  
22 have ..." We would have accepted that, but he left us  
23 thinking Robert had a sore throat and he was okay and  
24 got on with our lives, and that is the point to me he  
25 should have said to Robert, "No, wait a minute, this

1           could be ..." and we would now bothered. We would  
2           have sat back and waited until our tests come but we  
3           would have taken all the precautions that we should  
4           have taken instead of risking my life and my son's  
5           life.

6        Q. I should say, sir, Dr Ludlam has been asked for  
7           a response to a number of the matters set out in  
8           Alice's witness statement and Robert's witness  
9           statement and it's our understanding that he intends  
10          to provide a response where will be published in the  
11          normal way in due course.

12                 Alice, there's one further document I just  
13                 wanted to look at with you.

14                 Paul, it should be 2189004. It's a letter of  
15                 28 April 1989. That's it. If we could just have the  
16                 text highlighted, please.

17                 So it's a letter again from Dr Ludlam:

18                 "I should be most grateful if you could send me  
19                 formal HIV reports on the above individual. According  
20                 to our records he has serum samples tested on the  
21                 following dates", and then there are a list of dates,  
22                 12 January 1984, 1 February 1984, 14 March 1984,  
23                 27 March 1984, what looks like it might be 9, 8 or  
24                 9 May 1984, 13 August 1984, 21 November 1984.

25                 Was Robert informed, did he give his consent to



1           being tested, whatever the precise dates, for  
2           HTLV-III?

3       A.   No.

4       SIR BRIAN LANGSTAFF:   Just pausing there for a moment,  
5           although it could be the 8th or 9th in the list, if  
6           you look down to the penultimate paragraph, the first  
7           sera positive on -- and then there are two numbers, it  
8           looks like 29 or maybe 28 May so, obviously, because  
9           that date isn't in the earlier column it's either the  
10          8 or 9 May or 29 May, which is perhaps more likely.

11      MS RICHARDS:   Yes.

12                        So Robert was not aware of any tests being  
13           undertaken at this time for HTLV-III?

14      A.   No, definitely not.

15      Q.   It's again right to note that Robert has raised in his  
16           witness statement the question why he continued to be  
17           given Factor VIII and given it on a prophylactic basis  
18           once the risk of AIDS became known and he has said it  
19           would have been very easy for him to alter his very  
20           active lifestyle to ensure he didn't require  
21           treatment?

22      A.   It would have been.

23      Q.   If necessary by going back to the regime of --

24      A.   Robert would have stopped taking treatment altogether  
25           if there was any risk until something was found.

1           I know people say oh it's life saving treatment  
2           and this but Robert survived, his uncle survived his,  
3           friends survived without all this treatment. He  
4           didn't actually need it for all these things. Bed  
5           rest like they used to do when they were younger, all  
6           these things would have been quite happy for Robert.  
7           He would have stopped decorating, car laying and  
8           things like that.

9           Q. Your statement raises this question: when did the  
10          sample come back positive? When did Dr Ludlam first  
11          receive a positive result? Because you cannot tell  
12          from Robert's medical records when that was.

13          A. Yes.

14          Q. You have referred to the way in which the particular  
15          batch that infected Robert was written in the records,  
16          written differently in the treatment sheets, unlike  
17          other batches.

18                 What concern or suspicion do you have in  
19          relation to that?

20          A. Can I talk about Ludlam's AIDS study, because that's  
21          what the batch number is connected to?

22          Q. Yes.

23          A. We discovered when we got his medical records that an  
24          AIDS study was carried out on Robert and people, other  
25          haemophiliacs, from March or something 1983, and there

1 was 32 patients were getting studied, researched,  
2 studied, call it what you want. 50 per cent of them  
3 became infected. 50 per cent of them became infected  
4 with this batch, same batch, and this same batch  
5 that's written out in full.

6 Personally, I -- I'm trying to put it  
7 diplomatically here. Personally, I think that Ludlam  
8 knew that these haemophiliacs were eventually going to  
9 get infected and I think he knew that this batch was  
10 the one. I know I shouldn't say it. I put it down to  
11 maybe they were doing heat treatment and the only way  
12 you can test if something works in a patient is by  
13 giving it to the patient. You understand what I'm  
14 saying? I think it was maybe part of a heat treatment  
15 trial, 50 per cent got it and 50 per cent didn't.

16 I can't prove that so it's just my thoughts.

17 Q. You have referred to "AIDS study", and you found  
18 references to that in Robert's medical records. If we  
19 can have up on screen please, Paul, 2190010.

20 A. I just don't understand why the number is written out,  
21 the only number that infected them is written out in  
22 full and it's not just once it's whenever he had it  
23 and then the nursing staff, they wrote it out in full  
24 when they were completing their records for Robert and  
25 it's the only number again that's written out in full.

1           Why? It was highlighted for some reason and it's not  
2           retrospective highlighting either, because we filled  
3           in the forms, we had to return the forms, the nursing  
4           staff filled in their forms when Robert got his  
5           Factor VIII, they took a lot of the batches that he  
6           got before we took it home, so it was at the time this  
7           stuff was filled in, so why is this number  
8           specifically written out in full?

9                         It gets me angry to know that this number is  
10           written out in full and I don't know why.

11         Q. If we look at document 2190010, which should be on the  
12           screen in front of you, Alice, this is one of several  
13           references that you have found in Robert's medical  
14           records using the phrase "AIDS study."

15                         The date on the top on this is not particularly  
16           clear but it's a 1983 date. It might be 1 April 1983  
17           but we don't at the moment have better copy of it. If  
18           we turn to the next page we can see a stamp in the top  
19           left-hand corner which is March 1983 and, again, we've  
20           got the terminology of "AIDS study".

21                         If we turn to the next page, please, Paul, we  
22           can see a date at the top, 21 November 1984, then we  
23           see the words "Haemophilia AIDS study", and then to  
24           the right we also see the term "AIDS study", and the  
25           date there is 12 June but the year is cut off.

1                   Was Robert ever given any information at the  
2                   time about any participation in or enrolment in any  
3                   kind of AIDS study?

4       A.   No, and how could he have given permission for it if  
5           he didn't know that AIDS existed, because at this time  
6           when this AIDS study started according to Ludlam there  
7           was no disease, infection, virus, call it what you  
8           want, there was nothing there to worry about.  So how  
9           could he give permission for this to go on if he  
10          didnae know about it?

11       Q.   Is this correct: it was only when seeing his medical  
12           records years later that Robert saw this reference to  
13           AIDS study and understood or believed that he had been  
14           enrolled in some kind of study without his knowledge  
15           and permission?

16       A.   Yes, we were looking to -- one of the reasons we  
17           really read his medical records at the time is when we  
18           requested them it really took a long time and every  
19           time I phoned up I was told they were either at the  
20           legal department or they were with Dr Ludlam, and this  
21           went on for some considerable time.  I think the  
22           secretary I was speaking to was getting fed up me  
23           phoning.  I thought, well, what can they be clearing  
24           out?  In thae days, I didn't think that doctors would  
25           do these kind of things.

1           So when we got them and I started looking  
2 through them and the words "AIDS study" just hit me in  
3 the face, it really did, but everything just  
4 started -- as soon as I saw the words "AIDS study" it  
5 just fell into place for some unknown reason, because  
6 years before my Dad had given us an MRC booklet,  
7 didn't know why he gave us it, but inside the booklet  
8 was about Dr Ludlam and his Edinburgh haemophilia  
9 cohort. Well, at the time when I read it I didn't  
10 think it had anything to do with Robert. I kept it  
11 for 30 years almost now but at the time I just put it  
12 in a drawer and left it.

13           But as soon as I saw the "AIDS study" I went to  
14 the MRC booklet, it just connected straight with that,  
15 after that I went to the library and that's when I saw  
16 it was actually I could -- because I know the people  
17 that were infected, one of these research papers  
18 actually gives the dates of birth and their factor  
19 treatment and what not and I could connect it and  
20 Robert's was there. That's how I knew Robert was one  
21 of his haemophilia AIDS group.

22    Q. You have put it this way in your statement Robert  
23 became part of "the Edinburgh haemophilia cohort" and  
24 that's not your term?

25    A. No, it's not mine.

1 Q. That's the term you have seen in papers and documents  
2 from Dr Ludlam and from the Royal Infirmary?

3 A. Yes.

4 Q. You've set out in your statement again various  
5 extracts from later medical publications which refer  
6 to this cohort as one of the most extensively studied  
7 group of HIV-infected individuals in the world?

8 A. Yes.

9 Q. But Robert did not know he was being studied?

10 A. No.

11 Q. Your statement explains that in the course of 1984,  
12 whilst what we've seen in the records is there  
13 recorded, Robert was still asking when he went to the  
14 hospital about whether there were risks.

15 A. Yes. Robert -- I don't know what made him ask.  
16 Because sometimes I would even say to him, "What you  
17 keep asking for? Shh." Just because he went on and  
18 on and on about this and every doctor always said the  
19 same thing and in the end, whether he believed it or  
20 not, he accepted that there was no risk because you  
21 ask it that often you have to start believing.

22 He says now he wishes he had stuck to his own  
23 intuition but he didnae. He believed these people  
24 that he was meant to trust.

25 Q. In December 1984 Robert received a letter from

1 Dr Ludlam inviting him to attend a meeting in the  
2 lecture theatre at the Royal Infirmary.

3 A. Yes.

4 Q. You attended that meeting with Robert?

5 A. Yes.

6 Q. What can you recall about the meeting?

7 A. To begin with it was short notice, right. It wasnae  
8 well planned, it was short notice. It was supposed to  
9 be two lecture theatres that were next to each other  
10 but there wasn't enough people that turned up to fill  
11 the two. How they were going to do anything with two  
12 lecture theatres I don't know but we ended up in  
13 a little lecture theatre in the old Infirmary.

14 I would say maybe about 50 people at most was  
15 there and we were scattered round. We were sitting at  
16 the side with friends and family that was there, a lot  
17 of people we didnae know, I mean, fair enough. At the  
18 front was Dr Ludlam, Dr Forbes (I remember him because  
19 he was that tall), and I think it was McClelland but  
20 I couldn't honestly have said at the time, but I now  
21 know it was him, were standing at the front and they  
22 says to us -- Ludlam actually turned round and says,  
23 "It's come to our attention that some people have been  
24 infected with HTLV-III", is what they used at the  
25 time. "But it's safe now, because it's getting heat



1 treated, it's all safe now".

2 But at the time we thought, well, poor soul's  
3 that's got this thing because we've not been told, but  
4 we were sitting and they told us one or two bits just  
5 about the unfortunate people that had been infected  
6 and when Robert went -- it was open to questions but  
7 when Robert went to ask a question Ludlam turned round  
8 and says to Dr Forbes, "Just ignore him. He's  
9 a troublemaker", and they closed the meeting down, and  
10 we couldnae ask any more questions after that.

11 But when we were leaving his friends and family  
12 were all going, "Have you been told about this? Have  
13 you been?" They're all going, "No. No, thank God  
14 we've no got that", and that was the end of the whole  
15 thing. We never heard anything about it after that.  
16 So we thought, we'll get on with our lives,  
17 everything's okay, Robert's not infected.

18 Q. You have described in your statement that Dr Ludlam  
19 gave an explanation about HTLV-III, about methods of  
20 transmission and gave some advice about if someone was  
21 HTLV-III positive, about the use of condoms and  
22 cleaning up spillages and using gloves and so on and  
23 then talked about heat treatment and about the  
24 Scottish Factor VIII now being safe to use because it  
25 was going to be heat treated.

1       A.  Yes, but one of the things in there -- he said about  
2       gloves and aprons.  I was never, ever offered -- it  
3       was only in the past five years I've been offered  
4       gloves.  I have never been offered gloves or aprons or  
5       anything, and I thought if Robert had have been  
6       infected we would have been issued with these things  
7       and we were never.  It was never even offered to us  
8       for these gloves.  So we just, as I say, we just  
9       carried on our lives as normal.  We thought great, we  
10      got on with life, and that was it.

11     Q.  Your assumption, Robert's assumption, was that Robert  
12      had not been infected with HTLV-III, HIV --

13     A.  Yes.

14     Q.  -- because if he had been he would have been  
15      specifically told that?

16     A.  Before the meeting, yes -- well before the meeting  
17      I would have thought.  But even if they just got it,  
18      surely as soon as a doctor found the results, they  
19      would have made an appointment specifically to speak  
20      to the patient to tell -- it's not just a cold or flu  
21      you've got here, it's a sexually transmitted fatal  
22      disease and this was known to be sexually transmitted  
23      and fatal by the end of '84, and sometimes they'll  
24      say, "Well, we didn't know if you were going to get  
25      the virus because the tests and everything".  It

1           doesn't matter. If the risk is there we should have  
2           been informed before this meeting of this risk.

3           Q. Did Dr Ludlam or any of the doctors who were there say  
4           words to the effect, "if any of you want to know your  
5           specific test results make an appointment"?

6           A. No.

7           Q. You've said in your statement you left feeling thank  
8           God Robert is not infected with this thing.

9           A. Yes.

10          Q. Robert's statement says this:

11                        "Along with my wife and I, all the people at  
12                        this meeting that I spoke to thought that the people  
13                        who had been infected had been informed before the  
14                        meeting, so we all thought that we were all safe. We  
15                        would never have imagined that Dr Ludlam would use  
16                        a meeting like that as the only means by which he was  
17                        communicating to infected patients that they were  
18                        infected. All we could say to each other after the  
19                        meeting was, 'Thank God I don't have it'. We thought  
20                        that those infected had been told individually by  
21                        Dr Ludlam of their infection before the meeting and  
22                        that the meeting was to tell us the risk had passed  
23                        since we now had heat-treated Factor VIII produced at  
24                        the PFC", and then he says this:

25                        "I still do not understand how I was supposed to

1 know that I had received the infected batch if I was  
2 not informed by any doctor in any manner be it  
3 face-to-face or by letter."

4 A. Yes. I mean, not everybody at the meeting was  
5 infected. There was uninfected people at this meeting  
6 as well.

7 Q. As you subsequently have found out?

8 A. Yes.

9 Q. You have suggested in your witness statement that the  
10 trigger for this meeting was going to be -- was  
11 something that was due to be published in the press?

12 A. I've learned since that time that there was -- I can't  
13 remember, something posted. One of the English  
14 newspapers had got hold of it and they had contacted  
15 Dr Ludlam. They were going to -- they wanted  
16 a statement off him. They were going to publish that  
17 there was a group of patients in Edinburgh that had  
18 been infected.

19 So they quickly arranged this meeting. He  
20 managed to get the reporter to delay it for a couple  
21 of days and the meeting was just to cover his back  
22 before it went in the papers.

23 Q. Again, I should emphasise we don't yet know what  
24 Dr Ludlam's response will be to these criticisms.

25 After that meeting in December 1984, you've said

1           that at no time did Dr Ludlam or any other doctor or  
2           nurse at the Infirmary mention over the following  
3           three years or so HTLV-III or HIV or AIDS.

4       A.   It was never mentioned once.  Even in general  
5           conversation it was never mentioned.

6       Q.   There is a letter in Robert's medical records, 2190008  
7           please, Paul.

8                    Alice, your screen is tilted down but I don't  
9           know if you can still see it okay?

10      A.   It's okay.

11      Q.   This is a letter dated 31 January 1985.  It is from  
12           Dr Ludlam to Dr Love, that was your GP at the time,  
13           and you found this in Robert's medical records.  It  
14           says:

15                    "You will be aware from both the medical and  
16           popular press that patients with haemophilia are at  
17           risk of the developing AIDS as a result of the  
18           transmission of the HTLV-III virus in Factor VIII and  
19           Factor IX concentrates.  To date there have only been  
20           three cases of AIDS in British haemophiliacs and the  
21           chance of any individual patient developing the  
22           disorder based on our present information is very  
23           small, probably less than 1 in 1,000."

