

Monday, 8 June 2021

(10.00 am)

**SIR BRIAN LANGSTAFF:** Good morning. This morning we have Mr James, Robert James and I gather he would wish to be called Robert.

Would you like to come forward, please, Robert and Mary will ask you to take the oath.

Well, in Mary's absence, I'll ask you -- I can't remember the words!

**THE WITNESS:** I did practise but I've forgotten them as well. Sorry.

**SIR BRIAN LANGSTAFF:** Well, we'll just take a moment. It's important to get them absolutely right. So please state your full name.

**THE WITNESS:** Robert Magnus Lee James.

**ROBERT MAGNUS LEE JAMES, affirmed**

**Questions from MS FRASER BUTLIN**

**MS FRASER BUTLIN:** Robert, you're here to give evidence about your campaigning work but before we look at that I'd like to ask you a few questions about your own personal circumstances to give some context.

**A.** Yes.

**Q.** You have severe haemophilia A.

**A.** That's right.

**Q.** And initially, you were treated with cryoprecipitate?

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**A.** Okay, I hope that helps.

**Q.** I think that will help our technology team as well.

Your family moved a couple of times, and in 1977 you were registered at Taunton.

**A.** Yes.

**Q.** And by then you were receiving factor concentrates?

**A.** Yes, the last year, I think it was, in Rugby, or maybe in Gloucester, we shifted from cryo to factor concentrates.

**Q.** Are you aware of whether your parents or, I suppose, you, were given any advice about the risks involved in changing to factor concentrates?

**A.** I don't remember anything and I don't -- I don't remember my parents talking about it. I know I was aware there was a risk of hepatitis B, but -- I can't remember how I phrased it in my statement but it was something like, I knew it was there and I knew it was a manageable condition and it was one of the things you might get. But nothing about the change of that becoming, say, more risky or more likely with factor concentrate, nothing. It was just an advance. It was -- a really great thing was -- that was actually -- yeah, easier to store and easier to carry.

**Q.** In relation to hepatitis B, you recall, I think, being told about the risk of hepatitis B in the late

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**A.** That's correct, yes.

**Q.** That included home treatment with cryoprecipitate?

**A.** Yes. My parents bought a freezer specifically so that I could have cryoprecipitate at home, and I can remember mixing it up and making it, although I wasn't allowed to inject it. Yes.

**Q.** How manageable was cryoprecipitate as home treatment?

**A.** Well, at the time it was great. I mean, it was the difference between going to hospital two or three times a week in an ambulance, which would have been 20 minutes, half an hour away, or sometimes being driven by my father, so to have it at home when I had a bleed, to just be able to go to the freezer -- and it took a little bit of time, you defrosted it, you took a 50 ml syringe, you put a needle on it, you jabbed it into this plastic bag and you pulled out the orange gunk. And there was six or seven, I think, bags you used, and then it was injected into me. So I don't remember it being difficult.

I suppose the hard part about it was you couldn't really take it anywhere, because it had to be kept frozen. But as a home treatment, it worked.

**Q.** Now, Robert, you're very softly spoken. Might I ask you to go slightly closer to the microphone so that everyone can hear you.

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seventies, during your teenage years?

**A.** (Nodded)

**Q.** Can you remember what you were told about it?

**A.** No, and I don't know whether it was my teenage years or before, I just have this memory of being aware of it at the time. I can remember when it was -- Russell Harty died of hepatitis B, which would have been in the 1980s, I remember being quite shocked that someone died of it, because whatever my impression of it was, it wasn't that it killed people. That it was a condition you got and went away, I think. Mm.

**Q.** You've identified in your medical records that by the time you were being treated in Taunton, you -- your liver function tests were abnormal.

**A.** Yes, I wasn't aware of that at the time.

**Q.** And from your records, you've seen that that continued through the 1980s.

**A.** Yes.

**Q.** Do you recall anything being discussed about those tests at the time?

**A.** No. No. The system would be -- you went in, they took routine bloods, and things were just fine. There was never a ... yeah. That was never an issue that I can remember being raised at all.

**Q.** And then when you were 18, in April 1985, you were

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1 told that you had HTLV-III antibodies?  
 2 A. That's correct.  
 3 Q. Can you tell us how you came to be told?  
 4 A. I had got a bleed or a problem, there was some reason  
 5 I needed to go into the hospital, and I rang up,  
 6 I think, and said, "Can I come in tomorrow?" or "Can  
 7 I come in in a couple of days?" Something like that.  
 8 And by chance I went in with my father; because  
 9 I was 18, so sometimes I went on my own, sometimes  
 10 I went with him because if he was driving in then I'd  
 11 get a lift with him and, while I was there, after we'd  
 12 done whatever it was about whatever problem I'd got,  
 13 the doctor said that they'd done this test and I'd  
 14 got HTLV-III.  
 15 Q. Before you were told that, were you aware they were  
 16 testing?  
 17 A. No.  
 18 Q. After you were told, what did you then do?  
 19 A. Well, when I was told, the -- well, the doctor,  
 20 Dr Thompson, said it was very uncertain, I might be  
 21 immune to it, I might have antibodies, I might have it  
 22 as being ill, it might mean nothing at all. Then  
 23 I rang up, I think it was THT the next day or the next  
 24 couple of days and said, "What does this mean?" And  
 25 they said, "It means you've got the virus that causes

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1 people had?  
 2 A. A number of friends of mine who were diagnosed very  
 3 early with haemophilia -- or not -- or not many with  
 4 haemophilia but lots without haemophilia came in. If  
 5 you rang up then, they'd be really surprised. It was  
 6 "the gulp", I discovered it was called and it's  
 7 because, at that time, there were so few people  
 8 diagnosed with HIV, it was a few thousand, even though  
 9 it was the Terrence Higgins Trust and they were  
 10 a helpline, they didn't often actually get that many  
 11 positive people ringing up saying "I've got HIV" or  
 12 "I've got HTLV-III, what does it mean?" So it was,  
 13 yes, quite a surprised reaction. And I wonder also if  
 14 there was some surprise about what I'd been told.  
 15 Q. And you've described that "the gulp" was something  
 16 that several people experienced --  
 17 A. Yes.  
 18 Q. -- when they told people about their diagnosis.  
 19 A. Yes. Yeah, because it was so unusual at the time.  
 20 Q. You went on to university.  
 21 A. Yes.  
 22 Q. What difficulties did you initially face there because  
 23 of your diagnosis?  
 24 A. When -- at the time, because we didn't have anything  
 25 like an Equality Act or Discrimination Act, the way it

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1 AIDS."  
 2 Q. You've described that subsequently your father had  
 3 said to you that the doctor had thought very hard  
 4 about telling you?  
 5 A. Yes, he told me, I think it was once when we were on  
 6 holiday, that he had spoken to the doctor later and  
 7 she'd said she'd spent -- she'd been up all night  
 8 worrying about how to tell me, and that at -- I think  
 9 at the time I was the only patient at the centre who'd  
 10 got HIV.  
 11 Q. And the information she provided to you was -- it was  
 12 very uncertain?  
 13 A. (Nodded)  
 14 Q. The Terrence Higgins Trust phone call indicated that  
 15 it was HIV?  
 16 A. Yes, that -- they certainly said to me the idea of  
 17 immunity was not really sensible. Then they were  
 18 obviously cautious about saying the doctor is  
 19 completely wrong, because people were then, but it was  
 20 a very different slant on -- yeah, on the way it was  
 21 described. It was -- it was much more negative than  
 22 what she had said.  
 23 Q. And when you told the person on the end of the phone  
 24 at THT that you had HTLV-III antibodies, you've  
 25 described a particular reaction that you know many

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1 worked at university, if you were going to university  
 2 and you had any kind of disability you had to write  
 3 about a year, 18 months in advance to the university  
 4 and say, "Can I come to your university? Can you cope  
 5 with my disability?" And they'd write back and say  
 6 yes or no. And I wrote to a number, and Swansea,  
 7 which is where I went, wrote back to me and said,  
 8 "Fine, it's not a problem". And on my open day I went  
 9 up there, it was a beautiful sunny day, there was the  
 10 beach, and I visited the medical centre on campus, and  
 11 that was all fine about me having haemophilia. And  
 12 then, when I arrived to start my degree, I went into  
 13 the department and before I had signed up to join the  
 14 course I was doing, the head of department came over  
 15 to me and said, "Can you not do this? Can you not  
 16 sign up here? We'd like you to go and see someone",  
 17 the next day. And it was someone in administration in  
 18 the university.

19 And so the next day I went to the administration  
 20 building and the person I was meant to see wasn't  
 21 there. And I sort of moved around different people,  
 22 not quite sure what I was doing and nobody quite sure  
 23 what to do with me, and I ended up seeing the head of  
 24 undergraduate admissions, that I was a bit intimidated  
 25 by because that seemed like a really powerful

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1 position, and he had no idea if it was going on. And  
2 then he said, "Go away for half an hour, come back,  
3 and I'll find out what's going on."

4 And when I came back he said, "The problem is  
5 you've got haemophilia. The department is scared  
6 because of a lot of publicity recently", and it was  
7 particularly the case of a boy in Hampshire that  
8 I think was mentioned in evidence couple of weeks ago,  
9 that I might have AIDS. And I said, "Well, I do"  
10 which probably wasn't the best answer at the time.

11 And he then registered me with the university  
12 and for a few days I was a student without a degree.  
13 I do remember thinking, if I could string this out  
14 I'll just get a degree without doing any work. But  
15 I was then finally registered with that department but  
16 I couldn't really do the subject very well so  
17 I changed to a different department, and when I told  
18 them about my haemophilia they were just much more  
19 relaxed. So it seemed a lot easier.

20 Q. You also have hepatitis C.

21 A. Yes.

22 Q. How did you find out about that diagnosis?

23 A. I can't actually remember being told about the  
24 diagnosis, but it -- I knew I'd got it. I had  
25 a friend actually at Swansea who was living in Cardiff

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1 diagnoses was if -- if I went on a date or if I met  
2 someone I wanted to go out with, it took so long to go  
3 through all these things. And it must have been the  
4 point, I'm sure, with some of the women I was speaking  
5 to where they were thinking: what else is there? If  
6 he does have haemophilia -- which is probably fairly  
7 obvious, I didn't walk very well and that type of  
8 thing, but -- and then I'd do hep C, because often  
9 they'd never heard of it, and that felt like a gentle  
10 lead-in. If they could deal with that, then I went to  
11 HIV, and everyone had heard of that.

12 It made me a bit of a -- it's -- I don't know,  
13 I became very well known in the university, simply  
14 because -- what had happened in that department,  
15 the -- it was then published in the student newsletter  
16 and there was couple of weeks running about a student  
17 who -- with haemophilia, who had not been allowed to  
18 join. And the students were saying, "Isn't this  
19 outrageous?" And it was all a fear of HIV, and that  
20 the departments, particularly science departments,  
21 should be more competent than that, and, therefore --  
22 I was the only one with haemophilia at the university.  
23 Everybody knew it was me, once they'd met me. So --  
24 and I -- I would tell people I'd got HIV.

25 I'd found it really hard to tell my friends, who

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1 and I went to visit him, and it was one of those -- or  
2 it was a time when you could go to university  
3 libraries and they didn't block you at the door, so  
4 I could go in, and I went in and I just went through  
5 some medical journals to look. I must have heard  
6 something about non-A, non-B or hepatitis C being  
7 discovered. And I read some papers, that were US  
8 ones, where they tested their cohorts, and everybody  
9 got it.

10 So by the time it came to either being offered  
11 it or me asking at my centre -- and I'd got severe  
12 haemophilia and I was reading papers where people who  
13 had had one injection of Factor VIII had got it so  
14 I knew I had to have it. I'd had thousands at that  
15 point. So I don't really remember.

16 And of course I still had -- I'd got HIV and  
17 everyone was saying, "Well, this is going to kill  
18 you". So when you've got a short-term killer and  
19 a long-term killer, the short-term one takes  
20 precedence. So I was aware of it but I didn't -- I  
21 didn't -- I felt I didn't need to think about it  
22 because AIDS was what was going to kill me.

23 Q. And as a young man with that diagnosis, can you tell  
24 us a little bit of the impact of the twin diagnoses?

25 A. The -- one of the major impacts of having both

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1 I'd sort of grown up with, and that -- that's so hard  
2 to say to people you know and people who like you,  
3 "I've got this disease that's going to kill me."

4 So I'd sort of decided it would be much better  
5 to say it very early on and then if they were scared  
6 or bigoted, they'd just leave me alone, and if they  
7 weren't, they'd just stay friends and it was, in some  
8 ways, quite a good filtering process. But it -- it  
9 was very isolating, is probably the best thing. And  
10 I discovered about five years later that -- I went to  
11 a large-scale conference, a Body Positive conference,  
12 there were lots of people with HIV there, there was  
13 someone there from my university, and we'd both been  
14 in the same club together and he'd known and he said  
15 he was too scared to tell me at the time.

16 I suppose there was also that thing, I was at  
17 a university which is a very trendy lefty, so there  
18 was a sense of people -- it would have -- it would  
19 have been really wrong to be nasty to me, there was  
20 a sense. And there were certainly a lot of people who  
21 were very political who were, "Stigma around this is  
22 absolutely wrong, and if you get any, you will come  
23 and tell us, and we will make sure it doesn't happen".  
24 And there were a few times things happened but, in  
25 general, most of the people I knew were very

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1 sympathetic and certainly always very shocked when  
2 I told them.

3 **Q.** I want to come back to the question of stigma in  
4 a moment but just to finish off the sort of chronology  
5 of your own situation.

6 Subsequently you underwent a year of treatment  
7 with pegylated interferon and ribavirin for the  
8 hepatitis C.

9 **A.** Yes, that was horrible, absolutely horrible, and  
10 I wrote it up as a sort of diary in Birchgrove  
11 magazine, so there's four articles every three months,  
12 and I had to wait quite a long time because I had got  
13 HIV and they wouldn't let people with HIV have it,  
14 because the way they approved, it was people with only  
15 hep C, but I'd had people -- I'll come on to the  
16 annoyances I have about that later but I did  
17 eventually get access to it.

18 I had a particularly unusual genotype and the  
19 way the rules were written, it meant I ended up  
20 lobbying to have a year's treatment rather than six  
21 months. And I was successful in getting my primary  
22 care trust at the time to pay for those extra six  
23 months but it was also very hard thinking: I hate this  
24 drug, it is horrible, it's doing terrible things to  
25 me, and I'm asking for another six months?

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1 particularly remember, when I first got the results --  
2 or actually no, I should say once when I was away with  
3 my father we went to an athletics meeting in Spain,  
4 and I took my interferon and I injected it while I was  
5 there, and he told me the next day, when he had  
6 watched me and what happened over the next 24 hours,  
7 he thought I was going to die and he was wondering how  
8 do you bring someone dead home from holiday.

9 Then when it didn't work, I can think of another  
10 friend who was just really shocked and said, "It  
11 nearly killed you". I say it didn't work, it half  
12 worked. I discovered I'd got two types and it had got  
13 rid of one type, which was not seen before.

14 **Q.** You then subsequently had a shorter period of DAA,  
15 direct acting anti-virals, they were successful.

16 **A.** Yes.

17 **Q.** But you've described the side effects as still  
18 intolerable.

19 **A.** Yes.

20 **Q.** Can you tell us about that?

21 **A.** That was, yes, sofosbuvir and ribavirin, and I just  
22 started to become very photosensitive, I would get  
23 permanent headaches, and it -- yeah, just tired, not  
24 going out, not wanting to do so much. The headaches  
25 were particularly bad because I was working at

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1 I remember from my diary, I think I had 24 side  
2 effects, two of which were positive. My hair grew  
3 straight. It grew straight everywhere, which was very  
4 odd. And I used to get a warm feeling in my left  
5 foot. Then the other ones just -- you'd get a kind of  
6 succession of three or four one week and then you'd  
7 get three or four the next week, and I remember it  
8 was -- I think the interferon would give you diarrhoea  
9 and the ribavirin would give you constipation, so  
10 you'd move through a week from one to the other and  
11 there would be a day in the middle when you didn't  
12 have either.

13 I had to change my HIV combination during that,  
14 which made it very difficult, because that was very  
15 fixed around what food I could eat, at what time.  
16 I can remember a number of days of sitting at  
17 8 o'clock at night, or 9 o'clock at night thinking,  
18 I have to eat something because I have to take  
19 a tablet and I have to take a tablet with that, and  
20 then being able to go to bed and sleep.

21 It was exhausting and it made me a bit manic,  
22 particularly near the end of the week. I was doing  
23 a -- I started a degree part time, a masters, which  
24 probably wasn't a good idea but I was a bit manic, so  
25 it was only at the very end. The other thing I can

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1 university and I knew I was going to be looking at  
2 a screen and there was no way I could look at  
3 a computer screen for more than about 20 minutes  
4 a day, and term was coming up, and I couldn't teach  
5 with, yeah, a permanent headache 24 hours a day that  
6 would get worse through the day, and then go to sleep.  
7 So yeah, I had to stop early. But it was successful  
8 at least.

9 **Q.** You've described there working at the university --

10 **A.** (Nodded)

11 **Q.** -- can you tell us a little of what you do?

12 **A.** Yeah, currently I teach at Sussex University on the  
13 social work course. I have a qualification in social  
14 work. But I mainly teach law, because I did a PhD in  
15 law.

16 **Q.** You've only ever been able to work part time. Is that  
17 right?

18 **A.** My first job was full time. But since then, I've  
19 really only ever been able to work part time. I did  
20 have one other full-time job and I'd better not say  
21 what it is, but there was so little to do I actually  
22 only did it part time and pretended I was full time.  
23 But yes. And often that was fitting in things like  
24 treatments, interferon, problems with bleeds, I've had  
25 number of operations, joints being fused, lots of

16



1 elbow operations. And the last, yeah, at least  
 2 10 years I'm just too tired. I can't work full time  
 3 and do the other things I want to do in life. So  
 4 I work part time, and have done, yeah.

5 **Q.** I want to go back to the early 1980s and the emergence  
 6 of AIDS. We -- very briefly touched on stigma and  
 7 your time at the university in Swansea, can you tell  
 8 us a little bit more about what you were aware of in  
 9 terms of stigma and HIV in the early 1980s?

10 **A.** Well, it -- a lot of the things I am going to say  
 11 might sound obvious but it was very associated with  
 12 gay sex, particularly between men, although that kind  
 13 of homophobia spread across, and it was also  
 14 associated with drug use and, to some extent, sex  
 15 workers, and those were groups of people who were  
 16 reviled by society. We had laws incriminating --  
 17 punishing people or not giving them the same rights as  
 18 everybody else and, with that association, made it  
 19 very much a disease, yeah, nobody wanted -- nobody  
 20 wanted to be near you.

21 People were afraid, sometimes, of -- if I'd used  
 22 their cutlery or their crockery, they'd throw it away.  
 23 I can remember once in hospital being on a -- after  
 24 I was diagnosed, being on a trolley going to theatre  
 25 and outside of the sort of anaesthetist room where

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1 were teachers. And it was that association with  
 2 dirtiness, the -- James Anderton, the Chief Constable  
 3 of -- I think it was Manchester, who described people  
 4 with HIV as "swirling in a cesspit of their own  
 5 making". I hope I've got his quote right. But that  
 6 was quite common. That was the way people with HIV  
 7 were described and it was seen as normal to be bigoted  
 8 towards those groups.

9 **Q.** You've described a separation between "innocent  
 10 victims" of HIV and other groups with HIV.

11 **A.** Mm.

12 **Q.** From what you understood at the time, how did that  
 13 division, that segmentation, arise?

14 **A.** I think the segmentation arose initially because of  
 15 our clinicians, our doctors. They were scared of us  
 16 associating with all -- people from all those other  
 17 groups and also The Haemophilia Society was certainly  
 18 uncomfortable about associating with those groups for  
 19 a while. And the way haemophilia doctors saw us  
 20 were -- we were their "children". Because it was  
 21 predominantly a young person's disease at the time  
 22 because older haemophiliacs had died of bleeding  
 23 before we had cryo, there was an awful lot of young  
 24 children, and for haemophilia doctors, they saw us  
 25 like that.

19

1 you're waiting, the two nurses disinfecting and  
 2 bleaching the trolley I was lying on, and even having  
 3 a discussion whether to disinfect the tires and the  
 4 wheels, which was bizarre. They hadn't started  
 5 cutting me open at that point. I hadn't bled  
 6 anywhere.

7 That level of paranoia and the continuous  
 8 bombardment of tabloid stories about it, as it was  
 9 always being presented as the worst disease in the  
 10 world and it was being associated with "bad people",  
 11 and although those of us with haemophilia were  
 12 endlessly called "innocent victims", I hated that  
 13 term, and I hated the fact that that blamed people.  
 14 No one deserved this disease.

15 **Q.** What do you identify as the key drivers for the  
 16 stigma? Are there things you identify as key issues?

17 **A.** I think it's the links to those groups, particularly  
 18 around homophobia. We had a very homophobic society  
 19 in the 1980s. It's also the British discomfort of  
 20 talking around sex, and talking about anal sex even  
 21 more so. I think technically at the time anal sex  
 22 between heterosexual couples was still illegal. So it  
 23 was that fear and revulsion that we had no  
 24 anti-discrimination laws around at the time, so gay  
 25 people could lose their jobs, particularly if they

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1 And so they would just not refer us on to  
 2 an appropriate immunologist. They would -- yeah, they  
 3 exceptionalised us, they sort of pushed us away and  
 4 part of that speaking to other people was asking them  
 5 "Do you want to see someone who is an HIV doctor or go  
 6 to a GU clinic?" And people going "No", because they  
 7 didn't feel comfortable with it, and part of that was  
 8 them not even offering it.

9 I particularly remember when I was in Swansea,  
 10 my girlfriend at the time, it made sense for her to  
 11 have an HIV test, and we had to go to a GU clinic  
 12 cause the Haemophilia Centre wouldn't do it. And we  
 13 saw a GU doctor, and he sort of registered her as  
 14 a patient, and he would have treated her. And my  
 15 haemophilia doctor wouldn't treat -- would treat me  
 16 and I wouldn't be allowed to go and use them. I don't  
 17 know why, when we'd always had orthopaedic surgeons in  
 18 there. That was routine to have a joint clinic with  
 19 them? Why not have a joint clinic with the next  
 20 specialism?

21 And I think also, they were just as bigoted as  
 22 lots of other people. So they felt, I don't know,  
 23 maybe they'd catch homosexuality off people.

24 **Q.** Following on from that, in relation to how it affected  
 25 treatment and care going forwards, you've mentioned

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1 that there weren't necessarily referrals to  
2 immunologists or GU clinics. From your own experience  
3 and perhaps from the experience of those you've  
4 campaigned with, what effect did that have on the  
5 treatment that was provided?

6 **A.** Well, I think there were a number of effects. The  
7 effects initially, when there was very little  
8 treatment for HIV, were around treatment for  
9 opportunistic infections. And, certainly, I can  
10 remember inhaling nebulised pentamidine, which is not  
11 great, if anyone has had it, they'll remember that.  
12 But the knowledge of how you treat those got better  
13 and better over time. And if you were a doctor that  
14 treated people, an infectious disease doctor, an  
15 immunologist, whatever it was, you'd be seeing lots of  
16 that and you'd be getting better and better, and you'd  
17 be going to conferences to talk to other doctors about  
18 that.

19 Haemophilia doctors almost -- just didn't seem  
20 to do that and a lot of them -- there were a couple  
21 I mention, Mark Winter was one and later on Has Dasani  
22 were very good at keeping up-to-date with knowing what  
23 was going on, but the others, they just seemed to work  
24 on the idea "Well, I'll read a few papers and then  
25 I'll know what to do".

21

1 a GU clinic or going to a clinic with drug users and  
2 gay men who were ill with AIDS, and just other people  
3 with AIDS.

4 I can certainly remember one doctor when  
5 I asked -- I was forming a self-help group for people  
6 with HIV in that town, and he said I shouldn't because  
7 I shouldn't meet those people. I think, having -- the  
8 way those -- that group of doctors, having seen those  
9 people grow up, I just sometimes wonder if they just  
10 couldn't quite believe that it had happened, that this  
11 was too awful a thing, too terrible a disease, the  
12 disease of pariahs. They just wanted to keep it to  
13 themselves so other people didn't know, perhaps.

14 **Q.** You also speak about the belief of clinicians about  
15 the incidents of AIDS being a form of denial. So  
16 you've addressed in your statement some journal  
17 articles that for you show that it was wrong to carry  
18 on with large pool concentrates from late 1982 --

19 **A.** Yes.

20 **Q.** -- and you've highlighted the 1 in 1,000 statistic  
21 that the Inquiry has heard evidence about a number of  
22 times.

23 **A.** Yes.

24 **Q.** You say that's inaccurate but you also say that, in  
25 your view, it was a form of denial. Can you tell us

23

1 Then later when we got combination therapy,  
2 there was a particular issue with haemophilia doctors,  
3 and I know it was at my centre, and I suspect it was  
4 at number of others, they were just so behind. So  
5 they were prescribing one drug on its own, which at  
6 the time was not just useless, it was unethical. It  
7 was denying that person a future possibility of  
8 treatment by making them -- or leading to them  
9 becoming resistant to that drug and, at that point, we  
10 didn't have a lot of drugs. So I think there was  
11 about seven or eight at the start with, and I was  
12 allergic to three of them so I was always struggling  
13 a bit to fit a combination that was strong enough to  
14 control the virus but that I could actually tolerate  
15 or take.

16 **Q.** You've spoken about clinicians' view of patients as  
17 their "children", can you expand for us a little bit  
18 about why you think they were so hesitant in some  
19 situations to refer on? What was your understanding  
20 of what was going on?

21 **A.** I think it was an emotional response from them, and  
22 I think it was a mixture of emotions, one of which was  
23 probably guilt, that they had given this drug and  
24 infected this person. And also that I suspect they  
25 wouldn't have wanted their own children to be going to

22

1 what you mean by that?

2 **A.** Yes. I think that looking at those papers and looking  
3 at what was going on in the medical world at the time,  
4 when you have -- in the US, the numbers are going up,  
5 so I think it was the first MMWR report, it's two at  
6 then it's six, and then it's 11, so it's obviously  
7 rising. When we have Professor Kernoff talking about  
8 an epidemic being ludicrous and he says the risk is 1  
9 in 1,000 and then Professor Christine Lee says the  
10 incidence is 1 in 1,000, and I also think it is wrong  
11 to use that term. We were all group of patients, we  
12 were not thinking about the specific difference  
13 between incidence and risk, we were just seeing the  
14 statistic.

15 Also, was it, I think Professor Tuddenham said  
16 it breaks the first rule of epidemiology. Just  
17 because you've got two so far, doesn't mean you'll get  
18 none later and, therefore, it was a ludicrous  
19 statistic. And at the time there were papers  
20 published amongst -- about to be cohorts of  
21 haemophilia there was one I think in Newcastle and  
22 these were all at the start of 1983, which found that  
23 we had a reversal of the C4/CD8 ratio amongst our  
24 groups and exactly the same finding was being seen  
25 amongst gay men who were on the scene and having a lot

24

of sex and likely to have HIV, and was also seen amongst drug users and that had been published at the end of '82, and then, yeah, there's the article in the New England Journal of Medicine, Desforges, which talked about this.

Reading those papers, it seems to me almost impossible to see this wasn't going to get worse and, even if they thought it was going to be a smaller epidemic, the continuous -- "reassurance" is not quite the right word, but a desperate attempt to avoid panic, is what it seemed.

I can remember a friend of mine, I'm not going to mention his name, because it hasn't come out of this, who was the chair of Birchgrove at the beginning, and he talked about -- the expression he used was "don't scare the horses", that our clinicians were always "don't scare the horses, never frighten anybody, say anything to keep calm", and there was also your phrase, sir, which was "erring on the side on the optimistic", always, it seemed to me, and it happened later, I felt, with non-A, non-B hepatitis C.