24                    Then it refers to serological studies of  
25           patients in the United Kingdom, including Edinburgh,

1 and suggests:

2 "It is clear that many haemophiliacs have  
3 antibodies to the HTLV-III virus. The presence of an  
4 antibody does not necessarily confer immunity and such  
5 patients may be capable of transmitting the virus both  
6 by semen and blood."

7 Then he refers to the importance of precautions  
8 being observed. Then in the next paragraph says this:

9 "I write to let you know I have circularised  
10 your patient with an information sheet about AIDS",  
11 and says what the chief recommendations are and then  
12 over the page says:

13 "All Scottish Factor VIII concentrates are now  
14 being heat treated under conditions that are believed  
15 to kill the HTLV-III virus, thus Scottish Factor VIII  
16 no longer transmits the AIDS virus."

17 Did you ever see this document before you saw  
18 Robert's medical records a number of years later?

19 A. No.

20 Q. The assertion is that "your patient", that's Robert,  
21 had been given an information sheet about AIDS. Do  
22 you recall anything about that?

23 A. From the time we got married I was the one that opened  
24 up the mail. Robert used to just leave letters lying  
25 so I always opened up the mail and I never received

1 anything, any information leaflet, through the post.  
2 I would have panicked if I'd saw something like this.

3 Q. You have said in your witness statement this:

4 "Dr Ludlam put my life and our son's life at  
5 risk by not telling me or Robert", and that makes you  
6 very angry. It's also a source of great anger to  
7 Robert.

8 A. Yes.

9 Q. It was in I think 1985, please correct me if I'm  
10 wrong, that you were asked by Dr Ludlam if you would  
11 give some blood for research purposes.

12 What can you recall about that?

13 A. It was weird. He was asking family members to give  
14 blood for research. Fair enough. So I was up the  
15 centre and Sister Philips was the treating nurse by  
16 then and she says for blood. So we went into the  
17 treatment room and she started and I says to her,  
18 "What's it for? What's the research for?" Of course,  
19 she says genetic purposes and both Robert and myself  
20 looked at her and says, "But I'm not connected to  
21 Robert that way so why would you want blood?" When we  
22 were talking to her, her hands were like, it's worse  
23 than mine, her hands were shaking and she made a right  
24 mess in my arm taking the blood, but she didnae get  
25 very much blood but she got some and she ran out of

1 the room after that, and that's the last we even heard  
2 of it. We don't even know if she got enough blood to  
3 do what she was doing, but genetic purposes, I am not  
4 connected to Robert that way so why would I be  
5 involved.

6 They did take it from family members who were  
7 connected who had haemophilia sons or things like  
8 that, which is fair enough, but why would I be  
9 connected to it? I couldn't understand it.

10 Q. In the course of 1985 and 1986, you've said in your  
11 statement that Robert seemed healthy and well and by  
12 the end of 1986 he had been offered his dream job.

13 What was that?

14 A. A gillie.

15 Q. So lots of fly fishing --

16 A. Yeah, lots of it.

17 Q. -- and lots of walking?

18 A. Salmon fishing was his dream job, shall we say. That  
19 was his life. I mean, that was his life, that is what  
20 he always aimed for and he got offered it. We were  
21 all set and then it just all went out the window.

22 Q. You said in your statement:

23 "We couldn't have been happier. We had  
24 everything planned."

25 A. Yeah.



1 Q. Then in January of 1987 you received a letter from  
2 Dr Ludlam. What can you tell us about that letter?

3 A. I can't -- it asked us to go or Robert rather to go to  
4 an appointment. Robert didnae receive appointments  
5 for Dr Ludlam, so that alone was unusual. But what  
6 made it even worse was we had by now moved to ward 45  
7 and in ward 45 there was offices, there was treatment  
8 rooms, there was rooms that doctors spoke to their  
9 patients and that but he told Robert to go to his  
10 office. Now, his office was down in what I call the  
11 dungeons in the old Infirmary and that alone was  
12 unusual. I'd never, ever seen it but that's where he  
13 was asked to go to.

14 So the two of us thought, well, to it not be in  
15 the centre and a specific appointment there's  
16 something bad -- we didn't even think anything good.  
17 We automatically thought there's something bad on this  
18 otherwise it would just be up at the centre.

19 Of course we went down -- do you want ...?

20 Q. Yes, describe it.

21 A. We went down -- we were a bit early and it's down by  
22 where blood transfusion centre were, Blood Transfusion  
23 Services was down there and McClelland's office was  
24 there and Ludlam's office was there (*indicated*).

25 Q. For those who don't know, Dr McClelland was ...?

1 A. Scottish National Blood Transfusion Service.

2 Q. And we went in and we sat in and I thought, "My  
3 goodness, how can somebody work in this?" It was  
4 a small room and the whole place was full of files,  
5 filing cabinets, but files on top of the cabinets,  
6 files on the desks. He had his desk -- Ludlam's desk  
7 was there (*indicated*) and we were sitting under this  
8 high window, the seats were back here, so we sat there  
9 and when Dr Ludlam turned up he looked and he saw me  
10 there and he asked me to leave.

11 Of course, Robert says, "No, she's staying.  
12 Whatever you've got to say she's here", and he left  
13 the room. He says, "I'll leave youse to discuss for  
14 also it for five minutes". So he went away, he come  
15 back, and of course Robert says, "No, she's staying",  
16 and he wasn't really happy that I was staying there.  
17 You could see it in his face he wasn't happy, but then  
18 again I don't think he was happy whenever I was there  
19 at any time, I have to add that to it.

20 But we sat down and all he says -- the opening  
21 sentence was, "Have you had sex with any other men,  
22 women, drug users, intravenous drug users", if you  
23 want to be accurate", and Robert said, "No". It just  
24 come out the blue. He didnae lead us up to any of  
25 this, and then, "It's come to my attention you've been

1 infected with HTLV-III AIDS", and that was it.

2 Robert, of course, turned round and says to  
3 him -- but didnae think asking when he had tested, but  
4 what Robert says to him is, "How did I get that?" But  
5 what Ludlam went on to say was he had met the donor,  
6 the donor was a homosexual and he was dead and that  
7 sort of put us off track for a start and then Robert  
8 says to him, "Well, what's the prognosis?" Because by  
9 this time we didnae know much about AIDS but we knew  
10 enough to know that it killed, and he turned round and  
11 says to Robert, "Well, I've got more chance of dying  
12 of a heart attack, Robert, than you've got of dying of  
13 AIDS", and that was it finished. He got up and he  
14 walked out.

15 But every time he was talking to us he was  
16 writing in Robert's -- what I thought was Robert's  
17 medical records. He never looked at us. He never sat  
18 down and said anything. He never explained -- or what  
19 he did say was that we couldn't have any more children  
20 and he asked what protections we were taking. Well,  
21 we werenae because we were trying to have another one.

22 He got up and walked out. It was just that was  
23 the end of it, and we were left sitting and we got up,  
24 we left, and going home, from the time I left his  
25 office we went home, we never said a word in the car,

1           30 miles or something, we sat in the car, never said  
2           a word. We got in the house, Robert stayed down the  
3           stairs. I went up the stairs and I cried. That's all  
4           I could do. I couldnae cry in front of him because  
5           then I would have hurt him.

6                        So after, I think it must have been about an  
7           hour or two of us separate, I went down the stairs and  
8           we didn't really talk because at the time when we were  
9           told the two of our minds were active. We know,  
10          no-one can tell us when you get told bad news you do  
11          not remember. That's what people tell us and it's no  
12          true because when we get bad news we remember  
13          everything. But when we got home and we had time to  
14          sit and relax, if you can call it that, and things  
15          were going through in our minds, the two of us worked  
16          it out ourselves and then we got together and started  
17          to discuss it.

18                       All Robert could think of was his job, he  
19          couldnae do that. We thought he had actually just  
20          been tested so we didnae think my life was at risk,  
21          our son's life was at risk or anybody else's. We  
22          really just thought Robert. That was all that was in  
23          our minds. In my mind it was Robert. Robert was the  
24          one that I knew was going to die. When I don't know  
25          because I really didn't believe Ludlam when he said

1 about the heart attack because I knew haemophiliacs  
2 and people were dying of AIDS. You couldnae hide it.  
3 You had all these things in the newspaper and  
4 everything else telling you that people were dying of  
5 AIDS and we sat down.

6 My Mum had actually, for some unknown reason, we  
7 dropped my son off at my Mum's the night before  
8 because we just had this feeling and we couldn't even  
9 go and collect him that day. We left him with my Mum  
10 for a couple of days. We just says we had something  
11 else to do. We didnae say to my Mum what was wrong  
12 and we had to actually be on our own to get our heads  
13 round it and we collected my son. My Mum had said,  
14 "Well, what was the appointment about?"

15 "Ach, nothing, just routine", and that was all  
16 we said to her and everything was left.

17 Q. There's a couple of other details of that meeting that  
18 you and Robert have recorded in your statements I just  
19 wanted to ask you about. You were told by Dr Ludlam,  
20 you've said in your statements, not to tell anyone  
21 because of the stigma.

22 A. That was really emphasised. Not even to tell our  
23 families. At this time we didn't know that his uncles  
24 and cousin was infected, but we were even not to tell  
25 them. How on earth, if I wasn't there, how did he

1 expect Robert to go home and tell me? I really feel  
2 that it should have been the husband and wife that was  
3 there when he told them. I would have went crazy if  
4 Robert -- if I'd left the meeting and Robert was told  
5 that, because it's not something he should have been  
6 told on his own.

7 The way he was told and the way his family was  
8 told. It just is not -- I'll put it politely --  
9 acceptable. It's the only word I can put, that  
10 I wouldn't use words that I shouldn't use.

11 Q. Is it right that Robert or you asked Dr Ludlam how  
12 many haemophiliacs were infected?

13 A. Robert asked at the 1984 meeting to begin with. That  
14 was one of the questions he had tried to raise when  
15 the meeting was closed down. So when he had this  
16 meeting he had says to him, "Well, how many are  
17 infected with this", and all Ludlam says was just  
18 a few. That was it.

19 Q. That was the question he asked again in January 1987  
20 and the answer was just a few?

21 A. Yes, just a few.

22 Q. Your impression, is this right, and please correct me  
23 if I'm wrong, your impression as you've described it  
24 in your witness statements and in your oral evidence  
25 just now was that this was a recent diagnosis?

1 A. We thought he had just been -- it never even crossed  
2 my mind that it was all these years ago. We actually  
3 thought he had just been tested.

4 What we think about now is that it was heat  
5 treated so how could he have been infected, but we  
6 didnae think about that at the time. We actually  
7 thought Robert had just been tested and he had just  
8 gotten the result.

9 Q. Were you offered any counselling or psychological  
10 support at that time?

11 A. No.

12 Q. Was there is any offer of a test for you?

13 A. No.

14 Q. Robert describes the circumstances in which he was  
15 informed of the diagnosis in January 1987 in his  
16 statement as, I quote:

17 "Unforgettable and unforgivable."

18 A. Yes.

19 Q. And says this, again quote from Robert's statement:

20 "We were left to go home, keep secrets and just  
21 live the rest of our lives with nothing ahead of us  
22 but lies."

23 A. That's what we lived like. It was lies and secrets,  
24 secrets and lies. That's all we lived from that point  
25 on. That was it. That was our life. Secrets. You

1           couldnae talk to anybody. You couldn't tell them the  
2           truth. I don't know if I should say, we did say to  
3           one family member and we got asked to leave their  
4           house and that just -- well, Ludlam must be right.

5                        What can you do if a family member can't  
6           understand it, you don't tell anybody and that's how  
7           we lived. The three of us lived as a family from then  
8           on.

9           Q. I am just going to ask you about Robert's diagnosis  
10          with hepatitis C. You say in your witness statement  
11          that in February 1990 in a letter dated  
12          20 February 1990 from the Royal Infirmary of Edinburgh  
13          you were told this:

14                        "A new blood test has recently become available  
15          for assessing hepatitis and we would like to evaluate  
16          its usefulness. If the early promise of new test  
17          holds good it's likely to be very valuable for  
18          evaluating both the suitability of blood donors as  
19          well as the safety of Factor VIII and IX concentrates.  
20          We wish, therefore, to review case records to assess  
21          if and when individuals have had hepatitis or been  
22          jaundiced. We also want to relate the blood test  
23          results to the use of different forms of treatment."

24                        What was yours and Robert's understanding of  
25          what that letter was telling you?



1 A. It was just a new test for hepatitis and by hepatitis,  
2 we knew hepatitis as hepatitis A and B. We didnae  
3 know about non-A non-B or hepatitis C, and we actually  
4 thought that much about it we didn't even return the  
5 questionnaire and we didnae sign anything. So whether  
6 they actually went to Robert's records and done it or  
7 not because we didn't return anything giving written  
8 permission to do it, whether they actually checked his  
9 records or not I don't know.

10 Q. Then you have described in your statement a meeting  
11 in May of 1993 at ward 45 at the Royal Infirmary when  
12 Dr Ludlam suggested that Robert would need a liver  
13 biopsy or endoscopy to see if he had hepatitis C?

14 A. Yes.

15 Q. What can you recall of that discussion?

16 A. They says to Robert about this new hepatitis and as  
17 soon as they mentioned liver biopsy Robert, "No".  
18 Robert actually -- I'm putting it more politely when  
19 I say, told them it wasn't a good idea to cut into  
20 haemophiliacs and anyway. So he told them no and they  
21 offered him an endoscopy and he says he would think  
22 about it but he said no in the end to that as well  
23 because it was still too risky for him.

24 But they never said to him hepatitis C or what  
25 exactly it was. They didn't say that they could test

1 for it, they didn't say they could take a blood test  
2 or there had been taking blood tests for it, they  
3 didn't say any of these things and Robert -- well, we  
4 left the hospital thinking, well, when they come up  
5 with a blood test they'll tell us about a blood test  
6 and then we'll find out if you've got it.

7 We didnae know that they knew Robert was already  
8 infected. No-one told Robert that he was already  
9 infected.

10 Q. The basis for your understanding that it was already  
11 known that Robert was infected is again something  
12 you've subsequently seen in his medical notes.

13 Paul, it should be at 2190002, please.

14 If we look at the date in the top right-hand  
15 corner, we can see 29 April 1992 is the date received,  
16 12 May 1992 is the date reported and then we can see  
17 the test is -- the text is faint but the hepatitis C  
18 virus, the two tests there described are coming back  
19 as positive?

20 A. Yes.

21 Q. Did Robert know that he was being tested for  
22 hepatitis C in 1992?

23 A. No, but what I've not said here is from '83 onwards  
24 when I say Robert was given more blood samples, right,  
25 for his routine testing, it got that they were taking

1 50mls of blood, 60 -- I've even seen two full  
2 syringes, two full 50 mls syringes of blood getting  
3 taken off of Robert at one time, and the amount of  
4 times I actually says to these nurses, "What are you  
5 wanting all that blood for, because he's going to go  
6 need to go and get a blood transfusion if you dinnae  
7 stop taking as much blood off him" and all they would  
8 do is "ah-ah", turn round and walk away.

9 It's not as if when they were taking blood off  
10 Robert it was 20 mls, which is to me fine, it's  
11 suitable, but we're talking -- I don't know if you  
12 understand how much 50 mls of blood is in a syringe.  
13 It's a lot and it was a lot for me to keep on saying  
14 to them, not just once or twice, I'm telling you on  
15 a regular basis, every nurse that took blood off of  
16 Robert I would say to them about the amount and "What  
17 are you taking this for?" And they never said a word.  
18 They never even explained for research. They never  
19 explained for hepatitis. They never explained for  
20 AIDS or anything else, and we just assumed it was his  
21 routine blood tests for his haemophilia to check his  
22 levels.

23 Now I think I must have been that stupid,  
24 I really do.

25 Q. Robert says in his statement that he only understood

1           that he had hepatitis C in 2000 during a routine  
2           appointment with his HIV consultant?