But it seems extraordinary, looking at those papers, not to see there is an obvious link here, so it must be something that is being transmitted amongst all these groups, blood products is the obvious way of

25

fears.

Also, there's hints in some of the evidence we've had that it wasn't always successful. Professor Bloom doing at a talk at The Haemophilia Society AGM and people walking out because of what he was saying, which was that it's not going to be an issue or that it's very rare. The fact that those worries were there, the fact that, yes, the Daily Mail I think it was, produced an article about "killer blood" and people were worried about that, and the response to that was not to see that as an issue to be taken very, very seriously, and "What are we doing, should we be making changes?" but "We should complain to the Press Complaints Commission, and we should calm people after that". I'm not sure tabloid headlines were a great way but it was accurate.

**Q.** When we come on to hepatitis C, what was the impact, what was the situation in relation to stigma and hepatitis C?

**A.** Mm. My impression of the stigma of hepatitis C was it was a lot less but that was because the disease was not quite so public. So the first thing you had to explain often was what it was and a lot of people I told when I talked about having hep C would go "Oh, I think I've had a vaccine against that", and you go

27

doing it, and we also knew that blood products were much better at spreading viruses than something like cryo.

You take 20,000 people's blood, mix all their diseases together, and then you inject it into a haemophiliac. It's ...

**Q.** Can I ask you this: you've spoken about stigma in the early 1980s, and we know it went on for a long time, but at that very early stage, what impact do you think that stigma had on clinicians' assessment of the risks?

**A.** I think, because the condition was so stigmatised, they just couldn't believe it would happen to their "children". We were an innocent -- a nice group of people that they had looked after. We were not like these disgusting loathed groups and, therefore, I just think, as an emotional response, they couldn't -- they weren't believe it, almost. And because it was a disease that was seen as having almost a 100 per cent death rate, which is massive, extraordinarily high, for a disease, I just think they denied it both to themselves and to us, and that led to that continuous -- the phrase that appears in so many Haemophilia Society leaflets at the time, "allaying unnecessary fears", rather than recognising necessary

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"No, that's a different one", so to explain that.

But the main -- or the main area of stigma within that, again, comes out as -- it's relationships, trying to form a relationship when you've got to tell someone you've got something that is -- I mean, in that case, it took a long time before we knew how sexually transmissible it was, and just explaining that to someone. And in medical services, where they just were silly, so dentists, particularly bad for both diseases, if you were referred to a different department. And I think that also persisted with the haemophilia doctors, a lot of them, not referring to liver doctors. They hadn't done for non-A, non-B and they still weren't, when people were diagnosed with hepatitis C.

That, again, seems extraordinary: "I've just diagnosed a person with a new condition and I'm not going to get the experts to talk to them about it".

I think the way they did -- a lot of them did the hep C diagnosis was just so awful, and it's almost a terrible thing to say but they'd had a practice with HIV and they still got it wrong. It's the way it was done to so many people.

**Q.** You talk in your statement that part of the stigma was the connection between hepatitis C and intravenous

28



1 drug users.

2 A. Yes.

3 Q. First of all, in terms of the treatment approach. You

4 have said that clinicians didn't necessarily refer on.

5 A. Yes.

6 Q. How much do you think that the stigma attached to

7 hepatitis C influenced the treatment pathways that

8 were followed?

9 A. I think it influenced it a lot. I mean, certainly

10 amongst liver clinics, they were often very reticent

11 to treat me, certainly current drug users, which then

12 makes it odd that they would have been much happier to

13 treat people with haemophilia. But I think it was

14 that mixture of also not wanting liver doctors perhaps

15 to know that they'd got this disease as a treatment

16 from the haemophilia doctor. And that -- I'm sure

17 also there were people with haemophilia who are

18 struggling with this diagnosis, and they don't want it

19 then to be associated. Some of the stories we heard

20 at the beginning about people's treatment by just,

21 like, neighbours and stuff was horrible.

22 I think that stigma, and certainly when you're

23 diagnosed with a condition, you start to learn more

24 about it, you will pick up, if you've got hep C, "Oh,

25 it's predominantly a disease of drug users", or it

29

1 the other because they were also a bit mixed, the

2 stigma and the protection.

3 Q. And through your contacts in your campaigning and the

4 organisations you've been involved with, what impact

5 did that treatment approach have on the relationships

6 between clinicians and patients?

7 A. I think in the long term, it -- it ruined it. It's

8 the -- if -- for someone like myself, if you went

9 through the period of lots of repeated messages that

10 it's always better to take your factor, the risk of

11 the -- of AIDS is far -- you know, the risk of not

12 taking your treatment is far outweighed, I'd keep

13 taking it. And then so many of us were diagnosed.

14 And then you have the situation of hepatitis C.

15 So even for those who didn't get HIV, who must

16 have spent a couple of years wondering and hoping that

17 the -- and by the time they get to be more confident

18 they have not got it, we then go through that period

19 with non-A, non-B, and we get diagnosed with

20 hepatitis C, and the initial response is, "It's fine,

21 it's a mild disease, you don't have to worry", and

22 it's not. And when it becomes clear it's not, all of

23 us -- and there might have been a very small number of

24 very young children who would have been born after the

25 HIV thing, before hep C, but everyone lived through

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1 seems to be. It certainly was at that time. So if

2 you're also not comfortable with that and your

3 perception is going to be, "Well, if I go to the

4 clinic that's all I'm going to see and I don't want to

5 be sitting in a room with those people", then you're

6 not going to be pushing your doctor for a specialist

7 referral. And if your doctor is happy to continue on,

8 bumble away in an area that's not their speciality,

9 that's what's going to happen.

10 Q. So from your perception, how much of it was the

11 doctors being protective towards patients who were

12 uncertain, and how much of it was the doctors being

13 influenced by the stigma around the disease? Was it

14 six of one and half a dozen of the other?

15 A. Probably. They're sort of tied up because if the

16 doctor is prejudiced or thinks that drug users,

17 "That's a terrible thing, you don't want to be

18 associating with them", then they're acting on that

19 stigma, but if they're also -- if that's also a part

20 of being protective, and there's also that -- yeah,

21 just general protection of looking after their

22 patients. And if we had a very patriarchal 'Doctor

23 knows best' situation, and that they -- a lot of

24 people would just do what their doctor told them, but,

25 yeah, I suppose kind of half a dozen of one and six of

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1 that or everyone's parent lived through that, it's

2 really hard to trust a doctor, when they got it wrong

3 so badly twice, to have minimised the severity of one

4 and got it wrong, even when they knew that there was a

5 proportion of people with -- had cirrhosis, and there

6 were -- minimising that and saying, "Oh, well, it's

7 only a small number" -- it seemed quiet a large number

8 to me -- and then it progresses and gets worse, is --

9 and, yeah, one in a thousand and then over a thousand

10 people get HIV, it -- it's really hard to trust

11 someone when you think: well, what is your knowledge?

12 And so, yeah, for me that was: well, I need to

13 find this out for myself. I need to be the person who

14 knows about it. And certainly I always knew more

15 about HIV treatment than any of the haemophilia

16 doctors I saw. I knew more about which combinations

17 worked, which didn't, which you couldn't have

18 together, that type of thing. And I just -- I ignored

19 them if they ever wanted to speak about anything other

20 than haemophilia because I didn't think they had the

21 knowledge.

22 Q. You've worked with both haemophilia focused

23 organisations and broader AIDS organisations over the

24 years.

25 A. Mm.

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1 Q. Before we delve into some of the detail of that work,  
2 can you tell us -- give us an overview of the  
3 differences you've observed in the approach to  
4 treatment, particularly, between those two groups.

5 A. Um, well, it's particularly noticeable with HIV.  
6 Within the wider HIV community, knowing about your  
7 treatment, you make choices about what treatment you  
8 have. And even before we had treatments, it -- the  
9 older AIDS wards, the way that they were constructed  
10 was so different that -- I'll probably talk a lot now  
11 about patient-centred, but it was so much more.

12 So, little examples. I can remember visiting  
13 a friend on an AIDS ward and his partner is lying in  
14 bed with him. If you went on a haemophilia ward or an  
15 orthopaedic ward, if someone sat on your bed, they  
16 would be immediately moved away. On an AIDS ward,  
17 people were putting up decorations when someone was  
18 going in. The whole staff team's approach  
19 being: these are the options, this is the upside, this  
20 is the downside. What do you want to do? You're the  
21 one in control. You're the one making the decision.

22 And how -- I would try and take that into --  
23 with my haemophilia clinician, it was much harder.  
24 This is a kind of damning statement but I can  
25 particularly remember talking about one AIDS doctor

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1 organisations and in the support organisations that  
2 you were involved with as between the haemophilia  
3 support organisations and the broader AIDS  
4 organisations?

5 A. Yes, the -- I mean, the broader AIDS organisations  
6 were always much more comfortable with campaigning.  
7 It was part of what they had to do. Whether it was  
8 campaigning around stigma, whether it was campaigning  
9 for rights, anti-discrimination, for people to get  
10 treatment where it was expensive, and also that they  
11 promoted that idea that, as patients: here is the  
12 information for you, here is the treatment  
13 information, you can make the decisions.

14 So there were two organisations that their sole  
15 function was providing treatment information to allow  
16 patients to know things, because at the time, of  
17 course, the Internet wasn't available, or only came  
18 later, so they would produce a newsletter, which just  
19 listed -- and there would be summaries of trials of  
20 HIV drugs, of opportunistic infection treatments, that  
21 they would just post to you so you could get it and  
22 you could find it out.

23 It -- we just didn't have that. The Haemophilia  
24 Society didn't work in that way. There was, later,  
25 a number of meetings around hep C that I remember, but

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1 quite early on with my doctor for a long time and just  
2 saying, "The main difference is he's a human being",  
3 and that he -- yes, he did not take that attitude  
4 that, "I have decided what is right for you, and you  
5 should be following it, we shouldn't be arguing about  
6 it".

7 I suppose, like a lot of people with  
8 haemophilia, I started to develop techniques of how  
9 you manipulate your doctor into doing sometimes the  
10 thing that I've worked out is right, and sometimes the  
11 thing that I want. And I would always do it with  
12 knowledge. I would always try and make sure I knew  
13 more than them. And then the -- asking them questions  
14 they can't answer makes it harder for them to take the  
15 option that they've gone for.

16 That whole approach of, yeah, the patient being  
17 in charge of their treatment, the patient deciding on  
18 risks, the patient deciding on what treatment they  
19 have, was just so extraordinarily different. And it  
20 feels such a shame that there was something that if we  
21 had had that earlier ...

22 Q. That's very much the approach from the clinicians on  
23 the AIDS wards.

24 A. Mm.

25 Q. Did you see a similar difference in the campaigning

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1 I don't think there were ever any meetings around --  
2 going round the country saying, "There's this risk  
3 of HIV."

4 It wasn't a treatment organisation in that  
5 sense, and it didn't look to be knowledgeable about  
6 that. So certainly when there were issues like NICE  
7 appraisals, it would often be me who was the person  
8 representing -- because I'd read up on this, that  
9 it -- there were some from the Society, some people  
10 would know a bit, but -- and when I compare that even  
11 to something like the hep C trust, they would always  
12 have someone who knew what was going on with those  
13 drugs. And they saw that as part of the way to do  
14 things as a charity.

15 The other issue with -- yeah, a lot of the  
16 AIDS charities, they were expecting -- they knew you  
17 were going to die. They treated you as though you  
18 were going to die. They didn't deny it or hide it or  
19 get scared about it. That was what was going to  
20 happen. And I can think -- at Body Positive Brighton  
21 we used to have a corner and you'd go in every month  
22 and see what names were written on there, and that was  
23 the person who'd died this week, this month.

24 Q. You talked about how you came to seek to have as much  
25 knowledge as possible so you could influence your

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1 care. Has your campaign work impacted on the care you  
2 have received in any other way?

3 A. Um ... it's certainly not had any impact in the hep C  
4 or HIV sector. It's probably helped. And certainly  
5 there's a group of clinicians I know in those sectors,  
6 and they enjoy talking about medical stuff, that's  
7 their job, their hobby, their interest, so that works.

8 I mean, I -- in haemophilia, I'm sure it  
9 frightened some doctors, and I may not have got the  
10 most comfortable response from a number, and I know  
11 the Macfarlane Trust at one point, I was -- I was on  
12 the list of people who only ever spoke to the chief  
13 executive, which -- I can remember being surprised  
14 when I spoke to a friend and they used to speak to the  
15 social worker, and I was like: they've employed  
16 a social worker? When did that happen? Because --  
17 and I know this from a couple of other people -- if we  
18 ever rung up, we were immediately put through to the  
19 chief executive. And I'm sure that was because we  
20 were seen as the "difficult people".

21 Q. I want to work through some of the organisations  
22 you've been involved with. Very early on, you set up  
23 a self-help group in Swansea --

24 A. Yes.

25 Q. -- when you were first diagnosed. What can you tell

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1 to, and there is someone else in a wheelchair with his  
2 mum. And the mum says to me at one point, "I've seen  
3 you at the haemophilia clinic". And I thought: Oh!  
4 I know what the special dentistry clinic is for then.

5 So that was -- yeah, that was what we did. And  
6 we met a few times. And then we all got jobs. I came  
7 to the end of my degree and so we kind of empowered  
8 ourselves out of existence.

9 And, mm, that was -- none of them died. That  
10 was good. Mm.

11 Q. You weren't particularly involved with Haemophilia  
12 Society initially, but you've said in your statement  
13 you rejoined them in about 1983, when there were --  
14 when it was becoming apparent that AIDS was an issue.

15 A. Mm, yeah.

16 Q. What was your involvement with them thereafter?

17 A. Thereafter? I mean, I'd joined because -- and I think  
18 it was because I'd seen the TV programmes, either the  
19 World in Action or the Horizon ones, and I remembered  
20 that, and that was why I needed to join and then --  
21 and got information.