3       A.   Yes.  I can remember the shock on his face.  Robert  
4           had problems with sweating, right.  He could --  
5           crumbs, it could be 100 degrees outside, fine, I could  
6           understand it, and then when it goes down to minus 5  
7           he'd still have all the doors and windows open in my  
8           house.  We couldnae go into any shop; we couldnae go  
9           into any building without him actually really  
10          sweating.  His temperature would go through the roof  
11          and everything else.

12                        When we used to say to the doctors at the  
13           Infirmary they just made us assume that it was the  
14           AIDS that was the problem with it.  Well, when he went  
15           to see [redacted] at the AIDS -- well, for his AIDS  
16           treatment, [redacted] says him, because the sweats  
17           weren't stopping, he says to him, "Well, it could be  
18           down to your hepatitis C", and I could see Robert's  
19           face.  I'd never been told, right, but because I'd  
20           heard so many haemophiliacs with hepatitis C I suppose  
21           I just assumed.  Maybe I shouldn't have assumed but  
22           I did, but it was neither here nor there to me because  
23           all our protection was for the AIDS and that's all  
24           I was interested in because that's what I was fighting  
25           to keep Robert alive from.

1                   But when [redacted] says to Robert about  
2 hepatitis C, his face -- you could see the shock and  
3 he just shut down. He can remember being told about  
4 it and we left and I can remember him in the car  
5 saying to me, "When did I get hepatitis C?" And  
6 I says, "I don't know when you got it but I do know  
7 that I thought you had it".

8                   A doctor should maybe have told me but because  
9 I was not Robert's power of attorney at that time they  
10 wouldn't have discussed, I would imagine they wouldn't  
11 have discussed it with me anyway and I never even  
12 thought of saying to Robert because, as I say, we were  
13 fighting to keep him alive with AIDS and at that time,  
14 in about 2000, Robert was only given six weeks to live  
15 and any time after that it was a fight to keep him  
16 going and I didn't want to put any more pressure on  
17 him.

18                   There's loads of things that come up about that  
19 time that Robert couldn't even tell you about anyway.  
20 The first thing he remembers is [redacted] saying to  
21 him "hepatitis C" and then it all just blew up again.  
22 I thought here we go again and it just ...

23 Q. Your suspicion or belief that he might have  
24 hepatitis C was based upon your general understanding  
25 by then that many haemophiliacs had been infected with

1 hepatitis C?

2 A. Yes.

3 Q. It wasn't on the basis, as I understand your evidence,  
4 correct me if I'm wrong, of anything that was said to  
5 you by any medical professional?

6 A. No, no-one ever said. They used to say to Robert  
7 about drinking but you drink too much, a doctor will  
8 say to you cut down your drink, you smoke too much  
9 they'll tell you cut down your smoking. So Robert all  
10 this time just thought, I mean, he knew he was  
11 drinking, don't get me wrong, he knew he was drinking  
12 too much but it's just something a doctor says. They  
13 never says to him, "You've got hepatitis C, Robert.  
14 Take care of your liver for this reason or other".  
15 They never come out with anything like that to him.

16 Q. Robert received in 2004 letters about potential  
17 exposure to the risk of vCJD. We've got letters.  
18 I am not going to ask you to go through them in the  
19 course of your oral evidence, but what do you recall,  
20 if anything, about the receipt of those letters and  
21 yours and Robert's reaction?

22 A. We did receive -- we received maybe three different  
23 times we received them, and the first time I actually  
24 ticked the box and sent it back saying we didn't want  
25 to know anything because, again, I keep saying this,

1 I was more interested in the AIDS. CJD or anything  
2 else to me was just something extra. Nobody told me  
3 the seriousness of all these other things. To me the  
4 seriousness was the AIDS, so I returned the form and  
5 says we didnae want to know anything.

6 We got another one and I'm sure I done the same  
7 with the second one. The third one, Robert was  
8 feeling better again so we went and we turned up and  
9 Dr Ludlam says to Robert that he hadnae received any  
10 batches but he could have still received it through  
11 eating meat and Robert's reaction was, "But I'm  
12 a vegetarian". He's not -- let me say that, he's not,  
13 but his reaction was, "But I'm a vegetarian and  
14 Dr Ludlam just looked at him as if to say, "Oh my God,  
15 what have I done". He shouldn't have said that. But  
16 he was putting down if Robert got CJD it was because  
17 he ate meat not because of the Factor VIII or the  
18 blood or anything else that he received, which  
19 I really think was something that he shouldn't have  
20 been saying because that's where he would have got it  
21 from.

22 But even then to us -- people worry about it.  
23 To us, it's just another thing that you might die of,  
24 if you understand what I'm saying. It's nothing  
25 extra. Our life circulates round AIDS not hepatitis,

1           because AIDS is the thing I have to deal with. AIDS  
2           is -- when Robert's ill a doctor will say to us,  
3           "Well, I don't know if his haemophilia or if it his  
4           AIDS or if its hepatitis that's the problem", so what  
5           do you do? You have to narrow in on something and my  
6           problem that I narrow in is the AIDS because now,  
7           touch wood, he's cleared the hepatitis. I know he's  
8           got all the side effects and everything else that come  
9           with that, but that does not catch up with what he is  
10          actually dealing with, with AIDS, how he lives with  
11          it, what he has to do with it, all the illnesses that  
12          we have to actually solve ourselves because the  
13          hospitals aren't interested, and Robert'll no go to  
14          his GP because his GP does not understand haemophilia,  
15          they don't understand the AIDS, they don't understand  
16          hepatitis.

17                 So when you go to a doctor how can you say to  
18          a doctor, "Well, I've got this infection", and he'll  
19          say, "Well, it will clear up on its own", and you will  
20          say, "But I'm worried because I've got ..."

21                 "Oh that's okay. It will just clear up on its  
22          own", and you go away, so we've got to go and try and  
23          find cures, remedies, all these things to solve  
24          Robert's problems and we don't go to doctors and  
25          hospitals unless there's something that, after



1 a certain length of time, we cannot clear.

2 We go up to the Infirmary and it got to the  
3 stage they didnae want to discuss things with Robert.  
4 If he had an illness at the beginning of all this we  
5 were told any problems go to the Infirmary, the  
6 Haemophilia Centre, and they don't want to know. They  
7 really just don't want to know because they don't  
8 know. They don't know haemophilia, AIDS, hepatitis.  
9 They do not know the difference in the illnesses and  
10 they don't know what to treat.

11 We go to the Infectious Diseases Unit and she is  
12 very -- the doctor we have there is now very  
13 understanding and she will sit and listen and if she  
14 can help us with anything, give Robert a medication or  
15 that, she will. But she's very careful because it  
16 could cause bleeding. So the doctors don't know --  
17 what they need is somebody that is there to be able to  
18 tell and treat a haemophiliac that is infected with  
19 more than one thing, more than haemophilia and there  
20 is not anybody out there and the doctors will admit  
21 that. There is nobody out there that can treat  
22 a haemophiliac with all these different viruses and  
23 that is something that should have been done years  
24 ago.

25 We just keep having to fight ourselves. We

1 shouldn't have to fight for all this. Somebody should  
2 be there for us. Somebody should be there to advise  
3 us. "If something's wrong, tell us, it's okay, we'll  
4 sort something out, we'll get our heads together and  
5 we'll discover what's wrong", and not once I've never  
6 seen that.

7 I did complain once with Dr Ludlam and another  
8 doctor in the room about Robert's treatment because  
9 I kept asking, "Well, is this treatment for AIDS going  
10 to affect his treatment for haemophilia?"

11 "Well, we don't think so", and I maybe didnae  
12 say the right thing and Dr Ludlam says, "Well, she's  
13 doing the best she can", because I turned round and  
14 says, "Well, your best's not good enough", and he  
15 looks as if I'd said something I shouldn't have. And  
16 I don't think the doctor was too kind to me after  
17 that, since every time I saw her after that she wasnae  
18 really talking to me.

19 They just don't get it. Honestly they don't get  
20 it. They treat haemophiliacs not even as patients,  
21 not people, they just treat them as experiments.  
22 That's the way I look at it now. It doesnae matter  
23 what you go for, they take blood and they take that  
24 much blood, they don't tell you what they're taking  
25 blood for. They have stored blood. Nobody ever told

1 us that they stored blood. 20/30mls storage. What on  
2 earth are they doing with all this blood? Who's seen  
3 it? What are they using it for?

4 It's just not right the way they're treating  
5 haemophiliacs, as a whole. I'm not just talking about  
6 Robert. I'm talking about a whole group in the  
7 population that deserve to be treated better than they  
8 are. I'm sorry. I've got off track, I'm sorry.

9 Q. That's all right.

10 A. I'm really sorry.

11 Q. No, no, not at all, in fact, you have covered some of  
12 the questions I was going to ask you later so don't  
13 worry in the slightest.

14 Can I take you back to life after you discovered  
15 Robert had HIV in 1987 and the years that followed.

16 Robert did not embark upon his dream job because  
17 he felt he would have had to tell his employer and  
18 that would be the end of it?

19 A. Yes.

20 Q. You've put it this way in your witness statement:

21 "Normal life stopped", and you began a life full  
22 of lies, deceit, secrecy, more secrecy and lies and in  
23 a way a life full of loneliness and isolation.

24 A. Yes.

25 Q. You have explained you tried to tell some members of

1 the family and they didn't want to know.

2 A. Mm-hm.

3 Q. In 1988, you and Robert had your first encounter, this  
4 is how you put it in your statement, with full-blown  
5 AIDS, when you saw a patient, someone that you knew.  
6 Without mentioning any names, what can you tell us  
7 about that encounter?

8 A. Robert and him were raised together, if you can call  
9 it that. They were in the hospitals together. They  
10 were really close friends and this person was more  
11 scientific, if you want to put it that way. He used  
12 to read all these, if he got his hands on these  
13 research papers and that and he used to read them.

14 But this time when we went in it was late at  
15 night, Robert went up to collect some stuff and he  
16 heard somebody shouting, of course, Robert being  
17 Robert again, nosey, went in to check that everything  
18 was okay because he recognised the voice, and this  
19 person saw Robert and he started screaming at him and  
20 shouting at him, "They've murdered us, Robert.  
21 They've murdered us. Get the -- they've murdered us".  
22 He was going, really -- he was in a really bad way.

23 I can't even describe how bad he looked, which  
24 shocked me because I'd never actually seen anybody  
25 with AIDS and the next thing was the staff come in,

1 cut us off, literally threw us out the hospital. But  
2 the car -- the old infirmary, there was a car park  
3 just down the foot of where the wards were and we were  
4 getting in the car and he was still screaming and  
5 shouting and that's the last we heard.

6 Q. That friend died?

7 A. He died just not long after, yes. That was the first.

8 Q. It was the first but not the last of deaths amongst  
9 friends and family.

10 A. No.

11 Q. And by 1996 you have described in your statement how  
12 it all became too much for Robert and he began to  
13 change in his behaviour and habits.

14 A. Even before that it gradually, it really gradually  
15 got, if I think about it, but you learn to accept  
16 changes and I always -- I had this thing that he  
17 deserved anything he wanted, if you understand. Even  
18 if it was getting drunk or partying or whatever, he  
19 deserved it because he wasnae going to survive this  
20 and he just got worse and worse. But what -- Robert's  
21 brain worked in a stupid way. After seeing all these  
22 people dying, after seeing the way it affected family,  
23 Robert decided one day that he was going to make sure  
24 everybody hated him, and I mean hated him, and that  
25 goes for our son as well.

1 Q. Robert's reasoning --

2 A. Was that if he hated him he wouldnae miss him when he  
3 died. But now because he's on his feet again, shall  
4 we say, after 2000 he regrets it. We can never get it  
5 back. My son now understands because he didnae know,  
6 we didnae tell him. Maybe we should have but we  
7 didn't tell him.

8 Q. What did you tell your son?

9 A. We didn't tell him until he was 18. Before that we  
10 used to say your Dad was ill and then it got that bad  
11 I had to go to the school to say something so I said  
12 it was cancer. So all through [redacted] schooling,  
13 you could say the school thought his Dad had cancer  
14 because sometimes if Robert was up during the night  
15 [redacted] would be -- could you take out [redacted].

16 Q. Yes. Hold on a moment. We will stop the live  
17 transmission. *(Pause)*

18 We will not refer to any names.

19 A. Right. The school, because we were up during the  
20 night and things like that, he was going to school  
21 maybe late or his homework wasnae getting done because  
22 of the atmosphere in the house and things that were  
23 happening. We should have maybe said to him then but  
24 eventually I says to him his Dad was dying of cancer  
25 because his friends started to ask, "What's wrong with

1 your Dad", and all this.

2 In the end when he was 18 that's when we told  
3 him and he just ... I don't know if he was hurt at us  
4 not telling him or what but what I says to him at the  
5 time as well was, "It's up to you if you tell your  
6 friends because we know the difficulties that we had",  
7 and we he said to me was, "If there are any friends  
8 they wouldnae bother, they'll just get on with life  
9 and that will be it", and some, I have to admit he's  
10 still got some friends and other ones disappeared  
11 because of what was wrong. Fair enough.

12 But that was another thing. We should have been  
13 maybe advised on how to tell children because it's  
14 them that are the ones that suffer. They are the ones  
15 at home and I think we should have been advised or  
16 someone should have said to us do you want us to help  
17 you explain. All these years Robert went through  
18 trying to get our son to hate him and our son did hate  
19 him for a long time and it wasnae fair. It really was  
20 not fair. He couldnae do anything with him.

21 When his friends used to come in and would go up  
22 the stair because I liked my son to be close, if you  
23 understand. I liked to keep an eye on him. Maybe it  
24 was just over-protectiveness, I don't know, so his  
25 friends would come and they'd go up to their room and

1           they'd do play whatever it was up there, and his  
2           friends used to start asking questions but when Robert  
3           again started on the drink, it got that their parents  
4           were passing remarks about his Dad being a drunk and  
5           in the end I think [redacted] preferred ...

6       Q.   We'll stop the live transmission.   *(Pause)*

7                        You were telling us about the impact upon the  
8           relationship between your husband and your son.

9       A.   My son actually preferred going to his friends' house  
10       rather than stay in our house because of the way  
11       things were.  I tried to keep it calm, I tried to do  
12       things but when he was at his friends' house he would  
13       hear his friends' parents' talk about a drunk.  Yes,  
14       Robert drank.  I knew why he was drinking.  I knew it  
15       was his coping mechanism.  I knew what he was doing  
16       but nobody else did.

17                       Walking along the street people would, "Oh,  
18       she's the one that's married to ..."  I just thought  
19       I've had enough of this.  You just can only take so  
20       much.

21       Q.   There came a time when you stopped opening the front  
22       door to people.

23       A.   Even now I don't answer telephones, I don't open up  
24       the doors, I don't even -- I don't have any friends.  
25       I actually had to stop having friends in '87.  When



1 I say it became a life of lies and deceit and what  
2 not, that it was the three of us, right. I mean, it  
3 was the three of us. I had no friends because how can  
4 you -- you cannae keep telling the same lie because  
5 lies always come out, if you understand what I'm  
6 saying.

7 As for family, I stopped visiting them because  
8 I couldnae lie to my family, so I just stopped and my  
9 family, it's a big family as well, and we were close  
10 and I say the word "were" because not anymore.

11 Robert's family, Robert made them hate him so  
12 much they stopped visiting. Now, they are the people  
13 that always says to me, "If at any time you need us,  
14 we'll be here. If Robert gets it, we'll be here", but  
15 as soon as Robert started, because the way Robert  
16 ended up, everybody disappeared. His family all  
17 disappeared, and it is a life of loneliness. I did  
18 not answer the door. I don't answer the phone.

19 You'll find in Robert's medical records,  
20 "I tried to phone Robert but there's no answer".  
21 I told these doctors loads of times not to phone  
22 because they'll no get an answer, but what they put  
23 down is because there's no answer we're out enjoying  
24 ourselves, and that was the words from one of them.