22 For the first few years I was probably just  
23 receiving information. And then, after I was  
24 diagnosed, they sent out, I think, a request: was  
25 anyone prepared to do media work around HIV? And

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1 us about that group?

2 A. It -- I was a volunteer at the drugs agency there, the  
3 Swansea Drugs Project, and they'd come and done a talk  
4 on my psychology degree, and I thought: ooh, that  
5 sounds interesting, I'll go and do that. And I'd  
6 met -- I did some training for them, actually, around  
7 HIV. And I met a guy there who was positive, and then  
8 I also got a bit involved -- or I'd -- obviously I'd  
9 been in touch with The AIDS Line, which was the  
10 support agency, and there was a gay guy there who was  
11 positive. So I just suggested we -- "Why don't we  
12 form a self-help group, the three of us?" And they  
13 all met in my front bedroom -- the front room of the  
14 house I was renting as a student, and we saw each  
15 other.

16 And the only other person that I met was when  
17 I went to the dentists, and -- that was very bizarre  
18 experience of at the hospital, having arrived at  
19 reception and the receptionist obviously being scared  
20 of me, having seen my name and not wanting to touch my  
21 bit of paper that I'm holding with the letter on, and  
22 being led down a corridor, past a no entry sign,  
23 through a building site, to a -- it was really  
24 a corridor with some filing cabinets in and three  
25 chairs, and there are the two guys, that I say hello

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1 I wrote to the worker there, and said, "Yeah, I'm  
2 prepared to do media work." I was a student, I didn't  
3 have any children to worry about stigma towards. My  
4 parents were happy with it. I'd then got a -- or  
5 later on I then got a job with a drugs agency, so  
6 I was also working with people with HIV, so they were  
7 comfortable with it, so I -- it felt the right thing  
8 to do. I was in a position where I could do this,  
9 with minimal impact on my life and my dependents and  
10 carers. So that was the right thing.

11 And yeah, they -- I did a number of conferences  
12 for them, where they were kind of building  
13 relationships with some of the wider  
14 HIV organisations, so the Terrence Higgins Trust  
15 conference I went to and spoke about haemophilia a few  
16 times. The National AIDS Trust, after that formed,  
17 Body Positive, probably a few others. And I did --  
18 yeah, I was in some newspapers and I did -- I did  
19 appear on TV a few times, but I can't remember what  
20 programmes I was on. It was a news one, I think. Mm.

21 Q. First of all, taking the conferences that you spoke  
22 at, do you recall what the aims of those conferences  
23 were? What were you seeking to achieve by being part  
24 of them?

25 A. Um, for me, it was trying to bring haemophilia into

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1 the wider HIV world, because it wasn't involved, it  
 2 was separated off and, to a large extent, some people  
 3 choosing to separate off. But also to influence the  
 4 HIV sector, which was predominantly gay men. So the  
 5 culture, if that's the right word, around heterosexual  
 6 men, is quite different. Even the often very basic  
 7 and almost stereotypical things. Like nobody liked  
 8 football when I went to an HIV organisation, so if  
 9 they were going to put on an event during the World --  
 10 on the World Cup final or the FA Cup, I was going to  
 11 say, "No, because you're not going to widen your  
 12 audience and get people at that point", and to try to  
 13 move them so that not every event they did was always  
 14 in a gay club or a gay pub, that if they were going to  
 15 do prevention work they needed to be wider. And to  
 16 understand about haemophilia, that -- I mean, there  
 17 was always this perception of saying "blood  
 18 transfusions", and I was never sure how much to push  
 19 to say, "It's not blood transfusions, it's blood  
 20 products, the risk of transfusions is much less in  
 21 products", it's getting to the almost inevitable stage  
 22 sometimes. The fact that we had hep C as well, which  
 23 at that point wasn't -- was an issue amongst some drug  
 24 users with HIV but not really others. And to build  
 25 bridges between The Haemophilia Society and those

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1 that took part in that, and just talked about what had  
 2 happened in my life and what it meant to be a young  
 3 man who was going to die.  
 4 Q. We've got an example of one of those articles, if  
 5 I can put that up. Soumik, it's HOSC0022166, please.  
 6 If we can go to the first column. It's an article  
 7 from the Sunday Times, 15 October 1989, where you've  
 8 talked about your own situation, and also dealt with  
 9 the -- some of the legal process. If we can go to the  
 10 bottom of the second column, Soumik.  
 11 I'm sorry, it's the bottom of the first column.  
 12 It talks about you having been involved in the  
 13 legal action, and saying:  
 14 "How can people be put in my situation? I can't  
 15 tell you how used and worthless I feel sometimes."  
 16 A. Mm.  
 17 Q. "Money would not compensate me for the loss ..."  
 18 Sorry, could we have the top of the ...  
 19 "... at least it would give me the security to  
 20 make the best of the life I have."  
 21 So it tells your story but also talks about the  
 22 need for action.  
 23 A. Mm, yes. And that worthlessness and loss, that  
 24 mixture of the stigma around you've got this horrible  
 25 disease, but also that -- a health system that doesn't

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1 organisations. In some ways I felt I was the only one  
 2 who was -- being done for that because I was the only  
 3 one prepared to.  
 4 Q. In terms of your media work, again, what were the aims  
 5 of doing that?  
 6 A. That was part of the campaign for compensation. And  
 7 having been given this through our medical treatment  
 8 to then just be ignored by Government and then pretend  
 9 that, well, that's just what happens. Then there was  
 10 the initial -- I can't remember whether -- I think  
 11 I started before the initial announcement of the  
 12 Macfarlane Trust money, to make it public, that this  
 13 was a -- a wrong that was done, certainly. Under that  
 14 Government and the previous governments, they had  
 15 failed to protect the health of over 1,000 people, and  
 16 we expand later on for hep C., and that at they needed  
 17 to be held to account for that. And because I could  
 18 do public work, I could put my face to it and I always  
 19 felt it was better if you could have a face to  
 20 a stigmatised condition, if you're silhouette, it can  
 21 almost make it repeat and highlight that. I could do  
 22 that, and I wanted to do that. I was happy to appear  
 23 in -- it was part of one of the newspapers, I can't  
 24 remember if it was The Times or The Sunday Times, did  
 25 it as a sort of campaign, so I was one of the people

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1 care and a Government that doesn't care that people  
 2 are going to die, that's what happens, and, yeah, the  
 3 legal process, and I started -- I was fortunate being  
 4 a student when I started my legal action, which meant  
 5 I got legal aid, so I could start suing the --  
 6 I wanted to sue everybody. It was like you had to sue  
 7 your doctor, your health authority, your hospital,  
 8 Department of Health, the Secretary of State for  
 9 Health, everybody.  
 10 My doctor was at least very good about it. She  
 11 just said, yes, you should. She didn't take it at all  
 12 personally. And it became fairly clear to me actually  
 13 very quickly that the legal campaign was never going  
 14 to win, but that didn't matter. It wasn't about that.  
 15 It was keeping it in the newspapers, it was putting  
 16 pressure on MPs, it was also highlighting how the  
 17 continuous back and forth of "Will you make these  
 18 documents available", "No, in the national interest  
 19 they shouldn't be available", and you'd have minutes  
 20 of blood transfusion committee meetings being kept  
 21 secret for the national interest. Are they really  
 22 that exciting? And that was a way to do it. And also  
 23 there was a point where I realised, if we lose in  
 24 court, that looks so awful for a government: we  
 25 dragged everybody through this, probably half of them

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1 have died, and we're still refusing to do anything  
2 about it.  
3 **Q.** Just staying with the media work you were doing, was  
4 there any impact on you personally because of that  
5 media work? Did anything follow from that?

6 **A.** There was a few negative things. I did get dog shit  
7 through the door a few times but I don't know what  
8 that was -- I'm guessing it was about that, because it  
9 was about that time. But, again, that was pretty  
10 standard for people with HIV. It is horrible, but  
11 it's what would happen.

12 The strangest one was out walking my dog and  
13 a woman came up to me and said, "I saw you in the  
14 press" or something, and I was like "Oh, what's this?"  
15 and she said, "Yes, you were Disease of the Week in  
16 Bella Magazine", which completely took my breath away.

17 It wasn't huge. There were bits, and certainly  
18 some of the things -- I've also had some really  
19 positive things. I can remember doing something and  
20 it would probably be 10 maybe 15 years ago, just in my  
21 local paper in Brighton and going into the butchers  
22 and he'd read it, and he was just, "Wow, that's awful,  
23 what a terrible thing to happen to you". And I can  
24 remember going to football one day and one of the guys  
25 I sat next to, who I probably might have said I had

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1 then one of them new a landlord of a pub so they all  
2 met in the Birchgrove pub, which is in the Birchgrove  
3 area of Cardiff, and that's why it's called  
4 Birchgrove, and it started off, everybody would just  
5 go to the pub and it was the guys with haemophilia,  
6 their wives, parents, children, anyone kind of  
7 associated with it. And it was just to meet and talk.

8 And I was in Swansea, so a nurse -- I think  
9 they'd got a new nurse at the Swansea clinic and she  
10 knew about it from the Cardiff centre, and so I used  
11 to go across to see them, and then we -- or they  
12 organised, yeah, a week -- a holiday away for  
13 everybody, if we wanted to go.

14 It started off very much, it was, yeah, a place  
15 to talk about this that was safe. A place to drink,  
16 a place to make jokes about it, because everyone is  
17 always very serious about -- inevitably, when you've  
18 got a disease that's going to kill you. And to talk  
19 about the hassles we had, the difficulties we had.  
20 And to find out how other people had done things, and  
21 to share that kind of information. And it was also  
22 really nice at that point at the beginning, because it  
23 was so mixed. It wasn't just people with haemophilia  
24 and HIV having to meet and talk to each other, it was  
25 the wider family of all those people who lived

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1 haemophilia but I might not have, and he just -- we  
2 were on the bus and he sat down and he said he'd read  
3 the article and sort of, "God, yeah, you should  
4 campaign, what can I do to help?"

5 So if people were nasty to me, I didn't see them  
6 as people because, yeah, they would do things  
7 invisibly, if you like. But the majority of people  
8 were very sympathetic, that I spoke to.

9 **Q.** You were also very involved with the Birchgrove  
10 Group --

11 **A.** Yes.

12 **Q.** -- and the Inquiry has heard some evidence about  
13 Birchgrove, but can you tell us from your perspective  
14 the role it played in providing support to the  
15 haemophilia community? I want to come back to its  
16 interactions with McFarlane later --

17 **A.** Okay, yeah.

18 **Q.** -- but for now if we can talk about the support that  
19 it provided.

20 **A.** Yeah, well, it started off in Cardiff, and there was  
21 a social worker there, Mary Dykes, and she got  
22 together a group of people, and sort of pushed them  
23 a bit, and they decided, these four guys, that they'd  
24 start a group. And I think they first had a meeting  
25 in a hospital and that didn't feel at all right, and

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1 locally.

2 **Q.** That group developed to also provide information in  
3 a more structured format. What was your involvement  
4 in that?

5 **A.** Yeah, it went on -- Birchgrove had a number of phases,  
6 it would do something and then go away for a bit and  
7 then it would come back and do something. So the  
8 initial bit -- yeah, two particular people, one of  
9 whom has given evidence about editing the magazine, we  
10 produced a magazine, which looked -- we tried to look  
11 at issues that were relevant to us. I wrote articles  
12 for it. I think one of the articles that was shown  
13 during that day was actually written by me, because it  
14 had a lot of the things that I was very vexed about at  
15 the time, such as: why aren't people referred to liver  
16 doctors? But I -- yeah, I contributed to it in that  
17 sense and I would give ideas.

18 I also acted as a link between Birchgrove and  
19 some of the wider HIV organisations, because I was in  
20 touch with them. And when I moved away, I would just  
21 go back when I could, to see people in Cardiff.

22 **Q.** In terms of those communications with people who were  
23 part of Birchgrove, what were the sources of  
24 information that the group used to inform the  
25 communication?

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1 **A.** I mean, some of the magazines are very much about sort  
2 of feelings or, I don't know, support type things. So  
3 it was quite easy amongst our group to get that type  
4 of thing. In terms of the medical information, I can  
5 remember the chair, he would go to Cardiff University  
6 Library and he would read medical journals, so he was  
7 finding stuff, or we'd take stuff from some of the HIV  
8 treatment organisations, and a lot of them would  
9 happily let you reprint, republish. So we'd do that.  
10 In terms of things -- if it was about social  
11 care or things you might be able to get, or housing  
12 issues, it would often be speaking with social workers  
13 or people who knew that system. Those would probably  
14 be the main, those would be the main sources.

15 **MS FRASER BUTLIN:** Sir, I'm about to move on to  
16 Birchgrove's interactions with the Macfarlane Trust  
17 which would take us a little bit more time than we'd  
18 normally have before the break. I wonder if we take  
19 a break now and I will pick it up afterwards.

20 **SIR BRIAN LANGSTAFF:** Let's do that and take half an hour  
21 until 20 to 12, so a break for everyone, 20 to 12.

22 (11.11 am)

(A short break)

24 (12.40 am)

25 **SIR BRIAN LANGSTAFF:** Yes.

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1 The chair at the time, I can remember at  
2 meetings when anger was expressed to him, the  
3 Reverend Alan Tanner. He -- it just kind of didn't  
4 seem to have any impact on him. And I spoke to one of  
5 the trustees afterwards, and they said he interprets  
6 all this is anger about the poorness of the  
7 administration as us just being angry because we've  
8 got HIV, rather than we had a legitimate concern that  
9 this organisation was not doing what it was meant to  
10 do. It obviously dropped the bereaved very quickly.

11 And then later, with Birchgrove, as we would  
12 speak amongst each other about what grants people had  
13 got and what they hadn't got, how they'd got them, who  
14 they'd spoken to, who they hadn't, just complete  
15 inconsistency. The -- when something was available  
16 and then it wasn't. The push for -- eventually some  
17 guidelines were written, but they were just so vague:  
18 a "health need". And it was like, well, what can you  
19 get and what can't you? And some people are getting  
20 some things and some getting others.