25 I used to get up in the morning, go up to the

1 shop and come back and that has been my life for the  
2 past 30 years.

3 I know Robert's spoken out and things like that  
4 but me I'm still no there. I've still got no cameras  
5 on me. Yes, I'll talk but I still cannot stand in  
6 front of somebody and say, "Yes, Robert is such and  
7 such". I still cannot do that.

8 I don't know if it's because I've lived with it  
9 for so long the way I've lived with it or because, as  
10 you can see, I get very angry or because I'm still  
11 frightened.

12 Q. Robert's physical health and mental health over the  
13 years deteriorated to the extent that again, as  
14 I understand it from your statements, Alice, he  
15 effectively now requires 24-hour care which you give  
16 him.

17 A. Mm-hm.

18 Q. He can't be left alone because he has panic attacks?

19 A. Mm-hm.

20 Q. Or outbursts of anger?

21 A. *(The witness nodded)*

22 Q. You panic too. You get anxious, you don't like being  
23 in noisy places.

24 A. Mmm.

25 Q. And you took the decision after the January 1987

1 meeting not to try to have any more children.

2 A. It's not a case of we took the decision. We got told  
3 we couldn't and no-one ever informed us that there  
4 was -- when other things come there, no-one ever  
5 informed -- as much as we would have liked to but  
6 no-one told us it would maybe have been possible.  
7 No-one approached us to say, look, if you're still  
8 young enough, if you're still wanting, but no-one ever  
9 says that.

10 Q. So sperm washing, things like that were never raised  
11 with you?

12 A. Never. The first I heard of that was through someone  
13 Andrew Evans on Tainted Blood. Sorry.

14 Q. No, that's okay. He has already given evidence about  
15 it.

16 A. Him on Tainted Blood. That was the first time I even  
17 heard that it was possible for an infected person to  
18 do that but by then we're all too old.

19 Q. You describe that in your statement as one of your  
20 biggest sorrows?

21 A. Yes.

22 Q. In terms of the treatments that Robert has undergone  
23 over the years, he was offered AZT but he declined  
24 that.

25 A. It was a trial treatment and Robert will not do

1 something that he does not know what is there, and I'm  
2 glad he didn't because [redacted] did say to Robert  
3 that they had overdosed them on AZT and can we sit and  
4 think about it.

5 We saw family members taking AZT and, yes, they  
6 did deteriorate after that. I can mind Robert saying  
7 to one of them, "Just leave it, don't take it, it's no  
8 good for you, they don't know what it's going to do to  
9 you yet?"

10 "Ach, it's all right. The doctor says it's  
11 great." This person, believe it or not, believed  
12 Dr Ludlam to the point that he thought he was never  
13 going to die of AIDS. He actually believed he kept on  
14 saying to Robert, "Robert, it's okay, we're living,  
15 we're never going to die of this. This is just  
16 something that's there. I got told it's okay. I'll  
17 live for the next 100 years", sort of thing, and  
18 that's what Ludlam told him and he actually believed  
19 this and when he went on AZT, Robert had says to him,  
20 "I don't really think ..."

21 "Ah, but he says it will keep me going", and he  
22 died just not long after it.

23 Q. By 2000 Robert's health physically was very, very  
24 poor.

25 A. Yes.

1 Q. He described didn't know what was going on, he lost  
2 weight there were times when he couldn't eat or drink.  
3 He couldn't or wouldn't go to bed. He would sit in  
4 the chair for prolonged periods?

5 A. He sat in a chair for maybe two years. He started  
6 sitting sort of in a comfy chair living room and then  
7 for some unknown reason he got up and he went in the  
8 kitchen and he sat at the dining table and he sat  
9 there and he was like that (*indicated*). That's all he  
10 done, never moved all day. That was Robert's life for  
11 about two years.

12 It wasn't until we eventually -- I don't know if  
13 you are coming to it but we eventually met [redacted]  
14 but one of the reasons Robert wouldnae take treatment  
15 was (1) they were all dying, right, (2) he didn't  
16 trust the doctors enough, because if you look at the  
17 way things were going, right, they're giving these  
18 people medications but they're dying so what was the  
19 point? It's just trial treatments and Robert's not  
20 one for volunteering, shall we say. If you don't know  
21 what works out and doesn't work.

22 We were also told we would be treated at the  
23 Infirmary for everything and I don't understand that,  
24 that he said -- that Ludlam had said we would be  
25 treated at the infirmary for everything but because it

1 was so late Robert, technically Ludlam's cohort had  
2 died, right, apart from three Ludlam's cohort had died  
3 by the time Robert got seriously ill and Robert was  
4 told he would have to go to the Western Infectious  
5 Diseases Units in the Western and he refused and he  
6 refused, because of the place, he knew what the place  
7 was like and in the end they got [redacted] to see him  
8 at the Infirmary.

9           Anyway, [redacted] says to me that if he doesnae  
10 take his tablets he's got about six weeks. Now,  
11 Robert was sitting right next to me and he can't even  
12 remember going to the hospital, never mind sitting  
13 listening to what a doctor was telling him. So in the  
14 end they were going to send him home so I says to him,  
15 "Why don't you give me the tablets to take home for  
16 Robert and we'll see how we go because I've got more  
17 persuasion than what they have". When we come out he  
18 says to me he's give him about six weeks.

19           That's what he actually says to me but when we  
20 come out, I was speaking to the sister that was behind  
21 the desk and all she says to me was, "We'll have to  
22 start talking about palliative care", no leading into  
23 it. I knew Robert was ill, right. Don't get me wrong  
24 I knew he was ill but maybe I didn't accept how ill he  
25 was. It was our life. It was how we lived. It's how

1 I accepted life, right. I knew he was ill. I knew he  
2 was going to die but the word "palliative" care and  
3 I thought to myself no.

4 We walked out. She never mentioned it ever  
5 again. That was the only time help from the hospital  
6 was given, was offered, if you can call it offered.  
7 "We'll have to talk about palliative care", and we  
8 left the hospital and maybe a week it took me to  
9 persuade Robert to actually go on this treatment.

10 At the time, [redacted] says to me, "If there's  
11 any problems, if you find any concerns, just let me  
12 know and we'll listen to you", and I thought, "Fine",  
13 so we went away. I finally got him to start the  
14 tablets and I wish I hadnae, I really do. I wish  
15 I hadn't. Look what it put us through after it.

16 Q. There is was medication for his HIV?

17 A. Yes.

18 Q. And what was the effect of the treatment regime which  
19 he started with?

20 A. Life was bad. Believe me life was hell after it. He  
21 turned round, in a sense, where he wanted everybody to  
22 hate him, right, when he started this tablet our son  
23 or myself could not move he was that protective of us.  
24 I could not even step out the back garden without him  
25 holding my hand and making sure no-one was going to

1 hurt me. I couldnae walk along the street. If  
2 we walked along the street and somebody looked at me,  
3 just, you know you pass somebody and you maybe look at  
4 them, Robert would have went for them. He really  
5 was -- his whole manner and everything changed.

6 He was when I say aggressive -- he was bad  
7 enough before because he was ill and that but when  
8 I say aggressive Robert was aggressive. He started --  
9 because he was starting to feel a bit better he  
10 started fishing again. His friends by now -- Robert  
11 was lucky. He still had friends, fishing friends,  
12 right, but his friends didn't understand him but they  
13 accepted him for the way he was, and he was up fishing  
14 one day and this man come and parked his car in front  
15 of a farmer's gate. Robert just about went -- well,  
16 I say his friends had to actually keep him back only  
17 because the man parked in the wrong place but he  
18 shouldn't have been there. Robert would have killed  
19 him. I'm not joking when I say he would have killed  
20 him. He had that much anger. I can't even say. It  
21 wasn't even anger.

22 Anyway, he changed just like that. No-one and  
23 I mean no-one could speak to him and I says to  
24 [redacted] about this, "No, no", just ignored me.  
25 They really ignored me. We went through about nine



1 months of this and I'm telling you tell hell wasnae  
2 the word, it really was not the word that you could  
3 describe for the way we lived. Even my son, if his  
4 friends did come in the house they'd go up the stair  
5 and I'd be sitting on edge until they left.

6 I couldn't get them out the house quick enough, which  
7 technically was throwing my son out the house because  
8 the way Robert acted if his friends looked at him the  
9 wrong way.

10 Robert -- I just -- I can't even say it. Anyway  
11 I said to [redacted] lots of times and at this time  
12 when we're going up the infirmary he was marching  
13 about, he couldn't really, he had a really -- people  
14 here that know him will still say he's got this but he  
15 had a really aggressive manner the way he stood, the  
16 way he walked, he never walked, he marched. People  
17 are still scared of him because of his manners and  
18 I says to them at the infirmary and they ignored me  
19 and it wasnae for about eight/ten months there was  
20 a case in Perth where a young girl had done something  
21 anyway and it turns out that it was her AIDS  
22 medication that caused her aggressiveness and it turns  
23 out that this medication, one of the medications  
24 Robert was on, had psychotic side effects.

25 I'm telling you as soon as he stopped taking

1           that tablet he turned just like -- when I say he  
2           turned, he stopped being as bad as he was and it made  
3           life bearable after that but Robert still -- people  
4           are still afraid of Robert. When he walks, he talks,  
5           he is, he's a frightening person. I'm sitting here  
6           trying to not to laugh because I can see people here  
7           that are frightened of Robert, whether they'll admit  
8           it or not, they are afraid of him because of his  
9           manners, the way he goes, and Robert was never like  
10          that.

11                        He was -- yeah, before he was infected he would  
12           stick up for people, right, he was never one to back  
13           away from a fight, if you know what I mean. He was  
14           there. If he thought he was right, he would put his  
15           point but when he started this -- he was bad enough  
16           before this medication because of the anger that was  
17           building on what he had already seen and been through  
18           with his family and his friends. This medication  
19           just -- oh, I can't seen explain it, but he's never  
20           come down from it. He really hasn't. His family talk  
21           to him but there's still not what should be there.

22                        My family, some speak to him and some don't  
23           because he is not an easy person.

24    Q.   Does Robert continue to be on a regime of treatment  
25          for HIV?

1       A. Yeah, what he's got now, the doctor keeps on trying to  
2       update it, right, but we're happy in that what he's  
3       got works, we've got Robert to take it. I know I've  
4       never been to my bed before 12 o'clock at night for  
5       the past 20/30 years, right, but it's worth it because  
6       the medication he's on, touch wood, is working and if  
7       you change it we're always afraid in case it doesnae  
8       work and when it doesnae work he cannae really go back  
9       to what he's had, so we stick with what we've got,  
10      what we know works.

11     Q. What about treatment for hepatitis C? There did come  
12      a point where Robert did take treatment for that.

13     A. He did get offered all this interferon or what not  
14      eventually from the Western, from his AIDS doctors,  
15      but Robert, no, he's seen too many people go through  
16      what they went through and I'll tell you the doctor at  
17      the Western actually stated Robert is not in the right  
18      frame of mind to go through anything like that because  
19      he was bad enough as it is without having to go  
20      through the side effects and we suffered it, kept  
21      going through it, he had all these illnesses and it's  
22      the sweats is really the thing with him.

23                So when Harvoni come on the market we asked and  
24      his AIDS doctor says that he wouldn't be able to get  
25      it because of he wasnae ill enough in the sense of his

1 liver wasnae stage 2 or whatever it was. So we  
2 actually had to go to a haemophilia doctor in Dundee  
3 and he was speaking to Robert and he sent a letter  
4 down to say that he recommended that Robert go on the  
5 Harvoni, which no side effects except a couple of  
6 broken legs.

7 He walked about -- he kept going up the hospital  
8 and saying to them about his legs. He couldn't even  
9 walk, his legs were that bad and, "Oh there's nothing  
10 wrong. It's just arthritis", and all this carry on.  
11 I would phone them and I would say and all this carry  
12 on, and I shout at you, I'm sorry I shout at you, but  
13 the only way I can be heard at this hospital is if  
14 I shout and raise my voice, and I was on the phone to  
15 one of the nurses one day and I lost it on the phone  
16 and it was, "Well come in, and we'll maybe get him an  
17 x-ray".

18 So we went along for the x-rays and they come  
19 back, of course the doctor come, "Robert, Robert,  
20 you've got a broken leg. You have got a fractured  
21 leg", so that was it and we went home and the next  
22 morning, another phone call at 9.00 in the morning,  
23 "You have to come in right away, Robert. Your other  
24 leg's got a fracture in it". After months, and I mean  
25 months, of complaining of this pain and he told them

1           it wasnae bleeding. It wasn't anything to do with the  
2           haemophilia. There was something wrong, so now  
3           they're arguing was it his AIDS tablet or was it the  
4           Harvoni and, again, we're back in the catch 22  
5           situation.

6                     It happened when he was on this medication but  
7           it could have been the combination. It could have  
8           been just his age catching up with him and things like  
9           that. But you do not get these doctors to listen.  
10          They know what they know and that's it. You are not  
11          allowed to educate them and if you are living with  
12          something for so long, you learn to know more about  
13          what your body is like than what these doctors do and  
14          the doctors don't listen. Again, they still don't  
15          listen.

16        Q. In terms of employment and financial consequences,  
17        Robert, as we've heard, had to give up his dream job  
18        as a gillie and you have had to be for many, many  
19        years his full-time carer.

20        A. Yes.

21        Q. You have no pension?

22        A. No.

23        Q. Robert worries greatly about how you will manage when  
24        he dies.

25        A. Yes. The older we get the worse it gets in the sense

1 of a pension because even if Robert -- the Government  
2 keeps changing retirement ages, right, and every time  
3 I just about reach a retirement age they jump it up.

4 So all Robert sees is me working from the time  
5 if he's not here anymore to when I'm able to retire  
6 for a start and nowadays I have no qualifications that  
7 would do anything like that.

8 My health, I'm healthy, I'm fit, don't get me  
9 wrong, but I can't go into work in a shop because  
10 I couldn't cope with it. Certain things like that,  
11 and an employer nowadays would look at my past history  
12 and what history do I have for the past 30 years?  
13 I don't have any work history that is suitable, that  
14 takes a youngster more than they would take somebody  
15 my age that's only got another X amount of years to  
16 work.

17 So if I ever reached pensionable age, Robert  
18 would feel a bit more settled because I would have  
19 a pension, a state pension is what it is -- it's not  
20 much but it's a state pension and then he worries how  
21 am I going to survive on a state pension when he  
22 realises just how much a state pension is and he  
23 starts panicking on that.

24 We're lucky that the payments we received from  
25 the new Scottish scheme paid off our mortgage. That

1 was all we worried about was the mortgage because  
2 I couldn't have kept it up if I wasn't employed or  
3 that, and that's what we done with that money, was  
4 paid off the mortgage so that at least I have a roof  
5 over my head. It doesn't matter what else, I can  
6 starve, I can go round family, my son or that, get  
7 fed, that's no bother but I've got a roof over my head  
8 and that took some of the worry off of Robert.

9 But he does not want me to live in what he would  
10 call poverty and that really affects him. It upsets  
11 him a lot because of what we've went through and he  
12 just keeps saying he's ruined my life. That's all he  
13 keeps saying. I should have -- what he'll say is,  
14 "You should got rid of me years ago and married  
15 somebody rich that will set you up in your life", you  
16 know, that's the thing with him now. He really  
17 worries that I'm no going to survive it.

18 Don't get me wrong, I'm one of the lucky ones.  
19 Robert's still here. Robert is old. Robert is old  
20 compared to a lot of normal people nowadays his age.  
21 I've got -- I've had him all these years but it's not  
22 been a life. It really has not been a life and it's  
23 nothing that anybody could even ever have imagined it  
24 could be.

25 No-one, I wouldnae wish it on my worst enemy and

1 it's all because, to me, it all goes down to a doctor  
2 that thought he -- how will I put it? A doctor that  
3 thought he knew best, to put it mildly, that a doctor  
4 that preferred rather than inform patients of the  
5 potential -- I'll not say risks, I'll say potential  
6 risks, not to inform them of these potential risks  
7 that could have saved us all this hardship, all this  
8 worry, all this stress, this whole life.

9 We could have had a life because we had our  
10 plans worked out, we had it worked out. I know plans  
11 don't always work, well ours definitely didnae, but  
12 you change plans now and again, when you get married  
13 you have your set of things. Ours stopped. 1987 it  
14 just ... disappeared and our life stopped because we  
15 have any had a life for the past 30 years, really have  
16 not.

17 Q. Robert says in his statement that had he been warned  
18 of the risk of AIDS he would not have taken the  
19 Factor VIII products that infected him in 1984 and he  
20 describes it in his statement. His phrase is it was  
21 all completely avoidable.

22 A. It was. It definitely was. Had -- when Ludlam  
23 started his AIDS studies, right, his AIDS studies  
24 linked up a ubiquitous virus. What is a ubiquitous  
25 virus? This ubiquitous virus as I know it could have



1 killed Robert anyway, right. Maybe it wasn't  
2 infectious in the sense of transmitting it to me but  
3 he could have caught something from this so-called  
4 ubiquitous -- why didn't he warn him about this or  
5 other patients who got -- not just Robert, all these  
6 other patients, infected and non-infected, he should  
7 have warned them of this and he never.

8           That would have been the point to us where  
9 Ludlam said to Robert, "Look, we have got this. We  
10 don't know what it is. We don't know how it's going  
11 to affect you. Do you want to -- it's through the  
12 Factor VIII, do you want to keep taking this? You  
13 can't get cryo. We don't make cryo anymore", is what  
14 Robert was told, "but you can't get cryo even if we  
15 made it again. Do you want to go back to the old way  
16 of life", and Robert would have said yes because  
17 Robert's life was good enough for him. He was happy  
18 with it because he had a life.

19           When he was infected he didn't have a life after  
20 that and that's the difference. Without Factor VIII  
21 he could have survived and they come up with heat  
22 treatment a year later. Robert would have survived  
23 even right up to now, he would have altered his life  
24 completely and I mean altered it. Even if it meant he  
25 just sat in a chair and done nothing, Robert would

1           have -- and I would have been quite happy with that,  
2           but we didn't get the choice.

3                       It could have been avoided.

4       Q.   In 2003, you and Robert met with Dr Ludlam and you  
5           asked him about the AIDS study.  What was his response  
6           as you recall it?

7       A.   He stood up.  That's what he done, he stood up, went  
8           behind his chair, he pushed his chair in, thought for  
9           a minute and says to us, "That's all in the past" and  
10          walked away.

11      Q.   Was it all in the past for you?

12      A.   No.  That's what I -- when we were going home that's  
13          what I says to Robert, "But it's not in the past.  
14          We're living with it.  We are living with it.  We  
15          don't have any choice".  But the man got up, pushed it  
16          slowly.  He didn't even do it fast, slowly push it in,  
17          "it's all in the ..." -- and just disappeared.

18                    I mean, I don't swear.  I'm telling you the  
19          amount of times in my past that I've really, really  
20          would like to stand up and screaming the words that  
21          that man deserves because he doesnae deserve civil  
22          conversation with anybody because he doesnae have it.  
23          He doesn't -- Dr Ludlam whether he is afraid or  
24          whether he doesn't like females, I don't know.  I was  
25          going to this hospital from April/May 1982.  I can put

1           it down because it's when my son was born, right.  
2           I wasn't working and I went with Robert to the  
3           hospital and that man never acknowledged me. I could  
4           sit in that room in a corner and he didn't even know  
5           I was there. And I used to sit and listen to  
6           everything. That's why I know everything that's going  
7           on. I used to sit and listen and I would leave the  
8           room and he still wouldn't even acknowledge that I was  
9           there.

10                    It got to a point there was his GMC and  
11           whatnot -- I don't know if I can mention that -- but  
12           anyway it got to the point of that, and I'd had enough  
13           one day and I says to him, "Look, why do you never  
14           acknowledge me? Why do you never call me by my name?  
15           Even if it's Mrs Mackie, I wouldnae mind" and he gave  
16           a smile and the next time I saw him it was, "Hello  
17           Alice" and that's the only time he's ever called me my  
18           name.

19                    The man -- as I say, whether he's afraid of  
20           females, because there is some people that don't like  
21           talking to females about certain things, or whether he  
22           doesn't like them or whether it's just his attitude  
23           because his attitude to me is nae good. If it's the  
24           same with other people, I feel sorry for them.  
25           Just -- I don't know. He's not a people person, I'll

1 put it that way.

2 Q. You mentioned the GMC and, again, just so there's no  
3 mystery about it -- I am not going to ask you any  
4 details, it's referred to in your witness statement --  
5 but you made a complaint to the GMC about Dr Ludlam.  
6 You and Robert also made a complaint to the police.

7 A. Yes.

8 Q. Again, you have given some details about that in your  
9 witness statement.

10 A. When we made the second complaint to the GMC, that's  
11 when Robert ended up without a doctor, a treating  
12 doctor, for quite a while.

13 Q. We've made a number of references to your obtaining  
14 Robert's medical records. Do you believe that you  
15 have seen all of Robert's medical records?

16 A. No. I know we've not because -- well, I know for a  
17 fact his 1980s records aren't full because when he was  
18 telling Robert, he was sitting writing in his medical  
19 records when he was informing Robert of his infection.  
20 I know that for definite.

21 But I also know that according to that letter  
22 that he kept separate two blood test results and  
23 I also know that he kept a separate file on Robert.  
24 What's in it, I don't know because I can't discuss the  
25 police thing, right; so what's in it I don't know.

1           And ...

2                       Where was I?

3       Q.   I was asking you about what you think might be missing  
4           from Robert's medical records.

5       A.   Yes.  I don't understand how someone can do research,  
6           and I'm talking about research for 20-odd years, and  
7           not have records.  His blood test results, all the  
8           things that they mention in these research papers.  
9           Where's all this information?  Where's it coming from?  
10          So it must be out of Robert's medical records and  
11          somewhere else for him to be able to research, if you  
12          understand what I'm saying.  You can't research on  
13          something that there's no information on, if that's  
14          clear enough, is it?  You understand what I'm saying?

15       Q.   Yes.  In terms of the meeting you had in 1987 with  
16           Dr Ludlam where you were given the information about  
17           Robert's diagnosis, do you have or have you seen any  
18           records of what it was Dr Ludlam was writing?  You  
19           described him writing during that consultation.

20       A.   It's not in Robert's records, no.  We've never seen  
21           it.  We've had maybe three sets of medical records and  
22           it's not in any of them.

23       Q.   Now, I referred at the beginning of asking you  
24           questions to the research you've undertaken and I'm  
25           not going to ask you about the detail of that for

1 reasons I know you understand we will be looking at at  
2 a later stage of the Inquiry, but you've identified  
3 a number of pieces of correspondence and publications  
4 about the Edinburgh cohort and the studies undertaken  
5 on what's described as the "Edinburgh cohort".

6 A. Yes.

7 Q. You've worked out Robert's part, you believe, as  
8 a member of the Edinburgh cohort.

9 A. Yes.

10 Q. Amongst other matters, you've identified applications  
11 for an ethics approval in relation to a study --

12 A. Yes.

13 Q. -- which talks about obtaining informed consent from  
14 patients for their participation in that study, and  
15 talks about patients being given information about the  
16 study.

17 A. Yes.

18 Q. As far as you understand from yours and Robert's many  
19 dealings over the years with the hospital and with the  
20 doctors, was Robert ever asked for his consent to  
21 participate in any AIDS study?

22 A. No, and what we can't understand is the ethics one  
23 that we've seen, right, how can Robert have agreed to  
24 this if he didn't know he was infected? I don't  
25 understand how he can agree to research being carried

1 out on him for having AIDS if he didn't know he had  
2 it.

3 Q. Robert has in his statement sought to emphasise that  
4 not only was he not asked for his consent to  
5 participate in any study, he was not asked for his  
6 consent to be tested.

7 A. No.

8 Q. Other than the routine haemophilia tests which he  
9 understood would be undertaken, he was not informed of  
10 the outcome of any tests except to the extent that you  
11 and he have described in your statements. He did not  
12 consent to stored samples being given to any other  
13 person in relation to research.

14 A. Stored samples -- can I ask here what exactly happens  
15 to these stored samples? They seem to take blood  
16 continuously and we're talking -- I've got in Robert's  
17 medical records 20/30 mls for storage. What have they  
18 done with all this blood? Where has it gone?

19 As far as I -- I know one thing, not  
20 specifically Robert's, but I do know that students are  
21 doing their thesis on the Edinburgh haemophilia cohort  
22 and stored blood samples from this group of people are  
23 being used and students doing their thesis. Is this  
24 what the stored serum's for? Or is it for medical  
25 purposes like it's supposed to be?

1 Q. One of the things that has most upset Robert is what  
2 you and he have described as the culture of secrecy.

3 A. Yes.

4 Q. That's something that's had the most profound effect  
5 upon him.

6 A. Yes. Have you tried living in secret? Have you tried  
7 living without being able to tell someone why you're  
8 ill? Have you tried living constantly lying to  
9 someone? Have you tried -- I'm not talking about  
10 strangers, I'm talking about family, constantly lying  
11 to them. You can't do it. The secrets that you have,  
12 you talk and somebody walks in the room and we have to  
13 stop and they give you -- I'm talking about family  
14 members. They give you these looks as if to say  
15 you're talking about them and it sort of stirs up  
16 troubles. It's not. We're talking about what was  
17 wrong with Robert. You cannae live with secrecy, you  
18 really can't, and the Government, and I blame the  
19 Government as well, and Ludlam especially, by telling  
20 us not to tell anyone. This just emphasised or put  
21 the stigma for haemophiliacs that we were dirty.  
22 That's what is coming out, is because AIDS -- people  
23 were going on about drug addicts and that but, I'm  
24 telling you, haemophiliacs got put into their class  
25 and people used to treat you -- they still do if it's



1 AIDS that you've got -- as dirty, they really do.

2 I go to the Western with Robert and I have  
3 never, ever been in anything like that before. We  
4 turned up when we first started going and we were  
5 sitting in the -- I mean, when we go to the Western we  
6 get ourselves really uptight. It's just automatic.  
7 But when we first started going, we didn't like to go  
8 but we had to go, and everybody was there, as  
9 somebody's already mentioned about prison officers and  
10 all this.

11 Rather than sit beside this crowd, I went  
12 outside one day, Robert went to the toilet. He says,  
13 "I'll see you outside" and I went outside and this man  
14 come up to me and put a knife to my throat, right.  
15 Now, I was lucky that Robert wasnae far behind me but  
16 the man was lucky that he didnae see what Robert was  
17 doing. Of course, when I went in and I says to  
18 [redacted] and [redacted] put it down to that I didn't  
19 like his clientele. Youse have all to be treated the  
20 same, everybody's got an illness, blah, blah. Fair  
21 enough. I know everybody deserves treatment but  
22 I don't deserve what I got, and then you sit in the  
23 waiting room and we were sitting not just the males,  
24 the females, the things that they come out with. The  
25 language, the -- oh, just everything they said and

1           what they done and what they were doing, it was -- it  
2           is scary. Not "was", it is.

3                   And yet we can go in -- we would go in and  
4           there'd be people sitting and I have to say here it  
5           was the homosexual side, right, community and they  
6           would sit down and talk and that is where we  
7           learned -- believe it or not, that's where we learned  
8           a lot of things in how the treatments reacted and all  
9           this and they were really, really, friendly.

10                   But what happened was because I complained, they  
11           eventually put up a security camera in the waiting  
12           room and our day got changed to another day in the  
13           week. It doesnae make it any easier. We still turn  
14           up but there isn't really any other patients there now  
15           but it doesn't make it any easier to go there and it's  
16           the word, as the person before said, Infectious  
17           Diseases Unit. Everybody looks at you going in and I  
18           think, "What can we do? It's not our fault but what  
19           can we do?"

20       Q. Alice, before I ask you if you've got anything you  
21           want to add, I just want to read one bit from Robert's  
22           statement because he says this in his statement:

23                   "I want the following to be recognised as it's  
24           very important to me. The worst and saddest thing  
25           that this disaster has brought to me is that my wife

1 has given up so much and made the ultimate sacrifices  
2 in her life. She has given up her right to have  
3 children and her career. She has perhaps not suffered  
4 physically but has definitely suffered mentally, not  
5 only by having to watch her haemophiliac family and  
6 friends die a most horrific death but now she has to  
7 watch me suffer the same fate. Even after my wife has  
8 made all these sacrifices, she is still with me after  
9 all these years. This most of all to me is the  
10 ultimate sacrifice."

11 And that's one thing Robert wanted expressly to  
12 have recognised in these written statement about you.

13 Alice, I don't have any further questions for  
14 you. What, if anything, would you like to add?

15 A. I've just got a wee bit to say.

16 We were told, and continued to be told, that  
17 Scottish Factor VIII was safer than English and  
18 commercial products. Whether it was safer than other  
19 products is, however, not the point. The question is  
20 whether it was safe, and it was not.

21 Robert, his family and friends, which are 16 in  
22 total, were infected with HIV by the same batch of  
23 Factor VIII concentrate which was given to them in  
24 early 1984. Only three of them are still alive.  
25 Blood was collected to make it by the Scottish

1 National Blood Transfusion Service. It was  
2 manufactured by the Protein Fractionation Centre in  
3 Edinburgh and it was injected into them in Edinburgh,  
4 and it was not safe like they told us.

5 We were led to believe that Scottish blood  
6 donors did not carry harmful viruses. However, the  
7 only difference between Scotland and commercial  
8 manufacturers was that here in Scotland we did not pay  
9 for the blood which was collected. In Scotland, blood  
10 was collected from high risk donors, prisoners,  
11 borstals and from American forces personnel. By 1983,  
12 we lived in what was a global village. By that time,  
13 Edinburgh was populated by a well-established  
14 community of IV drug users and became one of the AIDS  
15 capitals in the world. The products made from blood  
16 which these people donated were not safe and, in  
17 addition to that, the products made here in Scotland  
18 were known to be 100 per cent infective for another  
19 deadly disease, which was hepatitis, and that was  
20 before the AIDS came along.

21 In conducting your investigation, please  
22 remember that this Inquiry is not just about products  
23 imported from abroad. It's also about products made  
24 here in Scotland. It is about whether they were safe.  
25 They were not. Their own risks were kept secret.

1           Further, you must identify those who are  
2           responsible for giving Robert, his family and  
3           haemophiliac friends these products. I've no doubt  
4           who was responsible. Robert, his family and his  
5           haemophiliac friends put their faith in their doctor,  
6           Dr Ludlam. He told them the products were safe. He  
7           told them that while conducting non-consensual AIDS  
8           research on them. Those patients are now recognised  
9           throughout the world as the Edinburgh Haemophilia  
10          Cohort. Dr Ludlam carried out research on this group  
11          before their infection, at time of their infection,  
12          and after their infection. His research was kept  
13          secret from them and he made sure they only received  
14          Scottish products. The question here is: why?

15                 They trusted Dr Ludlam to put them first.  
16          Instead, Dr Ludlam sat back and continued to give them  
17          what he knew to be harmful products. Personally  
18          I think he put his research before his patients  
19          welfare in any way, and even when Dr Ludlam knew of  
20          his patients being infected it took him over two years  
21          to inform us of Robert's infection.

22                 His infection was what was known to be  
23          a sexually transmitted and fatal disease was kept  
24          secret. Having not only put Robert at risk for many  
25          years he put me at risk and he put our son at risk.