21 The one I particularly remember, and we wrote  
22 about it in Birchgrove magazine, was the issue of  
23 sperm washing, that it wasn't available, then it was  
24 available, then it wasn't available, then, like, it  
25 was available, and it was just -- that seemed to

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1 **MS FRASER BUTLIN:** Robert, you were a registrant of the  
2 Macfarlane Trust from the outset.

3 **A.** Yes.

4 **Q.** And you attended meetings with Macfarlane Trust both  
5 in that capacity and also as part of the Birchgrove  
6 Group; is that right?

7 **A.** Yes, that's right.

8 **Q.** From 1989 you've noted in your statement that there  
9 were a lot of concerns being raised about the  
10 Macfarlane Trust, both by individuals and by  
11 Birchgrove. Can you tell us about those concerns?

12 **A.** Yes, they were -- I can remember a number of meetings,  
13 and there -- the main issues were about the  
14 organisation, how slow it was to make decisions  
15 initially, particularly on initial grants. When you  
16 had people who were dying of AIDS in hospital and they  
17 were going home to die for the last few days, you  
18 couldn't wait a month for a committee to meet to  
19 decide whether they could have some equipment.

20 The process that people would have to go through  
21 to get those single grants -- which, again, when  
22 you've got someone either -- who is really ill or  
23 someone who is caring for their person who is really  
24 ill, it was -- it always seemed too many hoops and  
25 boundaries and difficulties.

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1 typify this back and forth of the group that was  
2 making those decisions.

3 And the first two members of staff, one was  
4 the administrator and one was a social worker, and the  
5 administrator was just so gruff and blunt that -- they  
6 did not come across as sympathetic. And this was,  
7 yeah, to a group of people where, yes, a lot of us  
8 were angry about what had happened, but also we were  
9 angry because these systems were not working. It --  
10 it did not do what it was meant to do.

11 **Q.** And in the early nineties, Birchgrove produced  
12 a number of reports or commissioned reports.  
13 Sometimes with the Haemophilia Society --

14 **A.** Yes.

15 **Q.** -- and sometimes the Macfarlane Trust.

16 **A.** Sometimes we'd convince them to pay for it, yes.

17 [Laughs]

18 **Q.** Can you tell us about them and how they came to be  
19 produced?

20 **A.** They came out of frustrations, always, that -- I think  
21 the first one that the Macfarlane Trust did itself was  
22 a customer -- it was a customer service -- and that  
23 was because we were saying, "You're not doing what  
24 you're meant to do to, you're taking too long, your  
25 administrative processes are poor, you're

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1 inconsistent". And they employed a company and they  
2 produced a report, and the report just said they were  
3 really good because they answered the phone quickly or  
4 they answered -- they turned round letters very  
5 quickly. And it wasn't -- as I mentioned in my  
6 statement, my friend who was chair of Birchgrove at  
7 the time, it doesn't matter how long it takes them to  
8 answer the phone, it's what they say when they answer  
9 it that mattered. And that was what we were trying to  
10 get at.

11 So after that --

12 Q. Can we just stay with that survey report?

13 A. Yes.

14 Q. It's the Public Attitude Survey report?

15 A. Yes.

16 Q. The PAS report?

17 A. Yes, PAS.

18 Q. Which was in 1994. The criticism of Birchgrove, as  
19 I understand it, was that it had, as you say, dealt  
20 with the speed of answering the phone but not the  
21 substance.

22 A. Yes.

23 Q. Can you unpack that a little bit more for us. What  
24 did Birchgrove feel should have been addressed?

25 A. What should have been addressed was, first of all,

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1 the Macfarlane Trust, and why they were so difficult,  
2 and why they were not meeting needs and they were --  
3 why they had decided that their sole purpose was to  
4 give out little bits of money in a sort of slow  
5 process.

6 Rather than providing services in a wider way  
7 rather than supporting people and supporting each  
8 other, those types of things. And, yeah, a couple of  
9 the people in Birchgrove wrote that report, saying,  
10 "This is a better way forward", and widening their  
11 services, if not necessarily demanding lots of money  
12 off them.

13 So yes, it was then very disappointing when we  
14 got a report back of their own making which was just  
15 a process one. Mm.

16 Q. And then after the PAS report, there was the Keeping  
17 It in the Family study which was done in Birchgrove in  
18 The Haemophilia Society?

19 A. Yes.

20 Q. And after that the Voice of the Registrants  
21 document --

22 A. Yes.

23 Q. -- in 1998.

24 A. Mm.

25 Q. Those last two, what were their themes?

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1 being -- it sounds awful, but being nice to people on  
2 the phone, being sympathetic, being understanding when  
3 people were angry, because that shouldn't be  
4 surprising. And upset. That -- having a system that  
5 allowed them to make a decision quickly. And also  
6 being able to provide things that were needed and, as  
7 our needs changed, coping with that quickly. And I  
8 know to some extent that's difficult, but that's --  
9 that was their job.

10 It was that they would refuse things and then  
11 agree them later when they were -- it was out of date.  
12 It was the substance of the communication rather than  
13 the process of the communication. And we very much  
14 felt that the report just ignored substance. It went  
15 totally about process.

16 And yeah, it just missed the whole point of our  
17 complaints about the way -- what they were saying to  
18 us, the way they were being inconsistent.

19 Q. Before the PAS report, there had been a discussion  
20 document produced by Birchgrove in November '93 called  
21 Living with Haemophilia and HIV.

22 A. Mm.

23 Q. Just backtracking to that, what was that dealing with?

24 A. That came out of a conference, a Birchgrove  
25 conference, and just talking about the difficulties of

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1 A. With those, we tried to be a bit broader. When  
2 you're -- when you are continuously trying to get  
3 someone to do something differently or change or get  
4 better and you're -- it's not getting anywhere, you  
5 try different tactics. So the first one of those,  
6 Keeping It in the Family, was: well, maybe if we make  
7 it a wider thing and it's not just 'you need to do  
8 something' but it takes that much more politic line of  
9 "We need to do something, you need to do something,  
10 The Haemophilia Society need to do something, and  
11 let's all work together and then we all get something  
12 done". And that had a number of recommendations  
13 across different areas.

14 And the Voice of the Registrants I think came  
15 out because there was a need -- there was always  
16 a need for a needs assessment. Before the Macfarlane  
17 Trust were prepared to do things, they would always  
18 talk about, "Well, we need to do a needs assessment".  
19 So we'd do one and then it would be out of date by the  
20 time we'd got round to doing something, so they'd do  
21 another needs assessment. And that was one of the  
22 ways we thought that if we can get, yes, the voice of  
23 the registrants, what people feel they need and what  
24 is important to them, then it becomes a much longer  
25 lasting document. We can go back to it a few years

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1 later, and say: if we look at that, you can see here  
 2 some of the things that are needed.  
 3 Q. So Birchgrove are producing these reports over the  
 4 years, providing them to the Macfarlane Trust?  
 5 A. (Nodded)  
 6 Q. And what was the response you got in relation to them?  
 7 A. The response was generally -- it's kind of a Civil  
 8 Service response, I suppose. It was, "Oh, yes, yes,  
 9 we need to do better, and we can look at these  
 10 things". And I mean there would be small things that  
 11 would change, but the fundamental ability of the  
 12 organisation to do what it was meant to do never  
 13 changed. And the idea of it moving into other areas  
 14 just took so long.  
 15 We did -- they did, after a long time, start to  
 16 provide finances to run residential weekends so people  
 17 could get together, and so Birchgrove stopped having  
 18 to raise money for that, which was, of course, a great  
 19 help.  
 20 And then, when one -- they'd had the first  
 21 couple and it was suddenly, "Oh, this is such a great  
 22 idea", and that felt -- that felt so frustrating.  
 23 We've been telling you for ages to do this and you  
 24 finally get to do it, and you think: ooh, isn't it  
 25 really good?

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1 consultation. But as far as I can tell it never  
 2 consulted.  
 3 I wrote back and said I'd happily join, and  
 4 I got a letter saying I'd joined, and then I don't  
 5 think I was ever consulted on anything.  
 6 So the Partnership Group, we did at least get  
 7 the chance to discuss things, and some quite strategic  
 8 higher level, such as: the approach you're taking of  
 9 dribbling the money out very slowly will not work with  
 10 Government. You need to run it down to nothing and  
 11 embarrass them, and only when they're embarrassed are  
 12 they going to stump up more cash.  
 13 And that was a big source of tension on the two  
 14 sides between some of us and the way that those  
 15 running the trust were -- they'd -- yeah, not prepared  
 16 to support campaigning. That also seemed annoying.  
 17 If you won't do it publicly, will you provide support  
 18 facilities for it?  
 19 Q. One of the things you were particularly -- you  
 20 particularly sought to achieve was having registrants  
 21 on the trust board?  
 22 A. Yes.  
 23 Q. And you sought to become a trustee?  
 24 A. Yes, yes, I offered myself to be a trustee at  
 25 a meeting very early on, and it was when -- it became

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1 And they ran for, yeah, quite a long time. And  
 2 they had a big impact on people, as the Birchgrove  
 3 conferences had, bringing people together, and  
 4 families.  
 5 Q. The Partnership Group then came into existence. What  
 6 was your involvement in that?  
 7 A. I discovered a letter, actually, I'd had -- that I  
 8 wrote to Peter Stevens about the Partnership Group  
 9 quite early on, where I said, "What is the point of  
 10 this group? What is it trying to do?" And it  
 11 reminded me that it formed actually out of a previous  
 12 committee which was organising events, and that was to  
 13 organise some of the initial weekends. There was  
 14 a few from The Haemophilia Society, a few people from  
 15 Birchgrove and a few from the Macfarlane Trust, and it  
 16 was a very -- it was a task group. You did the event.  
 17 And then, yeah, they decided to introduce a -- the  
 18 Partnership Group, and they really just migrated  
 19 everybody over from that to this.  
 20 And it was meant to be a form of communication  
 21 between the registrants who were interested in going  
 22 forward and the Trust itself. It was actually the  
 23 second attempt they'd had to do that. When it first  
 24 formed, they -- they wrote to people and asked if they  
 25 could have -- I think it was a letter group for

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1 apparent, and I think it was announced at the meeting,  
 2 and it was probably the registrants at the meeting  
 3 asking: are any of the trustees paid for the role they  
 4 do? And it came out that: no, but it is possible to  
 5 be a paid trustee, and you can't be a trustee, as  
 6 registrants, because you get money out of us. It's  
 7 just not possible.  
 8 So I said: well, how about we convert the amount  
 9 of money you give me -- because I was getting my  
 10 I think it was £15 a week regular payment -- let's  
 11 convert that to a wage, pay me as a trustee, and  
 12 I won't apply for any single grants.  
 13 And the Reverend Alan Tanner then -- well, he  
 14 didn't really say no, he just said, "Well, what skills  
 15 have you got? How can you be a trustee?" And, rather  
 16 sweetly, my father pointed out I had a couple of  
 17 degrees, I was a qualified social worker, and I was  
 18 chair of a number of voluntary organisations.  
 19 But that -- that would seem to typify that  
 20 resistance. And yes, so ever after that we were  
 21 pushing -- or I was pushing. I have a particular  
 22 belief in patient involvement. If someone is making  
 23 decisions about me and my life, I want to be involved  
 24 in that decision. I don't want to be taken over my  
 25 head.

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1 And yeah, we pushed for many years at the  
2 Partnership Group meetings. I'm sure it appeared in  
3 some of those reports, that wouldn't it be useful to  
4 have that voice at trustee level? A decision-making  
5 level?

6 Q. You lobbied for user trustees for a very long time,  
7 and you say in your statement that the Trust's  
8 reluctance to agree was another sign of the reluctance  
9 of these trusts to expose themselves to criticism.  
10 What did you mean by that?

11 A. They were just very bad at criticism. As I say, there  
12 was that first point of the chair putting it down to  
13 our anger at our diagnosis rather than any problems  
14 with it. That the trustees often seemed aloof and  
15 difficult. That the way they would talk about some  
16 registrants didn't feel comfortable -- the nicest way  
17 I can put it. That a lot of them just lived in  
18 a different world.

19 If you were a well-paid civil servant who lived  
20 in the home counties and you had a family and you  
21 could decide what to do with money, that's very  
22 different to not having any money when one of your  
23 family is dying. And that lack of awareness of the  
24 way we were living our lives -- well, quite a number  
25 of us were living with, the issues around poverty and

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1 people with hepatitis C, of those, if you like, who  
2 have got no problems yet, those who are quite ill with  
3 it and is there a way of doing that?

4 And so I wrote back and thought, well, cirrhosis  
5 is an easy way of doing that, but there are problems  
6 with doing it with cirrhosis because if FibroScan is  
7 not common, then you can only find -- apart from  
8 certain symptoms like ascites, you will know that from  
9 a biopsy and we shouldn't be having biopsies because  
10 they're dangerous.

11 So you've got to have in a system that will  
12 accept cirrhosis more generously or acknowledge the  
13 effects that aren't just around the liver. In the  
14 hepatology world at the time there was quite a bit  
15 about are there -- they were just starting to accept  
16 that outside of problems that you get with the liver  
17 of hepatitis C, also you get problems with other parts  
18 of your body. The commonest we talk about is brain  
19 fog but there were other ones. And it was trying  
20 to -- you've got to acknowledge that at Government  
21 level as well when you are doing that.

22 Q. That was your kind of suggestions to them?

23 A. Yes.

24 Q. Did you participate in any discussions and meetings as  
25 well?

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1 stigma, they just didn't seem to get. And I thought:  
2 well, we've tried criticising them, "You don't get  
3 this, you don't understand this and you're not  
4 responding to this", let's have someone at that board  
5 level. And it would also cut out that ability of,  
6 say, the staff to go, "Well, that's a trustee  
7 decision", and trustees to go, "Well, that's a staff  
8 decision", and move it back and forth.

9 The response to criticisms are always things  
10 like "We haven't got enough money" or "We can't do  
11 that," "That's not campaigning," often are criticisms.  
12 Or yeah, as I've said, yes, we need to learn from this  
13 and we need to get better.