1 I find this absolutely unacceptable, unethical and  
2 indeed criminal.

3 This Inquiry is about secrets and lies. It's  
4 about secret risks. It's about the secret research.  
5 It's about secret infections. It's about making sure  
6 that these things are never kept secret again. I wish  
7 to thank you, Sir Brian, your Inquiry team, Jamie and  
8 Lynn, for giving me the opportunity to speak here  
9 today and I, and I know many others, hope that by the  
10 end of this Inquiry the secrets will be exposed along  
11 with those responsible for keeping them.

12 Thank you.

13 Q. Alice, I am just going to ask Mr O'Neill and Mr Dawson  
14 if there's anything further they would like me to ask.

15 *(Pause)*

16 Alice, there's just a small number of matters  
17 that I'm asked to raise with you.

18 The first is in relation to your understanding  
19 of Dr Ludlam's background and primary interests when  
20 he was engaged to take over as a director of the  
21 Haemophilia Centre in Edinburgh.

22 A. Well, Robert was friendly with doctors going up the  
23 hospitals and that, doctors and patients were quite  
24 close, and when Dr Davis was leaving and the job was  
25 advertised and Dr Ludlam got the position, Robert was

1 actually warned by several of his doctors to keep an  
2 eye out, to watch Dr Ludlam because he was employed as  
3 a scientist and not as a treating doctor, and Robert  
4 wishes now that he'd listened to what they were saying  
5 and how they were saying it.

6 They were, in a sense, warning him to be careful  
7 of what this doctor was doing and he never really paid  
8 the attention that he should have, because had he paid  
9 the attention he would have kept more eye on him and  
10 he would have -- he couldnae ask any more questions  
11 but he would maybe have been more alert to certain  
12 things that were happening.

13 Q. The second point was in relation to cryoprecipitate  
14 treatment. You described how Robert would have  
15 preferred to remain on cryo when he needed treatment  
16 but was told by Dr Ludlam that it would no longer be  
17 produced.

18 Did you as a result of the investigations and  
19 research you have undertaken uncover anything about  
20 the possibility of continued production of  
21 cryoprecipitate?

22 A. Well, at that time they were still making cryo.  
23 Robert could have still had cryo but, according to  
24 Ludlam, they were stop making it. He couldn't have  
25 cryo. Robert actually asked for cryo. He told them

1 he preferred cryo. I don't know if it was Dr Davis  
2 kept him on cryo and it was something he was used to,  
3 and Robert also thought cryo worked better on him than  
4 what Factor VIII did. And he was insistent quite  
5 a few times that he would have preferred cryo, but he  
6 didn't have a choice. He was told literally, "This is  
7 what you're getting, take it".

8 Q. You have referred to the genetic testing that was  
9 suggested that you should participate in. Without,  
10 please, mentioning either any names or precise  
11 relatives, is it right that other members of Robert's  
12 family were also asked to give blood and participate  
13 in that at the time?

14 A. Yes.

15 Q. Then in terms of the specific family impact, you have  
16 referred to some of Robert's wider family. Again,  
17 without mentioning either any names or anything  
18 particularly specific in relation to anyone who might  
19 still be alive, please, but two of Robert's uncles  
20 died?

21 A. Yes.

22 Q. You described in your I think it may be in one of your  
23 statements one uncle being in the unit next to his  
24 brother and lying there with his brother dead beside  
25 him.



1 A. Yes.

2 Q. Then there was also a cousin who died.

3 A. Yes.

4 Q. Again, as a result of infection through infected blood  
5 products.

6 A. Yes, and they all received the same batch.

7 Q. Then finally, as well as the blood tests and the blood  
8 samples that were being taken that you've described,  
9 is it right also that there were skin tests that were  
10 being undertaken by one of the doctors, Dr Tucker?

11 A. Yes.

12 Q. What can you recall about that?

13 A. Dr Tucker says to Robert -- this was '83/'84, you know  
14 that time period, and Dr Tucker was doing it with  
15 quite a few patients but he says to Robert for a skin  
16 test for sort of just virus infections -- not viruses,  
17 but infections. You know your BCG thing, you know how  
18 they stamp you with these wee needles on your arm  
19 first and see if anything comes up, and it was to see  
20 if Robert had any allergic reactions to whatever  
21 I don't know but it was whatever was in the  
22 Factor VIII according to them. Robert done it, fair  
23 enough.

24 But what we did discover was that this was  
25 actually part of Ludlam's AIDS study. Now, again,

1 I go back to Robert asked Dr Tucker about AIDS, not  
2 AIDS but this disease, and he denied anything of it.  
3 Then he's giving him this and this is part of the AIDS  
4 study. Why couldn't he just say? What was wrong with  
5 opening up his mouth and saying, "Oh, Dr Ludlam's  
6 doing some research on this new virus. It's called  
7 such and such. Is it okay if we try it out?" But  
8 they didnae. Again, they actually lied to his face.  
9 It wasn't even in secret. They lied to his face that  
10 they were doing these things, but not telling them the  
11 truth why.

12 Q. Your understanding that the skin tests were as a  
13 matter of fact part of the AIDS study is based upon  
14 the material that you've subsequently obtained through  
15 your various research?

16 A. Because an ethics request that was put forward  
17 actually mentions the continuation of a previous,  
18 which was the skin test.

19 Q. That's the ethics approval application that you've  
20 referred to in your statement in 1985?

21 A. No, that will be a -- there's two ethics requests: one  
22 for the AIDS side of it and one for the skin test, but  
23 Dr Ludlam says on his request form that he's already  
24 had acceptance for the first part and this is the  
25 second part.

1 MS RICHARDS: Thank you for that clarification. Thank  
2 you.

3 SIR BRIAN LANGSTAFF: Alice, thank you very much indeed  
4 for your evidence. Thank you.

5 We will take a break for lunch until just after  
6 2.30. 2.35.

7 **(1.28 pm)**

8 **(Luncheon Adjournment)**

9 **(2.38 pm)**

10 SIR BRIAN LANGSTAFF: Our next witness is anonymous.

11 Those of you who were here the first day we sat this  
12 week will know what that means and will know that I'm  
13 about to read out an order which is made restricting  
14 the extent to which you can identify her after she has  
15 given evidence or, for that matter, during her giving  
16 evidence.

17 It reads like this: it is ordered that the name  
18 and address of witness W2315 (that's Ms S to you and  
19 me) and any other identifying information such as the  
20 witness's image or a description of their appearance  
21 cannot be disclosed or published in any form unless  
22 express permission is given by me or by the solicitor  
23 to the Inquiry acting on my behalf.

24 Witness W2315 must be referred to only as Ms S.  
25 This order remains in force for the duration of the

1 Inquiry and at all times thereafter unless otherwise  
2 ordered and I may vary or revoke the order by making  
3 a further order during the course of the Inquiry. It  
4 goes without saying, of course, that you will take  
5 care in taking photographs around the place so that  
6 you don't inadvertently capture her.

7 Could we have Ms S please.

8 **MS S, affirmed**

9 **Questioned by MS FRASER BUTLIN**

10 Q. Ms S, you have von Willebrand's disease?

11 A. Yes.

12 Q. So did your mother and so do other family members?

13 A. Yes.

14 Q. You also worked as a technician in the Royal Edinburgh  
15 Infirmary haematology lab for a period of time?

16 A. Yes.

17 Q. First of all, can you tell us what your experience is  
18 of the difference in terms of the type of bleeding  
19 between haemophilia and von Willebrand's disease?

20 A. A couple of things. With haemophilia, it's my  
21 understanding from working there that in haemophilia  
22 if somebody in the family has severe haemophilia then  
23 any that inherit it will again have severe  
24 haemophilia.

25 In von Willebrand's disease one member can be

1 more affected, they can have more severe  
2 von Willebrand's and another family member further  
3 down the chain, a child, might have it a bit milder.

4 Also, in haemophilia they have more joint bleeds  
5 and in von Willebrand's it's mucus membranes tend to  
6 bleed: so nose bleeds, gum bleeds, bruises, heavy  
7 periods and, in my case and my mother's case, as we  
8 got into our 50s, gastrointestinal or GI bleeds.

9 Q. We are going to start by discussing your mother?

10 A. Mm-hm.

11 Q. And over the course of her life, did she require much  
12 treatment for her von Willebrand's?

13 A. Not too much given her length of age but she did go  
14 through a particular time in the early '80s one where  
15 she'd fallen downstairs in her house and had hurt her  
16 ankle and she had cryoprecipitate for that and then in  
17 '82 when she had banged her thigh and that proved  
18 particularly troublesome and she was in and out of  
19 hospital for quite a period of time and had a lot of  
20 cryoprecipitate, bed rest, would come out, have to go  
21 back in hospital because it had reoccurred and then in  
22 order to get her home in the February of I think it  
23 was '82, she was -- it was '82 or '83, I can't --

24 Q. '83.

25 A. '83, she was sent home with some Factor VIII so it

1           would get her out of the hospital and needing to be  
2           just lying in a bed all day.

3       Q.   You're clear that that was Factor VIII rather than  
4           cryoprecipitate?

5       A.   Yes.   The reason it was Factor VIII instead of  
6           cryoprecipitate is at that point I was still working  
7           in Edinburgh Royal Infirmary and part of my job was to  
8           go and take bloods off people, get their results ready  
9           before they saw the doctor, if they had leukaemia,  
10          anaemia, et cetera.  Because I was used to taking  
11          blood, they said that if we could take -- couldn't  
12          take the cryoprecipitate home but if they put my Mum  
13          on to Factor VIII could send her home and I could --  
14          I wasn't staying at home but I could go, have my tea  
15          at home and then give her the Factor VIII that she  
16          needed on that day.

17                    This only happened two or three times from my  
18                    memory because her veins had been used quite a lot and  
19                    I wasn't used -- I am now because I take prophylaxis  
20                    myself, but I could take blood out but to find  
21                    her veins it was difficult, so then she had to go back  
22                    and get it done at the hospital as an out-patient.

23       Q.   We can see in your Mum's records that by  
24           21 February 1983 it's recorded that she had had  
25           multiple Factor VIII infusions?

1 A. Yes.

2 Q. When your Mum was changing from cryoprecipitate to  
3 Factor VIII, are you aware of whether she was warned  
4 of any risks of doing so?

5 A. I'm not aware and neither was I warned of any risks  
6 when I was asked, "If we give you this product to take  
7 home to give to your Mum, are you willing to do that?  
8 It will get her out of hospital. It will much easier  
9 for everybody", my Dad, everybody involved, and  
10 nothing was said to me about any risks, and I was the  
11 one infusing the product.

12 Q. During that time-frame were you receiving any  
13 treatment?

14 A. No.

15 Q. You and your Mum attended a meeting at the Edinburgh  
16 Royal in about 1984. Can you tell us what that  
17 meeting was and what happened at it?

18 A. I don't remember too much detail about it. I do  
19 remember it being in -- by that time I had left  
20 Edinburgh. I was working in Falkirk but I'd come back  
21 for this meeting and there was a big group of people  
22 from the bleeding community, as I'll call them, and it  
23 was in the ground floor of the old Royal Infirmary in  
24 a lecture theatre and it was about some people might  
25 have been infected but I don't have a huge

1 recollection.

2 But I do remember, I think my Dad was there as  
3 well, and I do remember going away not being overtly  
4 worried about anything we'd been told. So I think if  
5 I was told anything too much in detail I'd have  
6 been -- remember, in those days there weren't  
7 computers, there wasn't, you know, mobile phones and  
8 things but I don't remember leaving that meeting  
9 thinking, oh, this will really be affecting my Mum or  
10 me or ... so I don't have too much -- I do remember  
11 the meeting but the detail of it ...

12 Q. And the infection that was being discussed was  
13 HTLV-III?

14 A. Yes.

15 Q. Shortly after that meeting your Mum was told she  
16 tested negative for HTLV-III.

17 A. Mm-hm.

18 Q. And then Dr Ludlam sent your mother's GP a letter. If  
19 we can have 2315005, please, Paul, and if we look at  
20 the second paragraph we can see reference there to  
21 a letter that had been sent about AIDS and  
22 haemophilia/VWD.

23 This morning we looked at a copy of what we  
24 think is the letter that's being referred to there  
25 which was dealt with by the previous witness.



1 A. Yes.

2 Q. Then it says:

3 "I really think the chances of her having  
4 received the virus are infinitesimally small,  
5 particularly as she is anti-HTLB3 V3 negative. I,  
6 therefore, do not think it appropriate for her husband  
7 to wear a contraceptive sheath. We are much more  
8 concerned about the possibility of virus in sperm on  
9 a haemophiliac male being transmitted to his sexual  
10 partner. I have reassured Mrs X on these accounts."

11 Before you saw your Mum's medical records, were  
12 you aware of any letter like this?

13 A. No.

14 Q. In her records, your Mum's liver function tests were  
15 abnormal over a number of years and you have  
16 identified those records. You've also noted that from  
17 1987 her blood requests had risk of infection on them.

18 Do you think your Mum was aware of that in 1987?

19 A. No. She wouldn't have seen -- when you go you were  
20 just told your results. You don't get shown, "Here's  
21 your results".

22 Q. Was she aware that her liver function tests were  
23 abnormal --

24 A. I don't.

25 Q. -- as far as you're aware?

1 A. As far as I'm aware, no.

2 Q. Is that the kind of thing your Mum might have said to  
3 you if there was a concern?

4 A. I don't know because, you know, there's that bit of  
5 protection and not saying but she might have queried  
6 it, knowing that I was a scientist and worked in the  
7 lab, she might have asked what does this mean and she  
8 never had that conversation with me.

9 Q. In September 1992 your Mum attended the hospital and  
10 said she was more tired than usual but put that down  
11 to her age.

12 A. Mmm.

13 Q. Her bloods were taken and if we can have 007, please,  
14 Paul, date reported is 1 October 1992 and we can see  
15 that she tested positive for hepatitis C.

16 Then if we can have document 2315012, this is  
17 a letter from August 1993 from a consultant physician  
18 to your Mum's GP. They had been treating her for  
19 resolving pneumonia, and if we look at the second  
20 paragraph there, it's noted that her gamma GT and ALT  
21 were both raised.

22 "I checked her liver function tests again today  
23 but wonder if there is any record from the haematology  
24 department of abnormality in her liver function."

25 At that stage in August 1993 was your Mum aware

1           that she was hepatitis C positive?

2       A. No, she wasn't told until the September.

3       Q. It seems from here that other treating physicians were  
4           also unaware in August 1993?

5       A. Yes.

6       Q. Then if we have 009, we have a letter dated  
7           September 1993 from a clinical assistant to  
8           Professor Ludlam to your Mum's GP and it says at the  
9           bottom:

10                 "This patient, as with a number of others, has  
11           been found to be hepatitis C antibody positive and  
12           this must relate to her having received blood products  
13           in the past, when hepatitis C could not be identified.  
14           I have discussed this with [your Mum] and said that we  
15           are currently running a joint clinic with one of the  
16           GI and liver consultants ..."

17                 As far as you're aware, 15 September, around  
18           about that time, was that the first time your Mum was  
19           told about hepatitis C?

20       A. Yes. Well, she's not told me but since looking  
21           through her notes and I've spent many an hour looking  
22           through her notes a couple of times and this is the  
23           first thing I could find about her.

24                 Can I just go back to her being tested and found  
25           hepatitis C positive in the September of '92, that the

1 letter in September she went and saw the doctor and  
2 said that she was feeling lethargic and unwell on the  
3 very day that the sample was sent for hepatitis C  
4 testing and it was put down that her increasing  
5 lethargy -- the letter from that doctor to her GP  
6 about increasing lethargy and tiredness she put down  
7 to her old age. She was 65, the same age just about  
8 as I am. I take great offence to that because on the  
9 same day as they have taken a sample or sent a sample  
10 to virology to be tested, and two days after this  
11 letter has gone to the GP to find she's positive,  
12 never mentioned to my mother or to the GP that, in  
13 fact, this lethargy and tiredness could be to do with  
14 having hepatitis C affecting her liver but let her  
15 think, and for a full year after, that it was her "old  
16 age", being that "old age" myself I take great offence  
17 at that.