14 Q. You were also involved in the consultations about  
15 setting up of the Skipton Fund?

16 A. (Nodded)

17 Q. How did you come to be involved in those discussions?

18 A. Well, if I remember rightly, when they announced the  
19 Skipton Fund, and -- I can actually remember being at  
20 work because someone said to me, "I think you've just  
21 been given some money", which was a bit odd. And they  
22 then had a system of how was this going to work? What  
23 is it going to be? Partly about how much, how many  
24 categories will there be, and that type of thing. And  
25 one of the consultations was about can you divide up

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1 A. No, I didn't go to any meetings. I did have  
2 conversations with Peter Stevens about it, who was  
3 chair of the Macfarlane Trust, because I thought it  
4 was inevitable they would get asked to run it. And  
5 that was lobbying, arguing, that if it was going to go  
6 to people with hep C, it had to go to everyone with  
7 hep C and that it shouldn't be -- it shouldn't exclude  
8 those with HIV. And particularly because, at the  
9 time, as the hepatitis group pointed out, and I'd  
10 noticed in one of Professor Hay's very early letters  
11 about hep C, he even noticed it, HIV accelerates  
12 hep C. So the people who died first of liver disease  
13 were predominantly -- and it was a huge predominance,  
14 80 per cent, 90 per cent, the first 100 -- had HIV as  
15 well, and we were the group, at that point in large  
16 part, getting ill, with other people with mono  
17 infection getting ill later on. So to exclude us, I'd  
18 found -- I was -- I thought that was completely wrong.

19 And I also felt the Government isn't going to  
20 work on dividing money up. It's going to set a figure  
21 that sounds nice and then it will just calculate how  
22 much that's worth, which is what they did. They  
23 picked a 20,000, and I can't remember the other one,  
24 was it 50? Then it multiplied up. It wasn't that  
25 they started with a set figure of 3 million and

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1 divided it up.

2 **Q.** So you made the suggestions of how you thought that

3 particularly the categorisation should be done. What

4 response did you get to that?

5 **A.** I didn't get any individual response, I don't think.

6 I assume the Government produced a document which

7 highlighted what had been said in a consultation.

8 That's a fairly standard practice. But -- and then

9 they, yeah, they set it up the way it was, with the

10 rules as they were.

11 **Q.** Robert, I want to move on to your involvement and

12 patient involvement in the development of treatments,

13 your role as a treatment activist. Firstly in

14 relation to HIV, can we start with the UK Community

15 Advisory Board?

16 **A.** Okay, yes. The UKCAB is a group that I was part of

17 the setting up of, and part of making it a bit more

18 independent from the original organisation it was very

19 closely linked with. It brings together treatment

20 activists in the HIV sector, so it's predominantly

21 people with HIV. It has about 300 members, with

22 an online forum, and the specific reason for bringing

23 it together was because pharmaceutical companies would

24 often claim to have done consultation with the

25 community, which was -- in HIV, they'd invite the half

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1 a profit so they don't want to trial it -- they want

2 to trial it in the people it's most likely to work in.

3 So it was often around that. The other issue

4 particularly at the start was side effects: tell us

5 what the side effects are, and in detail what those

6 side effects are.

7 Certainly at the very beginning there was this

8 phrase that they would say about any drug "generally

9 well tolerated", and all that really meant was that

10 nobody died during the treatment. You had no sense of

11 what that was.

12 So it was getting -- and now you can see in most

13 trial papers when they're published, it will list the

14 side effects, they're specifically mentioned and

15 graded in terms of severity. So a lot of it was

16 around that, and then also interactions with other

17 medications. So if you're going to produce

18 a treatment, people take other medications. If it's

19 going to be available to women, some of them take the

20 contraceptive pill. You need to know if it works

21 together, if there's a problem. If they've got liver

22 disease and they're taking interferon, if it works

23 with that. A variety of those medicines, and those

24 have become more standard, not just through UKCAB, but

25 there's also a European group and some US groups that

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1 a dozen people with HIV they knew, and talk to them,

2 and then it would come out.

3 A friend of mine, Simon Collins, he felt that

4 was completely wrong, we needed something independent.

5 If you're going to consult, actually consult. And so

6 he got together a group of people that he thought

7 would be good, which included myself, very nicely, and

8 we would then invite those pharmaceutical companies

9 who were presenting their trials or planning a trial,

10 to come and expose themselves to us, and talk about

11 it.

12 We did initially try charging them for it but

13 they were so bad at paying and so slow that we gave up

14 trying to get them to contribute money. It just

15 wasn't worth it. It cost more staff time or work time

16 or volunteer time than it did for the few hundred

17 pounds to pay for the room and people's travel

18 expenses.

19 We would then question them on that, and we

20 would push them to make those -- to trial those drugs

21 in the right sort of people. So in HIV, if you have

22 people who are resistant to some drugs and there's

23 a new drug in that category, you want to know if it's

24 going to work in that group or not. From the

25 pharmaceutical company perspective, they want to make

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1 have been lobbying that.

2 **Q.** You've also been very involved in relation to

3 hepatitis C treatment --

4 **A.** Yes.

5 **Q.** -- and you've been involved in two international

6 groups, firstly H-CAB, can you tell us who they are?

7 **A.** Yeah, H-CAB was set up by a woman, a friend of mine,

8 Tracy Swan, who worked in New York, the Treatment

9 Action Group, I think they're called, and it was just

10 when the DAAs were appearing for the first time, and

11 we knew that -- well, they looked very promising, and

12 we desperately wanted to make sure that they

13 trialled -- their trials included the people who had

14 cirrhosis, and who had HIV, and that they wouldn't be

15 excluded from the trials in the way they had been

16 excluded from the first trials within interferon,

17 pegylated interferon, ribavirin. And also to try

18 to -- particularly get drug companies, when they were

19 setting up trials, to set up trials to include those

20 groups but also to include more women in the trials,

21 more black people, to make them more similar to the

22 group of people who were actually going to be treated

23 with the drug.

24 And, I mean, it's an interesting experience

25 because once you start to learn this stuff and you

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1 read all these papers repeatedly, when you meet some  
2 of the pharma companies, they know less than you. And  
3 that's quite a valuable source of influence. But  
4 also, certainly for me, that was very surprising,  
5 that I know the results of another trial that you  
6 don't. That's only because I read it, you know, you  
7 could have read it in a journal.

8 And it was a group of us, and we developed some  
9 trust with the pharma companies in that they would  
10 give us results in advance sometimes. Not always.  
11 And some would take on board changes to the way they  
12 ran trials, some were much more resistant. One, in  
13 particular, they -- all their trial design was done by  
14 head office, was never done locally or regionally, and  
15 it didn't even seem to be done by the person who was  
16 specialist in that area. It was just cut and pasted.  
17 So we had -- they would forever have exactly the same  
18 exclusion criteria.

19 Change -- yeah, to try to get -- when you've got  
20 a new drug, you want to give it to the sickest people.  
21 So you want to know how it has an impact in those  
22 people. And I got a few free trips to the US, which  
23 was -- they're silly with their money, drug companies.

24 Q. You were a member of that group from 2007 to 2013 --

25 A. Yes.

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1 Eastern Europe, there's no network", and we'll send  
2 them the same document that we've been sending for the  
3 last so many years saying, "Here is the list of all  
4 the hospitals that can do it and have done trials in  
5 Eastern Europe".

6 It's also a way of spreading knowledge between  
7 different countries in Europe. So I can particularly  
8 remember an email contact with a member in Greece, and  
9 she was saying at the time -- it was during Greece's  
10 financial crisis -- how unavailable the DAAs were  
11 there and they'd only treated -- I think it was four  
12 or 600 people and I wrote back and said, "Well, we're  
13 not in a financial crisis and we've treated exactly  
14 the same number, it's not just your Government that's  
15 slow".

16 Q. You've also been a member of the British HIV  
17 Association Hepatitis Committee; is that right?

18 A. Yes. It's the group that -- it writes the clinical  
19 guidelines. BHIVA, from its second set of guidelines  
20 onwards, has always had patient involvement or  
21 community involvement, as it's called, and I'm the  
22 community person on the guidelines for co-infection,  
23 HIV and hep C, HIV and hep B, and it also used to  
24 organise a co-infection conference that hasn't been  
25 needed so much since the DAAs have become much more

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1 Q. -- and then there's also the EATG that you were member  
2 of, you became a member in 2014?

3 A. Yes.

4 Q. Can you tell us about the EATG?

5 A. It's the European AIDS Treatment Group and it's  
6 a group of people across Europe and Central Asia, and  
7 it follows -- the World Health Organization has  
8 regions, that's the Europe region and they lobby  
9 around -- a lot on treatment availability in Eastern  
10 Europe, but also again, meeting pharmaceutical  
11 companies to try to get them to change their trial  
12 criteria. It was another way of lobbying the same  
13 companies, so they could lobby their US  
14 representatives through H-CAB and their European ones  
15 through EATG, and they had specifically a particular  
16 regular meeting.

17 We also -- I always argued with them about  
18 price, because they are obscenely overpriced, drugs,  
19 almost always. We never get anywhere on that one but  
20 sometimes it can be nice to just have a go at someone  
21 who works for a company "Why is your company so  
22 obscenely over-pricing this drug?"

23 And to promote trials in Eastern Europe, because  
24 again, pharmaceutical companies are just rubbish at  
25 this. They'll say, "Oh well, you can't do it in

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1 prevalent and available, and yeah, it does odd bits of  
2 pressing about availability of drugs, and at the  
3 moment it's main feature is writing guidelines.

4 Q. Through that committee you've participated in number  
5 of health technology assessments, and I want to look  
6 at one in particular, but --

7 A. Yes.

8 Q. -- before we go to the detail, can you explain what  
9 the purpose of those assessments is and the role the  
10 Hepatitis Committee plays?

11 A. Right, yes, initially we had an issue around postcode  
12 prescribing as it's called so you get different drugs  
13 in different parts of the country. Then the  
14 Government set up NICE, the National Institute for  
15 Health and Clinical Excellence, if I've got its title  
16 right, because it changes it. And the idea was they'd  
17 look at a drug, they'd say it's cost effective and  
18 then three months later it becomes available to  
19 everyone on the NHS where a doctor has prescribed it.  
20 And when it's doing new drugs, it invites what it  
21 calls stakeholders, so people interested in -- around  
22 that to comment on those drugs, and generally you  
23 register yourself so you can push to be involved in.

24 So, in terms of the hepatitis drugs, the DAAs,  
25 yeah, B, the hepatitis group, would have involved the

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1 British Society of Gastroenterology, all those sorts  
2 of things, the Hep C Trust, all those are registered  
3 as stakeholders, and then we could put in comments  
4 about this drug, lobbying for or maybe against it.

5 **Q.** Your involvement in the health technology assessments  
6 in relation to hepatitis C treatments had a very  
7 personal perspective?

8 **A.** Yes. Initially --

9 **Q.** Tell us the personal perspective, and then we'll go to  
10 the general?

11 **A.** All right, yeah. Initially, when they did pegylated  
12 interferon and ribavirin, and they were looking at it  
13 being -- was it cost effective, was it not, and  
14 therefore, would it be available on the NHS? I had --  
15 well, first of all, I was co-infected with HIV so one  
16 of the things I was lobbying for, make it available  
17 for me as well. Don't just say everyone with hep C  
18 only and nobody else. And also make it available for  
19 people who have got hep B as well as hep C. And  
20 I also had a genotype. Yeah, the type of hepatitis  
21 I had was genotype 5, which was extraordinarily  
22 unusual, I ended up writing a paper about it simply  
23 because I was -- I couldn't find any information about  
24 it.

25 As far as I could tell at that point, there were

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1 And then thankfully, DAAs came along and made it  
2 a lot easier.

3 **Q.** So you were lobbying through the health technology  
4 assessment --

5 **A.** Mm.

6 **Q.** -- alongside the lobbying you've already spoken about  
7 in terms of funding for your own treatment --

8 **A.** Yes.

9 **Q.** -- et cetera?

10 **A.** Yes, I produced that document that put together as  
11 much information as I could find, including some  
12 information from South Africa, which is one of the few  
13 places where it's prevalent, the genotype 5 is  
14 prevalent, and I managed to get in touch with the  
15 doctor there who had treated a few patients. It was  
16 only about six, I think, he'd treated but that made it  
17 the biggest cohort we'd got of genotype 5 published  
18 anywhere. And I sent it to my PCT to say "Please give  
19 me 12 months", and they did agree to it.

20 And I collected opinion from as many experts in  
21 the hepatitis C and co-infection field as I could  
22 find. In effect, I produced a consensus statement on  
23 it.

24 **Q.** As you say, in your work in the Hepatitis Committee,  
25 that resulted in changed guidelines in relation to

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1 very few people who had been treated with it and  
2 I don't think anyone had been treated with pegylated  
3 interferon or ribavirin, and the way the initial  
4 guidelines were written I felt was logically  
5 inconsistent, in that initially it talked about there  
6 being three genotypes, which was annoying because  
7 there were six at least, and that if you had type 1  
8 you needed treatment for a year, if you had anything  
9 else you needed treatment for six months. And we were  
10 at the point where we knew genotype 4 was -- almost  
11 certainly needed 12 months, so 5 and 6, I didn't want  
12 to be in a situation of taking it for six months and  
13 it not working, and then taking it for 12 months.

14 It also struck me as using the precautionary  
15 principle: you go for the treatment duration that's  
16 longer, because then if it needs it, you get it. If  
17 it doesn't need it, we can work that out later,  
18 perhaps.

19 So I lobbied for it to be available to me, as  
20 well as certainly other people with HIV. I don't know  
21 of anyone else who had got genotype 5. And it didn't  
22 work with the first one, but over successive repeat  
23 guidelines it did work and I did get the guidelines  
24 changed, so that it said if you've got 2 and 3, it's  
25 six months, everything else we'll treat as a year.

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1 different genotypes?