18 Q. In your Mum's records, and it seems to be connected to  
19 the September 1993 diagnosis, it's a little bit  
20 difficult to tell, but there's an information sheet  
21 enclosed. It's 2315014.

22 We can see at the top that it sets out that:

23 "The sheet is to give you more information  
24 regarding the hepatitis C virus. Your blood tests  
25 show that you have the hepatitis C virus. This may

1           cause inflammation of your liver, known as hepatitis.  
2           In some individuals the inflammation in the liver may  
3           become chronic giving rise to more long-term damage to  
4           the liver which can in some cases be severe."

5                     There is then discussion of a possible treatment  
6           of interferon.

7                     If we go to the next page, we can see the  
8           heading "Sexual transmission and pregnancy", and the  
9           information sheet provides that:

10                    "Studies have shown that there is a very low  
11           risk of sexual transmission of hepatitis C. This can  
12           be discussed with you at the clinic. We will be  
13           offering testing to all sexual partners of patients  
14           who have hepatitis C infection."

15                    Then if we go down to the section headed:  
16           "Alcohol. You will know that alcohol can damage your  
17           liver. As you may have inflammation of your liver due  
18           to the hepatitis C virus it may be prudent to limit  
19           your alcohol intake to a moderate level", and they  
20           recommend no more than 21 units of alcohol per week  
21           for a man, 14 units per week for a woman and it says:

22                    "The lower your alcohol intake the better."

23                    Are you aware of whether your Mum received this  
24           information sheet?

25           A. Yes, that was the --

1 Q. It was in the records but at the time were you aware  
2 of her receiving anything?

3 A. No, she wouldn't, again she ...

4 Q. But does this chime with the advice that you think  
5 your Mum and your Dad were given about the  
6 hepatitis C, of what was discussed at home?

7 A. Yes, because one thing I do remember, my Mum was never  
8 a bigger drinker, but then interestingly in her older  
9 age she went totally teetotal.

10 Q. So this marries up with your experience of what your  
11 Mum seemed to be doing in response to her diagnosis?

12 A. Yes.

13 Q. Just before we leave this document, if we can look at  
14 the second page again, something we'll come back to,  
15 the second paragraph discussing the interferon  
16 treatment. It says in relation to side effects:

17 "At the beginning of a course of treatment  
18 injections maybe followed by a fever for a few hours.  
19 This is less troublesome if the injections are given  
20 in the evening along with two paracetamol tablets.  
21 With interferon persistent side effects are uncommon.  
22 Occasionally, there may be tiredness, depression and  
23 a fall in the blood count. These side effects are  
24 reversible if the dose of the drug is reduced."

25 That's what was in the information sheet then.

1           We will come back to your Mum's experience shortly.

2           SIR BRIAN LANGSTAFF: Do we know who drafted the  
3           information sheet?

4           MS FRASER BUTLIN: Unfortunately, it's not very clear  
5           where it's come from but it appears to have been  
6           drafted within Edinburgh Royal because of the letters  
7           it's with, but I'm afraid that's somewhat inferential  
8           of who's drafted it.

9           SIR BRIAN LANGSTAFF: Thank you.

10          MS FRASER BUTLIN: After her diagnosis with hepatitis C,  
11          you and your Mum had a conversation about having  
12          treatment in preparation for any procedures she was  
13          undergoing. Can you tell us about that.

14          A. Yes. My Mum was always the doctor's right, you do  
15          whatever the doctor tells you, he is God, basically,  
16          whatever he tells you, you know, we'd never question,  
17          and I remember her saying, you know, "Oh, I'm going to  
18          the dentist, I'm going to hospital, I need something  
19          to do with my teeth scaled and polished but I need to  
20          go and I need to get", she actually said to me,  
21          "Factor VIII before it", and I said, "Why, when you're  
22          just getting, you know, scaled and polished? I go to  
23          the normal dentist get scaled and polished no  
24          problem". She said, "Because they told me I had to  
25          have it". I said, "No, it's your choice. You could

1 have it on stand-by and then if you bled you can have  
2 it but you don't have to have it before it, if you  
3 don't want to", and she went, "But they told me", and  
4 I went, "It's your choice. It's your body. It's  
5 your ..." she went, "Can I?" I remember her phoning  
6 me after that going, "I didn't take it, I didn't take  
7 it, I didn't need it", and being so excited that she  
8 had been the one to decide, you know.

9 Q. After your Mum was diagnosed with hepatitis C what was  
10 her health like?

11 A. Well, she was -- my Mum and Dad had planned to travel  
12 quite a bit, to go on different holidays, to bowl and  
13 she was just no energy, lethargic and, I'll be honest,  
14 my Mum could be a bit nippy and, you know, my husband  
15 would pick up, you know, "Your Mum's not right", and  
16 I go, "What?" He said, "Because I can tell by her  
17 behaviour", and I was putting it down to normal  
18 behaviour but now, you know, it's when, sorry, I  
19 preempted but it's when she was having interferon  
20 treatment it was just like couldn't live with her and  
21 I just put that down to normal. But my husband picked  
22 up when she was feeling -- either going through that  
23 treatment or feeling particularly bad, queasy, she  
24 couldn't eat a lot of things, eggs in particular. She  
25 just couldn't eat, no energy, just not -- not feeling



1 well.

2 Q. You've said in your statement you thought that your  
3 Mum was an old 65.

4 A. Yes. Well, I suppose given now people are, you know,  
5 50 is the new 40 or whatever but, yes, she didn't have  
6 that. You'd think that because she would retire at 60  
7 and you think, well, the family have grown up, this is  
8 the time to go out and enjoy yourself and, you know,  
9 go and do different things and they just, my Dad and  
10 her just couldn't do anything.

11 My Dad will say there was one particular, went  
12 to Spain to enjoy a holiday, got one day out of it and  
13 then could only go out for a meal at night and it  
14 ruined and they've never been on holiday again since  
15 because what was the point, just you know wanting the  
16 comforts of home, didn't want -- couldn't go anywhere.

17 Q. You have said that your Mum tried some interferon  
18 treatment. That was in about 1995. What happened  
19 with that?

20 A. Just felt absolutely awful, was flu-y, shaking,  
21 shivery, just sick, just everything to the point that  
22 she just said, "I've tried it", and totally point  
23 blank refused from that point on to put herself  
24 through that.

25 Q. Could we have document 2315013, please, Paul.

1           It's a letter from August 1995 which notes that  
2 she'd had quite a bad reaction, particularly with  
3 headaches, to her recent trial of interferon therapy  
4 for HCV:

5           "I would be quite keen for her to try the  
6 interferon therapy again because she has type 3A which  
7 is particularly responsive to interferon. She was,  
8 however adamant today that she did not want it at  
9 present."

10           If we look at the last paragraph she had been  
11 warned of the long-term risks of liver disease,  
12 particularly cirrhosis and hepatocellular carcinoma  
13 but she wasn't prepared to try interferon again.

14   A. It shows how bad it was that she would rather go  
15 forward and maybe -- and she did get cirrhosis, get  
16 carcinoma, than put yourself through that treatment.

17   Q. Ultimately, your Mum's liver did become cirrhotic but  
18 she continued to decline any treatments?

19   A. Yes.

20   Q. Did your Mum talk much about the hepatitis C?

21   A. No.

22   Q. Why do you think that was? Why not?

23   A. A couple of things. One is she wanted to protect her  
24 family but also my Mum and Dad are very private people  
25 and they didn't want, you know, people to know their

1 business and even though my Mum's been dead for  
2 a number of years she did get the Skipton payments and  
3 just this year, earlier this year, a relative said to  
4 my Dad, you know, oh -- I nearly said my mother's name  
5 there, that my mother, you know, "Oh, they would have  
6 got some money. Aren't you lucky getting some money".  
7 My Dad was like, "Money, it's worth that (*indicated*).  
8 You can do nothing with it. Might as well be a piece  
9 of paper and what are you talking about? I don't know  
10 what you're talking about. Infect, what infection?"  
11 So even all this time later and then went, "There's  
12 the door. Go through it".

13 So there was -- he got that feeling that people  
14 weren't interested in her health and how it affected  
15 her but weren't you lucky you got some money. So no,  
16 they wouldn't -- they would keep -- they even didn't  
17 say -- I didn't know until they got a stage 2 payment  
18 that they'd even got the first stage payment.

19 Q. Your Dad's reaction was a little bit different,  
20 though, wasn't it? He was much angrier?

21 A. Oh, yes.

22 Q. Can you tell us about that.

23 A. Well, for him, you know, they've brought up a family,  
24 they've been together, this is, you know, "We've got  
25 our plans. We can go holidays. We enjoy bowling. We

1           like dancing. This is our time", and that time was  
2           taken, taken away from them.

3       Q. Since you have got through your mother's records you  
4       discovered that in 1996 your mother wrote to the  
5       Health Minister at the time, Mr Horam.

6                       Can we have 2315011, please.

7                       This is the reply she received on his behalf.  
8       It was written by one of his -- who seemed to be one  
9       of his staff members, and it says this in the second  
10      paragraph:

11                      "As ministers have consistently stated, for  
12      example, in the adjournment debates in the House of  
13      Commons in July and December 1995, the Government has  
14      great sympathy with those patients who may have become  
15      infected with hepatitis C through blood transfusions  
16      or blood products. Factor VIII brought many  
17      advantages to people with haemophilia. It greatly  
18      increased life expectancy as well as improving the  
19      quality of life."

20                      If I can pause there, you were upset by that  
21      reference in the letter to haemophilia, weren't you?

22      A. Well, my Mum's got von Willebrand's disease. It  
23      appears to me to mention haemophilia not  
24      von Willebrand's. My Mum had von Willebrand's.

25      Q. Your concern is this: a generic letter that's gone out

1           rather than anything responding to your Mum.

2       A. Yeah, it was like, "Somebody writes in. Throw that  
3           one out at them".

4       Q. It goes on:

5                        "However, medical procedures rarely come without  
6           risk and these are not always fully known or capable  
7           of being guarded against at the time. Most  
8           haemophilia patients were infected with hepatitis C  
9           before blood products were treated to destroy viruses.  
10          Those patients received the best treatment available  
11          in the light of medical knowledge at the time."

12                      It goes on to say that the Government does not  
13          accept that there's been negligence and they have no  
14          plans at present to make payments to such patients.  
15          If we go over the page it is explains why payments  
16          were being made to those with the HIV virus and it  
17          says this:

18                      "In the case of patients inadvertently infected  
19          with the HIV virus the decision to make payments to  
20          those affected, and to establish a hardship fund, was  
21          taken in light of their very special circumstances.  
22          Those affected were all expected to die very quickly  
23          and were subject to significant social problems,  
24          particularly ostracism. Hepatitis C is different from  
25          HIV. Many people infected with hepatitis C may live

1 for a long period without any symptoms occurring and  
2 only a very small proportion are expected to die from  
3 the disease."

4 It then indicates that the Government is always  
5 ready to listen to further evidence. Were you aware  
6 of what your Mum thought of this letter? Was anything  
7 around the Government's position discussed at home?

8 A. No.

9 Q. You just found this in her records?

10 A. Yes.

11 Q. In about 2002 you think your Mum applied for money  
12 from the Skipton fund and, again, in her records  
13 there's a letter from Professor Ludlam to her GP  
14 saying your Mum had been to see him and she had been  
15 told by the Scottish Office that compensation would  
16 only be given if infection occurred after March 1988.

17 Were you aware of that at the time?

18 A. No.

19 Q. She did ultimately receive Skipton payments, as you  
20 have said. When your Mum had to go into a care home,  
21 what difficulties did those payments cause you?

22 A. Quite a bit. Because my Mum and Dad, they've shared  
23 everything so they've got a joint bank account, so the  
24 money all went into their joint bank account and  
25 because at that point I had got power of attorney for

1 my father for his financial affairs, it was actually  
2 too late. I would have had to have gone to  
3 guardianship for my mother because at that time she's  
4 deemed to have dementia. So I was filling in the  
5 forms that Edinburgh Council needed on my mother's  
6 behalf but really for my father. So it was about all  
7 the income you got, your pensions, and also -- and  
8 I was aware -- and you had to give six months' bank  
9 statements to the Council.

10 But I was aware a big amount of -- they only had  
11 a pension, a small pension, so I was aware a big  
12 amount of the money that they had was Skipton money.  
13 It wasn't anything that they had got from anywhere  
14 else. So I was saying to them, "Well, my Mum's got  
15 this money", and I also had someone that knew somebody  
16 that worked at the Care Inspectorate and they had  
17 spoken to a lawyer and they said -- and I said, "So  
18 it's not to be counted", and he said, "Oh, I've spoken  
19 to the lawyer, and what I was being told by the  
20 Council is you've got this extra money, you can  
21 voluntarily give extra to pay for your Mum's care",  
22 and I said, "No, but that was because my Mum had  
23 hepatitis C", so I was being told it had to be counted  
24 in and somebody from the Care Inspectorate, I had  
25 spoken to the Care Inspectorate lawyer who had said,

1 "No, no, no, this money does have to get counted in.  
2 It's like Disability Living Allowance. It's meant to  
3 improve your Mum's care and if that money can be used  
4 to get your -- you know, used towards her care in the  
5 care home then it should be counted", and I said --  
6 I looked her in the eye and I went, "You're wrong".

7 Then I had to get in touch with Skipton who got  
8 a letter from the Caxton Fund saying it was to be  
9 discounted, but I had to go through all the hoops at  
10 a very difficult and emotional time to prove to them  
11 they didn't know that this was true. I had to get the  
12 evidence to prove, "No, you cannot use it when trying  
13 to" -- because they've got to work out how much  
14 because, for example, my parents' married couple's  
15 pension had to be separated into single people's  
16 pension and my Mum's attendance allowance, et cetera,  
17 but then I had to go through that loop to say you  
18 cannot take this amount into account because it's to  
19 be discounted.

20 But I was the one that had to prove it. They  
21 didn't -- they were telling me the contrary.

22 Q. For you that was an added stress when your Mum was  
23 really very unwell?

24 A. Yes.

25 Q. And she died --



1 A. It was more even, you know, maybe not even so much for  
2 my Mum, she had dementia and didn't know so much, but  
3 can you imagine the loss for my Dad of over 60 years  
4 together of having to give up that care of somebody  
5 you love to strangers. No, it was horrible trying to  
6 deal with it and deal with our emotions, his emotions,  
7 and all the loss then.

8 Q. Your Mum died about three months later --

9 A. Yes.

10 Q. -- in 2012 when she was 85.

11 A. She was just -- she would have been 85 quite soon  
12 after.

13 Q. On her death certificate it records that she died of  
14 pneumonia as the main cause and it lists  
15 cerebrovascular accident, dementia and  
16 von Willebrand's disease.

17 You're unhappy about that. Why is that?

18 A. Well, you know, there's no mention at all of  
19 hepatitis C and I can only surmise but one of the  
20 things I think why that happened is when my mother was  
21 moved to the care home. It was in a different part of  
22 Edinburgh and so the GP that comes to the care home is  
23 the GP that my mother had. So that GP only knew my  
24 mother for three months before her death, maybe he saw  
25 her, I don't know, two, three, four times, whereas the

1 GP that we'd had since 1954 and who knew the family  
2 history, who knew how much better and I think would  
3 have attributed hepatitis C -- I think it was just put  
4 down -- well, the first two are pneumonia and CVA, so  
5 it was just put down to, "Oh, she's got to 84, old  
6 age".

7 Q. You feel quite strongly that the hepatitis C and the  
8 cirrhosis should have been recognised on her death  
9 certificate?