2 **A.** Yeah, and that was the general hepatitis C, not -- the  
3 BHIVA ones, if I lobbied hard enough, they'd change  
4 instantly, but it was the general guidelines for  
5 everyone with hep C, so that anyone, it didn't matter  
6 if they'd got HIV or not, if they had genotype 5 or 6,  
7 they'd have that option at least.

8 **Q.** I want to look a little bit more in the health  
9 technology assessment for ledipasvir and sofosbuvir,  
10 which I understand you were involved in, in relation  
11 to the BHIVA Hepatitis C Committee?

12 **A.** Mm.

13 **Q.** Before we get to the committee's response, I would  
14 like to turn up a covering letter from NHS England to  
15 NICE.

16 Could we have WITN1004007, please.

17 This the covering letter of the NHS England  
18 response to the ACD consultation, and we can see they  
19 set out the significant change that's arisen from the  
20 introduction of oral treatment for hepatitis C, in the  
21 third paragraph:

22 "The introduction of the oral treatments for  
23 hepatitis C is a major change in the management of  
24 this disease and NHS England is supporting the  
25 implementation of these treatments in a stepwise

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fashion with our previous early access scheme for decompensated cirrhosis, the second access scheme for all patients with cirrhosis soon to be available, and the formation of the work programme to establish access to oral drugs for patients with F3 liver fibrosis in conjunction with an effective program of surveillance for other patients and a focus on the specific needs of the complex patient groups with hepatitis C."

And then over the page, we see in the second paragraph:

"The potential impact of not adopting the stepwise implementation approach described above needs to be considered explicitly in terms of both suboptimal treatment of those with hepatitis C and the impact on the ability of the NHS to meet its wider obligations."

That's the covering letter. I'm just going to go through some other documents and then ask you a question about them.

If we can then turn to WITN1004008, please, Soumik. This is the NHS England response in full. We can see the question at the top:

"Has all the relevant evidence been taken into account?"

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around capacity in feedback relating to TA330: Sofosbuvir for treating chronic hepatitis C. NHS England believe these issues still remain despite feedback from clinicians that say otherwise."

Then there are two further headings dealing with implementation of guidance and investment in increasing uptake of cheaper treatments.

This is obviously their response that was produced for NICE.

What was BHIVA's Hepatitis Committee's understanding of what NHS England were seeking to persuade NICE to do?

A. Basically not make the drug available, or ration it.

I remember this. I had a rant about this, I remember, to the BHIVA Hepatitis Committee, about the way this was written and the way they were doing it. The -- these drugs, they're tablets. You take them for 12 weeks at most. Some take a bit less. It is not like interferon, which is six months, a year, involves injections, it involves tablets, difficult times. It's difficult to take a tablet. Most of these tablets it was a single tablet once a day. The side effects, actually particularly for that combination, were much, much less.

The idea that you needed suddenly new

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To which the answer is:

"Yes all current evidence has been taken into account. However, NHS England understand that new data in specific patient groups is continuing to emerge and it would seem prudent to allow for a more extensive time period to enable NHS England to assess the emerging evidence under an evaluative process that can be managed centrally rather than dictated by statutory guidance."

Then over the page, there is the question:

"Are the summaries of clinical and cost effectiveness reasonable interpretations of the evidence?"

And we see the headings in relation to uncertainty in treatment effects.

If we go to the next page, "Development of the evidence base" and, further down, "The static nature of the cost-effectiveness models", "The omission of relevant treatment strategies: watchful waiting and treatment sequences", "The opportunity costs of high cost medications affecting large populations".

Raising points about the costs of treatment.

And then, "The capacity constraints to offer treatment to all eligible patients", which reads:

"NHS England have already highlighted issues

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infrastructure to do it was just made up. And this -- I think every clinician and certainly a number of the patients had understood this was a way of desperately delaying the availability of this drug to people and to ration it without having the confidence to say, "We want to ration it". And went against the purpose of NICE, which was to make decisions about whether drugs were or weren't available.

And I particularly remember going through that document and pointing out things that I felt were -- did not make sense, such as saying that -- yes, that phrase "it would [be] prudent", I think I said that's the kind of thing an academic says when they haven't got a reason and want to sound like they've got one.

And the -- they were saying there was uncertainty and that the group that they didn't want it made available was the group where we had certainty. And that they were using the uncertainty in other groups as a justification for not making it available for the groups where we knew it worked. That just ... The way they cheated about the price. So with medicines, you get a list price, which is the official one, kind of recommended retail price, which is always far more than the actual price anyone pays. And they used in their cost effectiveness calculation

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1 the list price of the new drugs. And, okay, they then  
2 went to interferon and ribavirin and they used the  
3 actual price not the list price. And it's like you  
4 use both the same price or you don't do that  
5 comparison that way.

6 There were a lot of things that really annoyed  
7 me about that. The way they -- the restrictions that  
8 they were just desperate to place on it, the sort of  
9 punitive petty type restrictions that came later on  
10 with run rates.

11 Yeah, that annoyed me, that response.

12 **Q.** The understanding of the Hepatitis Committee was that  
13 there were two issues: one was the suggestion from  
14 NHS England that there needed to be a new  
15 infrastructure to be able to manage how the drug was  
16 provided to patients --

17 **A.** Yes.

18 **Q.** -- and how it was to be used, and the second was the  
19 cost and cost effectiveness question?

20 **A.** Yeah, and the cost effectiveness and the cost question  
21 is understandable, and we get that, and NHS England  
22 are paying the bills and I can see that, but yeah, the  
23 need to set up a new structure was simply a way of  
24 delaying it. Because if there was a need to set up  
25 a new structure you could delay NICE approval. But it

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1 fourth page of the pdf, please, Soumik -- which  
2 reads -- it's headed:

3 "NICE: we strongly advocate that NICE's robust  
4 and validated processes remain independent both in  
5 terms of external influences on their decisions and  
6 that interventions are assessed on their own merits,  
7 not relative to the potential impact on other disease  
8 areas.

9 "We would urge NICE to move forward with its  
10 recommendations and for NHS England to engage fully  
11 with all stakeholders (including national  
12 organisations, patient advocacy groups) so that  
13 DAA-based treatment can be delivered efficiently and  
14 equitably. We would also suggest use of  
15 evidence-based clinical guidelines to guide use of  
16 particular DAAs in subgroups of patients."

17 Why was that view taken and presented?

18 **A.** One of the things that NHS England did was, well, if  
19 we -- if you say these drugs, the DAAs and ledipasvir  
20 and sofosbuvir initially, if they are given approval,  
21 then they did a calculation of taking everyone with  
22 hep C in the country and assuming they would want it  
23 within the first six months of it being licensed --  
24 which obviously was not going to be true --  
25 calculating it using that list price and then saying,

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1 wasn't meant to be you set one up purposely to delay  
2 things. You set one up when you need to. This was  
3 going to be easier. This needed less infrastructure.

4 **Q.** And the BHIVA Committee responded to the NHS --

5 **A.** Yes.

6 **Q.** -- response --

7 **A.** They turned down my rant, yes. They didn't use --

8 **Q.** If we could look at that, WITN1004011, please.

9 It was a joint response from BHIVA, and the  
10 British Association of Sexual Health and HIV, and it  
11 starts off with:

12 "We're grateful to the NICE Appraisal Committee  
13 for allowing us to respond to comments received from  
14 NHS England with regards to the following treatments  
15 ...

16 "Although we appreciate the financial  
17 constraints facing NHS England, we are not in  
18 agreement with their comments with regards to the  
19 publication (and implementation, thereafter) of NICE  
20 technology assessments for the listed drugs."

21 The letter then goes through challenging various  
22 parts of NHS England's response, we can see that the  
23 headings in the letter follow the headings of the  
24 response.

25 But I want to go through to part 10 -- on the

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1 "We will have to cut all these areas". So it becomes  
2 a horrible emotional argument when -- if someone is  
3 saying something like, "Well, we'll have to cut  
4 children's cancer budgets in order to fund your  
5 drugs". And that's not the way you should do things.

6 I would say, I was -- it reminded me also a lot  
7 of when we had an issue around Herceptin and a lot of  
8 PCT chief execs at the time were all saying, "If  
9 Herceptin is licensed, we will have to cut every other  
10 budget we've got", and it was licensed and it didn't  
11 result in that, because it just -- the expectation and  
12 the way they'd done their calculation was just wrong.

13 So -- and it was playing -- trying to play off  
14 patient groups against one another. Although they  
15 didn't involve the other patient groups, using, yeah,  
16 emotional blackmail on us to, say, accept the way they  
17 want to do it. It's -- the job of NICE was to make  
18 decisions about cost effectiveness, not -- that was  
19 it. And that was what it should do.

20 **Q.** And this has been signed off by the chair of BHIVA  
21 hepatitis society -- sub committee?

22 **A.** Yes.

23 **Q.** As well as the BASHH general secretary.

24 Were the views in this letter those of the whole  
25 committee?

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1 A. Yeah, yes. And also just -- ten points, four pages.  
 2 There was a lot we weren't -- yes, there were the  
 3 whole committee. And there were other supportive  
 4 letters that said similar things from some of the  
 5 other clinical groups. The Royal College of  
 6 Physicians I think lobbied about how delayed this  
 7 health technology appraisal was -- had been, the  
 8 British Society of Gastroenterology, the British Viral  
 9 Hepatitis Group. A number of other bodies were  
 10 lobbying with very similar sorts of points.  
 11 Q. And what was the outcome of this?  
 12 A. It was approved. It was -- passed its health  
 13 technology appraisal. And then NHS England introduced  
 14 rationing, which was not meant to be the way it was --  
 15 happened, but for reasons I am not -- I don't quite  
 16 understand, it was allowed that this was to be  
 17 rationed. And so it was rationed in the way that  
 18 there were -- only specific hospitals could prescribe  
 19 the drugs. They all had to be in an ODN. And I heard  
 20 from one doctor in London that they all had to meet on  
 21 a Sunday because they wouldn't authorise an ODN unless  
 22 every single clinician who was going to be involved in  
 23 the prescribing was sat in the same room at the same  
 24 point to set this up.  
 25 And they would then -- each hospital would be

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1 produce lists of best thing you can get in England  
 2 rather than guidelines of what would be the best drug  
 3 to prescribe. It was much easier in Scotland, because  
 4 the Scottish -- it's the SCM, I think the Scottish  
 5 Committee on Medicines, if I've got the name right --  
 6 they had approved far more DAAs. So in Scotland they  
 7 could prescribe the best combination whereas in  
 8 England it was whatever NHS England is paying for.  
 9 Q. I want to move on to my final area with you, and  
 10 that is that you were particularly involved in the  
 11 Living Histories Project that was established. Can  
 12 you tell us how that came to be set up?  
 13 A. That came to be set up -- I'd met Sian Edwards -- who  
 14 has sat on one of the expert panels on the Inquiry --  
 15 when I'd moved to -- near London and become a patient  
 16 at St Thomas'. And she would run -- it was a nursing  
 17 course and they wanted to appoint -- where someone  
 18 with HIV would come and talk about living with HIV.  
 19 So I went and did that and I became friends with her.  
 20 And then, later, she came back and actually got a job  
 21 as a nurse in the Haemophilia Centre. And just  
 22 chatting with her over the time, we both felt what had  
 23 happened to people with haemophilia and HIV was so  
 24 dramatic, and a piece of history that shouldn't be  
 25 lost, and we both wanted some way of capturing it.

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1 given number of patients per month they were allowed  
 2 to prescribe this for. They were not allowed to  
 3 prescribe for any more. If they prescribed any less,  
 4 it would then be cut. In the way Government budgets  
 5 work, if you don't spend it all, they immediately  
 6 reduce you the following year. And -- yeah, it -- it  
 7 was just a very -- it was in a way of doing rationing.  
 8 And they also managed to get it delayed I think  
 9 an extra -- I can't remember because -- it was an  
 10 extra period of time before it was even available on  
 11 the NHS. So -- and sort of continuously pushing it  
 12 back before people could get access to these  
 13 medications.  
 14 Q. You've indicated in your statement and referred to the  
 15 judicial review by the Hepatitis C Trust on the  
 16 rationing system which was refused in 2016?  
 17 A. Yes, they took -- judicial review on the grounds: this  
 18 is rationing and we don't have rationing when a drug  
 19 is approved by NICE, but it seems we do.  
 20 Q. Did the Hepatitis Committee do anything further in  
 21 relation to that, or was that really there at the end  
 22 of their involvement?  
 23 A. The end of our involvement in terms of the NICE and  
 24 approval, but then we would still produce -- well, in  
 25 some ways we stopped producing guidelines. We'd

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1 And then a good friend of mine died, and he had had  
 2 a very dramatic life, and we'd missed doing it, and so  
 3 we were sort of looking for a way to capture this, and  
 4 we hadn't really got any idea at the beginning. And  
 5 then Sian started going out with a guy who did oral  
 6 history, and I thought: oh, that sounds good! So  
 7 presumably if she'd gone out with a publisher, we'd  
 8 have written a book.

9 So we got some training in oral history through  
 10 his contacts, learnt how to do it and how to do the  
 11 interviews, what type of things you ask. We applied  
 12 for funding and we were turned down by one trust, and  
 13 then we got funding from the Lottery, Heritage  
 14 Lottery, and we collected together -- well, we then  
 15 advertised through Birchgrove, The Haemophilia  
 16 Society, the Macfarlane Trust weekends, I think we  
 17 managed to get things in the Macfarlane Trust  
 18 newsletter as well, who would like to have their --  
 19 record their story, and it's their life story.

20 So not just the HIV bit but the haemophilia bit,  
 21 the hepatitis C bit, treatment, early life, childhood,  
 22 and we collected that, and the British Library wanted  
 23 to store it, so we stored it there, and once we'd  
 24 finished, we then realised, it became a very obvious,  
 25 there's a whole group of people we'd missed here and

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1 that's the ones who have died, and it's the families,  
2 the relatives of these people. So we got another  
3 round of funding, and we interviewed, oh, parents,  
4 children, nephews, uncles, um, mothers, brothers,  
5 sisters, as many people who were close to someone, and  
6 they weren't all someone who had died, but in a lot --  
7 for the majority of them it was where someone had  
8 died.