10 A. Yes.

11 Q. That in itself caused problems for your Dad in terms  
12 of financial assistance?

13 A. Yes.

14 Q. What happened?

15 A. Well, in Scotland there is -- my Mum was getting  
16 money. That stopped, but then there's a Scottish  
17 system where a widower can get 75 per cent of the  
18 money and I asked a couple of people and they said,  
19 "Oh well, if hepatitis C's not on the death  
20 certificate ..." and I suppose in people's defence  
21 I could have looked it up but also in their defence  
22 how many people have actually reached into their 80s,  
23 but I was told if hepatitis C isn't on the death  
24 certificate then the chance of your Dad continuing to  
25 get any money is nil, and so when money became

1 available, and it wasn't until I was up one morning,  
2 quite early, leafing through my iPad as I do,  
3 I thought, "Oh", well it was a bit ambiguous as well  
4 because it said if it's a widower still staying with  
5 the person I thought, "Ah, my Mum was in a care home  
6 so they're not actually staying", but I thought  
7 I might as well find out because my Dad did used to go  
8 and visit every day and he has been awarded that money  
9 and, on a personal note, gets an amount every month.  
10 And on the 15th of the month, although he doesn't walk  
11 very well, will -- I'm going to get upset now -- will  
12 go to Tesco's with his cash Link card on 15th of the  
13 month, put it into the machine, so that he can see  
14 he's got "Mammy's money", that he can do diddly-squit  
15 with but it's "Mammy's money" and it's still  
16 a connection to her.

17 Q. But he worries every month whether the money will be  
18 there?

19 A. Yes, "What if it's stopped. What if they don't give  
20 me it", you know, and it's like, "But you don't need  
21 it".

22 "But it's Mammy's money."

23 Q. And he's worried that one day it will be taken from  
24 him?

25 A. Yes.

1 Q. I want to move on to talk about your own situation.  
2 First of all, your work in the haematology lab at the  
3 Infirmary until 1983. Professor Ludlam was your boss?

4 A. Yes.

5 Q. Can you tell us about your experience of testing  
6 bloods and in particular the handling and labelling of  
7 high risk blood.

8 A. Well, when a blood came in you've got a whole load of  
9 bloods together and you would put a sticker on the  
10 form that would ultimately go back to the patient's  
11 notes and a sticker, it's good that I've got this with  
12 me, a sticker on the sample that would then go through  
13 machines, and these samples would come in, you'd have  
14 the form, it still happens today, form and the sample  
15 of blood and it would be in a plastic bag.

16 But those that were labelled as high risk would  
17 be kept to the end. So there would be a sticker on it  
18 saying "Risk of infection", you would keep them to the  
19 end, you would put all the other samples through the  
20 machines and then at the end the ones that were  
21 high-risk would be labelled and some tests would be  
22 done in a fume cabinet but other ones would be put  
23 through the machine. At the end of the day you would  
24 have to get dressed up in a neck to floor apron,  
25 gloves on, a visor over your face, and once the

1 samples were put through, results out, the machine  
2 would be cleaned at the end of it.

3 Q. What did you understand the risk to be at that stage  
4 before 1983?

5 A. Well, before -- you discuss -- well, I suppose 1983 it  
6 would have been query HIV or maybe even hepatitis B  
7 was a big problem in the labs.

8 Q. At the very least you were conscious that it was  
9 high-risk blood and there was something you had to be  
10 careful of?

11 A. Yes.

12 Q. In the lab were you aware of blood samples being taken  
13 and stored?

14 A. Yes, because some had "Serum for storage", you know,  
15 maybe put on the side, so you would test the blood and  
16 then keep a little sample and these could be frozen or  
17 put elsewhere, some to be tested maybe straight away  
18 and others, I don't know when they're tested, but  
19 maybe stored for a later date.

20 Q. Were you aware of people in the lab undertaking  
21 research?

22 A. Yes. I wasn't involved in it but there were a group  
23 of maybe four people that were for research. That was  
24 a new thing. You didn't have people doing research  
25 and then there was a few people taken away to do

1 research.

2 Q. But you're not sure what that research was?

3 A. No.

4 Q. Because you weren't involved?

5 A. No, I wasn't involved.

6 Q. What's your understanding of the high risk blood meant  
7 for you when you've needed to receive blood products?

8 A. Well, high risk is -- well, I can only give my example  
9 of when I was pregnant in 1990 and then had an  
10 emergency caesarean in '91. Dr Ludlam wasn't only my  
11 boss he was my doctor, and when I was having the  
12 amniocentesis, said, "Oh, I want you to have  
13 Factor VIII before you have amniocentesis", and  
14 I went, "No". I remember we had -- because I remember  
15 at one point I said, "Oh, we had this argument about  
16 it and he said, "No [redacted], we had a discussion".

17 Q. Can we just stop the live stream, please. *(Pause)*

18 You were just saying that Dr Ludlam wasn't only  
19 your boss he was your doctor and you needed to have  
20 the amniocentesis and you had and argument about  
21 whether you should have Factor VIII.

22 A. Yes.

23 Q. What did he say to you about it?

24 A. And he told me -- and I said, "No, I'll have it on  
25 stand-by but I don't want it", and he said, "It's

1 safe, you can have it now", but I said, "No, I don't  
2 want it", and then the same when I needed the  
3 emergency caesarean, had wanted me to have Factor VIII  
4 before the caesarean and I said, "No, I'll have it on  
5 stand-by if I need it. I don't want to put myself at  
6 any risk, unnecessary risk".

7 Q. You've not been infected with HIV or hepatitis C but  
8 what are your feelings about that now?

9 A. My feelings are that I've kind of dodged a bullet  
10 because -- can I speak a bit about when I was at the  
11 Penrose?

12 Q. Absolutely, I was going to ask you that next.

13 A. Okay, I went to the Penrose Inquiry final report and,  
14 as I said, in kind of October '90 and March '91  
15 Factor VIII was -- and then a heard -- what I heard  
16 was, you know, blood until 1991 wasn't tested for  
17 hepatitis C and I think at that point I went into  
18 shock because I thought October '90, March 1991, my  
19 Mum's got hepatitis C, because the Penrose was in  
20 2015, I could have had hepatitis C.

21 And then it wasn't actually until I spoke to  
22 Jamie, you know, from Thompsons -- thank you, Jamie --  
23 that he assured me that it was, the Factor VIII was  
24 tested for hepatitis C before that. It was the blood  
25 that wasn't, like red cell concentrate wasn't tested

1           until '91.

2                        But then I thought later but if after the  
3           amniocentesis or I had the caesarean, if I'd bled  
4           I would have just been given a blood transfusion no  
5           questions asked. It would have been you need this and  
6           so I could have got the hepatitis C.

7                        So, yes, I think I was just in a bit -- you've  
8           told me it was safe and it wasn't.

9           Q. That had quite a significant impact on your mental  
10          health.

11          A. Mm-hm.

12          Q. You have had some psychological support and  
13          counselling but only very recently?

14          A. Yes. I mean, I'm known as -- I'm actually known as  
15          the eternal optimist; so the fact that I went into  
16          shock and that after I don't think ever in my life  
17          I've felt so bad as after that Penrose report.

18                        There was -- I did go -- there was a church  
19          round the corner from the museum where the final  
20          report was read out and there was people from  
21          Haemophilia Scotland, it was great. But I just --  
22          I spoke to a couple of people but then I thought  
23          I need to get away. I remember going down to Prince's  
24          Street and there was a really lively band and normally  
25          I'd be dancing along the street, and I felt so low, so



1 sick to my stomach.

2 And I kind of laugh about it now but as I was  
3 waiting for the bus, there was this man, he looked  
4 a bit dishevelled and down and out and I went up and I  
5 said to him, "Excuse me, I've had such a horrible day,  
6 I want it to end on a better note". I thought he was  
7 homeless. "Would you take £10 off me, just to make my  
8 day a bit better" and he went, "Okay, thanks",  
9 thinking he's homeless. He might have a guy just  
10 going home from his work or something. But it was  
11 what I did to make myself feel better.

12 And then I can't prove it but, interestingly,  
13 although I'd been quite steady, chronic and acute  
14 blood-wise in my gut, two weeks later I had an acute  
15 GI bleed and went through a horrendous time and had to  
16 have -- from then started to need prophylaxis for my  
17 GI bleeds.

18 Going back to something you've shown before  
19 where it was the letter from the Government,  
20 I remember reading that and being so incensed and  
21 a family member was in and known about that I'd had  
22 the bleed two weeks after the Penrose Report and not  
23 being able to link it 100 per cent, but when I was  
24 actually spitting blood at the wording on that letter,  
25 said, "Mum, please take care of yourself. You know

1           what happened to the Penrose. Please, please, calm  
2           down. Think of yourself. Stop". It was difficult  
3           but ...

4       Q. You have also said in your witness statement that  
5           people have said to you that that's all in the past  
6           now and move on and you've said:

7                        "I remember inside thinking for you maybe but  
8           not for me. I think that's what happens a lot with  
9           hepatitis C. There's some money, let's move on but it  
10          doesn't go away. I injected my mum a couple of times  
11          and it could have been me that gave her the infected a  
12          products too. Can you imagine doing that to your  
13          child."

14                       That's something else that you've struggled  
15          with?

16       A. Yes, and I can't tell my Dad.

17       Q. Your Dad's too frail to cope with --

18       A. He's not frail at all. He's really --

19       Q. -- too elderly to manage it.

20       A. I just don't want to be the one to tell him that  
21          possibly I could have injected Mum. How can I say  
22          that to my Dad? He loved her to bits. How could  
23          I say it?

24                       I didn't even realise myself until I actually  
25          read the notes, and I swore. It could have been me

1           that gave that because I took it home only maybe two  
2           or three times but it still could have been me. And  
3           then I have that huge empathy for people given what  
4           they thought was the best thing for their child to  
5           use, you know, and I've done it to my Mum. My Dad  
6           still misses my Mum all these years later. "By the  
7           way, Dad it could have been me injected it". No. So  
8           I can't tell him. If he asked me it, I'll say it's to  
9           give you and mum a voice but if he was sitting there  
10          now, I couldn't speak. I couldn't tell any of this  
11          because I couldn't say that to him.

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

14        A. Yes, a couple of things.

15                 Going into -- I know maybe you don't want to  
16                 dwell on Penrose but there was one thing I remember  
17                 also from being in shock of I could have been infected  
18                 and I remember -- what I was left with was from the  
19                 Penrose final report was to think of the doctors, they  
20                 were affected to. And I was like -- I've held that  
21                 for all these years. So when I had this and I knew  
22                 I'd sworn an oath and I thought, did I really hear  
23                 that? So I actually went online and I looked at the  
24                 Penrose Inquiry final report and I've got it word for  
25                 word, the executive summary, and it was March 2015,

1 and it's under "communication of results", the last  
2 paragraph.

3 Is it okay if I read out where I've taken that  
4 from?

5 Q. Of course.

6 A. "Were a new disease like AIDS to emerge today, the  
7 patients would probably be made aware of the medical  
8 profession's ignorance of it [and this is the  
9 sentence] and share all the uncertainties and  
10 anxieties consequent on that."

11 So the doctors are holding the uncertainties and  
12 anxiety.

13 "There would still be suffering and probably  
14 anger against the disease but the sense of betrayal  
15 would be absent."

16 Sorry, but I still say it's crass in the  
17 extreme. So that, you know, the medical -- so I read  
18 the doctor's share, they were the ones with all the  
19 uncertainties and the anxieties and if they'd shared,  
20 we could have shared that too. What about all the  
21 uncertainties and anxieties and ill-health that you're  
22 putting down to your old age? That just infuriates  
23 me, sorry.

24 Q. I'm just going to turn and ask Mr O'Neill and  
25 Mr Dawson if there's anything they would like me to

1 raise.

2 (Pause)

3 Mr Dawson has said that he thought you had  
4 something you had wanted to read out, not just the  
5 point about Penrose?

6 A. No, I've got a final thing.

7 Q. Now's a good time if you want to say something else  
8 before I ask you Mr Dawson's.

9 A. I've written it down because I'll probably get upset  
10 again.

11 I wanted to take this opportunity to tell my  
12 parents' story to give them a voice. The Inquiry's  
13 heard what happened to my Mum and I'd like to conclude  
14 by using my Dad's words, something he says on  
15 a regular basis but I also feel has further meaning.

16 Firstly, my Dad says this as he fondly  
17 reminisces about the 60 plus years he spent with my  
18 Mum. That saying is: thae days, they'll no come back.

19 Secondly, in recognition of both the quality and  
20 quantity of time those infected and affected have been  
21 denied, thae days, they'll no come back.

22 And, finally, to Sir Brian and his team guarding  
23 the responsibility and, dare I say, hopes resting on  
24 their shoulders to get answers, to sort out  
25 inequalities in the financial and psychological

1 support people are afforded and to hold those  
2 responsible for this disaster to account, thereby  
3 ensuring thae days, they'll no come back.

4 Q. Mr O'Neill and Mr Dawson have two points they wanted  
5 me to raise in addition.

6 Firstly, you spoke earlier about Dr Ludlam  
7 telling you that the products were safe in 1990/1991  
8 when he told you you needed it for the amniocentesis  
9 and the emergency caesarean section. Did he explain  
10 to you what he meant when he said they were safe?

11 A. No.

12 Q. How do you feel about that?

13 A. Incredible. I worked in labs. I've got a scientific  
14 background. But that's how it was. It was like, "You  
15 take my word. I tell you something. You believe it.  
16 You do it. Full stop". Even the fact we had the  
17 argument, which was then called a "discussion", about,  
18 "No, I'll have it on standby" that didn't please him  
19 but I was adamant, no, I will have it on standby.

20 Q. Secondly, we mentioned that you had had some  
21 counselling and that was actually bespoke counselling  
22 for people with a bleeding disorder?

23 A. Yes.

24 Q. What has your experience of that been?

25 A. Oh, invaluable because I think it is important because

1 things you think you've dealt with, they're over or  
2 whatever, they don't. Actually, today thankfully I've  
3 had the Red Cross to speak to as well because it's not  
4 just going in this process, it's not just going  
5 through the notes that are pertinent to this Inquiry,  
6 but it's finding out other stuff in the notes nearer  
7 my Mum's death that I wish I hadn't read but I had.

8 I'd like to say actually one more thing. For  
9 those infected and affected who feel they can't give  
10 a statement or can't come here and give evidence,  
11 I salute you. Take care of yourself because for you  
12 that's the right thing, because this isn't easy.

13 Q. Part of why you found that counselling so positive is  
14 because it is specialist to people with bleeding  
15 disorders?

16 A. Yes.

17 Q. And there's a real understanding, you've said, of that  
18 situation?

19 A. Yes, because it's just for -- because it's so  
20 specific, that the kind of counselling. I actually  
21 have a counselling advanced diploma so in part of it  
22 I had to have counselling about this, that and the  
23 next thing. But to actually have focused counselling  
24 about what it's like being in hospital, going in  
25 hospital, everything involved in it, and fears around

1           that is invaluable and should be expanded.

2       SIR BRIAN LANGSTAFF: Can I make one comment. In my view,  
3           you are no more guilty of infecting your mother than  
4           was the syringe. It needs to be said publicly.

5                    But I do appreciate and thank you for your  
6           courage, despite your feeling that you were guilty, in  
7           coming to tell us about your mother. It takes -- as  
8           you said, it's not easy. You've done it. Thank you  
9           very much.

10       A. Thank you.

11       SIR BRIAN LANGSTAFF: That is the end of the evidence for  
12           today. Tomorrow we start at 10.00, and who are we  
13           hearing from tomorrow?

14       MS FRASER BUTLIN: We will be hearing from Bill Wright,  
15           Rosemary Wright and Richard Titheridge.

16       SIR BRIAN LANGSTAFF: Tomorrow 10.00.

17       **(3.33 pm)**

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

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PAMELA PENNYCOOK, affirmed .....1  
Questioned by MS FRASER BUTLIN .....1  
  
ALICE MACKIE, sworn .....18  
Questioned by MS RICHARDS .....18  
  
MS S, affirmed .....116  
Questioned by MS FRASER BUTLIN .....116