9 And we then stored that, at the British Library,  
10 and made a website. And I know the Inquiry has taken  
11 those transcripts and recordings and it was very  
12 powerful. I was actually here the day when a widow  
13 came and spoke and she asked that a recording of her  
14 husband be played and I knew him. But that, allowing  
15 him to give evidence after he'd died was, yeah, a very  
16 powerful thing. And those stories are very powerful.

17 **Q.** That sense of capturing the stories, capturing the  
18 history, it may be an obvious question, but why is it  
19 so important? Why do you consider that to be such  
20 an important part of what has happened?

21 **A.** Partly because it was so silent before that, because  
22 there were very few people with haemophilia who  
23 would -- who had done things like media work or been  
24 open, very few had been involved in the HIV sector  
25 itself and therefore the story was very unknown.

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1 1,200 people who were infected. And it came about  
2 because -- well, it looked like The Haemophilia  
3 Society were never going to do a memorial of any kind  
4 to people infected through blood products or infection  
5 with HIV. They had their service, but that was all.  
6 As Birchgrove, we didn't want something that was just  
7 about the people who had died; we wanted it about the  
8 people who were still alive and so we sponsored  
9 1,200 trees in a wood near Swindon, and then we worked  
10 with the Woodland Trust to provide some other  
11 additions, such as a bench, so you can sit down,  
12 because a lot of people with haemophilia can't walk  
13 very well, and we commissioned a large stone, piece of  
14 sandstone, that's about -- oh, it's probably 3-foot by  
15 4-foot, so it's quite big, and it has a legend,  
16 I think they call it, which is, yeah, "This wood  
17 celebrates the lives of the 1,200 people infected with  
18 HIV through blood products". And then it could be  
19 a place people could come to know that there was  
20 a physical representation of what had happened or as  
21 a place to act as a memory.

22 And it's a nice walk, just to walk around the  
23 wood and trees there. And then we had a day when we  
24 unveiled the stone, and two people, one who has now  
25 died, Haydn, and his wife who gave evidence, they

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1 There was that, yeah, drama of the impact of,  
2 first, cryo, then changing to concentrate, and then  
3 HIV, and then hep C, and living or -- for certainly  
4 a lot of the relatives -- the deaths of people. And  
5 I'd mentioned a bit about patient involvement as  
6 a thing -- I certainly, and Sian as well, we wanted  
7 people in the future to be able to go back and  
8 discover what had happened and to recognise how that  
9 had affected people, for them to describe it in their  
10 own words, for it not to be a history written by other  
11 people, but a thing for those people said by those  
12 people.

13 And I know a number of people used their own  
14 stories as a way of providing background to relatives,  
15 or some in the case of a new partner, and for the  
16 bereaved a way of having something that they'd got of  
17 the person who had died.

18 **Q.** Similarly, but different, while you were chair of  
19 Birchgrove you were also heavily involved in  
20 establishing the memorial at Birchgrove Wood. Can you  
21 tell us a little bit about the role that has played  
22 for the community as a whole?

23 **A.** Mm, it becomes more of a memorial as time goes on.  
24 Although the phrasing on it is a celebration, we  
25 wanted it to be a celebration of the 1,200 lives. The

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1 created a -- it was a sort of green cloth with a red  
2 ribbon made out of 1,200 red ribbons -- it was  
3 actually 1,000 because the last 200 didn't fit -- and  
4 we draped that over, and then we pulled that off to  
5 reveal it, and a number of us made speeches, and  
6 I believe a recording of one of the things said was  
7 played at Cardiff.

8 This feels to me an important piece of history  
9 and it's a bit odd now that we've had a public inquiry  
10 that's made it so much more public and it wasn't at  
11 that stage. And both that and the life history  
12 project were ways of making it more public but without  
13 breaching anyone's confidentiality, not doing anything  
14 people didn't want.

15 And it's a place, yeah, people will go to. And  
16 we've used it for meetings every so often and it  
17 becomes an excuse to go to the wood.

18 **Q.** Just pausing there and thinking more broadly --

19 **SIR BRIAN LANGSTAFF:** Do you want to take a moment?

20 **MS FRASER BUTLIN:** I'm so sorry.

21 **SIR BRIAN LANGSTAFF:** Don't worry, we can have  
22 a five-minute break, if you like.

23 **MS FRASER BUTLIN:** I think I'm back to normal, sir.

24 Sorry, my voice just caught in some water.

25 Thinking about those projects to capture the

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1 history and the lived experience of people who have  
2 been through this situation, what is your view of  
3 whether your lived experience and those of others has  
4 been valued by the medical community or the  
5 establishment?

6 **A.** It's definitely been valued in the HIV sector. That  
7 sounds awful, and I suspect it was valued a bit more  
8 in the hep C sector.

9 The current -- I don't know that many current  
10 haemophilia clinicians but they certainly seem easier  
11 to get on with than the previous generation. It is  
12 important -- and I've used particularly the life  
13 history project in teaching. There's a nursing course  
14 for haemophilia nurses, it runs every few years. And  
15 so predominantly because it's a speciality haemophilia  
16 nursing, and the nurses have often been working in  
17 a centre for a little while, it's not one you do  
18 before, it's one you do after you've got the job. And  
19 it's on a range of things, and I teach a bit about the  
20 history. And that's important for them, particularly  
21 because -- again, it's an obvious thing to say, but  
22 haemophilia is a genetic condition. So when -- if  
23 a woman who has got the haemophilia gene is pregnant  
24 and coming in for antenatal care, if it's been in her  
25 family a while, she will know people who have got HIV

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1 make the decisions about what drugs I take. I want to  
2 use the information to make it. And a doctor comes  
3 and gives me advice, information, their thoughts,  
4 maybe their opinion, and then I make the decision.  
5 I suspect partly because that didn't happen in  
6 haemophilia that's why I ended up being a treatment  
7 activist, and trying to know about it, so that I  
8 didn't even have to rely, often, on a doctor. I could  
9 make decisions about it myself and then go in and ask  
10 for it.

11 But that's the way I should see it. We are the  
12 people these things happen to. We are the people who  
13 take these drugs. We are the people who have these  
14 bleeds. And our voice has to be -- I hope -- our  
15 voice is at least of an equal value with that other  
16 clinician when we are deciding about what happens to  
17 us.

18 **MS FRASER BUTLIN:** Sir, those are the questions I have for  
19 Robert. I am conscious there may be some questions  
20 from those behind me and those legal representatives  
21 who are watching online. I wonder if we take a short  
22 break at this stage.

23 **SIR BRIAN LANGSTAFF:** Well, yes, let's take a break and,  
24 to allow people to participate fully, we'll come back  
25 at 2.

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1 or hep C, people who have died.

2 And it is very likely they will come in with  
3 fears from the past, which makes sense, because  
4 particularly after someone dies, a family has no  
5 contact with the Centre again. And if that's the next  
6 thing that brings them back, that comes with all the  
7 memories of that time, and the fears of that time, and  
8 often a lack of knowledge that things might have  
9 changed.

10 And that also, certainly for some of the nursing  
11 staff, they felt it helped them understand why some  
12 patients were so resistant to some things, so  
13 cautious, not really trusting, and yeah, why it was so  
14 hard, particularly for when other family members came  
15 in, particularly around that -- a newborn, and the  
16 fears they brought.

17 So it has been really useful with that. There's  
18 a point where I hope in some ways we've got so old and  
19 past it that it will be much less useful, but it's  
20 always going to be an issue in haemophilia, and what  
21 a disaster that happened with the treatment.

22 **Q.** A lot of your work has been around patient involvement  
23 and patient voice within medical decision-making. In  
24 your view, what role should patient voice have?

25 **A.** Well, it should be powerful. As a patient, I want to

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

2 **SIR BRIAN LANGSTAFF:** So two o'clock.

3 (12.45 pm)

4 (Luncheon adjournment)

5 (2.00 pm)

6 **MS FRASER BUTLIN:** Robert, I just have a few questions  
7 that I've been asked to raise by the recognised legal  
8 representatives.

9 In your evidence, you talked about the stigma  
10 that people faced and the approach of haemophilia  
11 doctors in relation to maintaining treatment within  
12 the Haemophilia Centre. To what extent was that  
13 evidence based on your own experience or was it  
14 a reflection of your understanding of the experience  
15 of others -- other infected people within the  
16 community?

17 **A.** It was a reflection on other people, both meeting them  
18 through Birchgrove, meetings, weekends, the  
19 Macfarlane Trust events, some of the life history  
20 stories, also people talked about that. No, I went  
21 and saw another doctor, because I just thought this  
22 was silly. So in terms of HIV, I actually went to  
23 a different hospital, because that was where there was  
24 a specialist AIDS clinic, and that made a lot more  
25 sense to me.

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1 Q. You also spoke about your view that the stigma  
2 affected the attitude to risk. Do you mean that the  
3 lack of belief amongst haemophilia clinicians that  
4 their "children" could be infected with this disease  
5 affected their attitude to the risk that it might  
6 happen, in other words that they underplayed the risks  
7 because they didn't take them as seriously?

8 A. Yes, I'm not sure if it was not taking it seriously.  
9 I think it was disbelief and in their group -- our  
10 group, have one or two -- their "children", compared  
11 to this disease of pariahs, as I've put it, and just  
12 not being able to see that group as related, and  
13 therefore not being deal with that risk in a rational,  
14 calm way, and make assessments about it.

15 SIR BRIAN LANGSTAFF: By "children", for the sake of the  
16 transcript, we probably need to put inverted commas  
17 round it, don't we?

18 A. Yes.

19 SIR BRIAN LANGSTAFF: That's how you've been using it and  
20 that's how I've understood it.

21 A. Yes, I did notice -- I think Professor Colvin actually  
22 did use the phrase as well, he talked about his  
23 "children", when he talked about his patients, but  
24 yes, that notion of us as children.

25 MS FRASER BUTLIN: I'm sorry, as it's written down it's

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1 I'd never heard of them going to a conference. And  
2 I think there was one HIV clinician involved in  
3 writing the paper but it just seemed to me bizarre  
4 that they were writing it, and I suppose maybe they  
5 had to because they were haemophilia patients.

6 But they just -- I suspect they didn't want to  
7 be involved in it. Even the medical profession  
8 particularly at the beginning, there was a stigma  
9 attached as a doctor working in that field because of  
10 the patient groups and therefore other doctors were  
11 probably less comfortable about going to it.

12 Q. In your evidence you've talked about the fact that  
13 your view was that haemophilia doctors had got it  
14 wrong twice.

15 A. (Nodded)

16 Q. And we talked a little bit about the impact of that  
17 upon the patient-doctor relationship. In your own  
18 experience and the experience of those who you've met  
19 through things like Birchgrove, did doctors try to  
20 confront that difficulty of trust in terms of the  
21 management of ongoing treatment or was it something  
22 that was just parked and ignored? You may not be able  
23 to generalise in that --

24 A. Yeah, I can't think of anyone ever talking to me about  
25 a clinician who ever raised it in those sorts of

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1 got inverted commas around it but obviously in the  
2 transcript --

3 SIR BRIAN LANGSTAFF: Not on the transcript.

4 MS FRASER BUTLIN: Thank you.

5 When you spoke about the interplay between that  
6 stigma and the treatment that people received, in your  
7 evidence today you said that many haemophilia doctors  
8 didn't go to conferences like other doctors. In your  
9 view, why did haemophilia doctors not network or share  
10 their experiences in the same way as others?

11 A. I think there was, to some extent a lack of interest  
12 in HIV and hepatitis. Their own conferences, I think  
13 they saw as the primary source for their information,  
14 rather than it being other conferences in other  
15 specialities, apart from the couple I mentioned.  
16 I think they saw it -- they just didn't see them as  
17 big important meetings that they needed to find out  
18 things about.

19 I can certainly -- there was a paper written  
20 a bit later by three clinicians about the increased  
21 level of bleeding, if you were on a particular HIV  
22 drug, protease inhibitors, and I'd never seen any of  
23 the three authors who were haemophilia doctors as an  
24 HIV conference anywhere, any of the regional updates  
25 from international conferences. I'd never seen one,

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1 terms. The closest I can think of to this was at  
2 I think it was a Haemophilia Society conference, and  
3 there was a pharma company and they were giving away  
4 soft toys, and they were little dolls and the dolls  
5 were orange, so I made a joke to the rep giving it  
6 away that, "Oh, it's nice you're giving them  
7 hepatitis", and the rep's response was, "Oh, I hoped  
8 we were past all that."

9 But I can't think of any doctor who has done  
10 it -- who would have done that, certainly not one at  
11 the time. More, I think -- not wanting to confront  
12 that issue.

13 Q. Different topic. We talked about the work you did in  
14 lobbying to change the guidelines for the treatment  
15 length of hepatitis C treatment. In that time that  
16 you were lobbying in relation to the treatment, was it  
17 ever suggested that extending the period of treatments  
18 could lead to unintended resistance to, for example,  
19 interferon or ribavirin?

20 A. There was discussion about the idea of interferon  
21 resistance. No one had ever actually demonstrated it  
22 ever existed. There were obviously people for whom it  
23 just didn't work, but whether that was because the  
24 virus was just some how resistant to interferon or it  
25 was just your immune system couldn't build up and get

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(25) Pages 97 - 100



rid of it, it was -- it was never confident. And there was almost the opposite point of view, which was that the -- well, if you're taking it and you get what's called a breakthrough, so you can now detect hepatitis C in the person, then you stop. Obviously it's not working, you stop. And that would be the situation where you'd be thinking maybe someone is resistant.

If they're still undetectable for hep C at six months and you continue for another six, even though it may come back, as it did in me, you know, a few weeks after that, no, there was no -- it wasn't seen in that sort of way, I don't think. It was talked about very differently to, say, resistance to HIV drugs, where we certainly had tests after a while of resistance for HIV drugs.

**Q.** Finally, we talked about patient voice. What role do you consider advocacy organisations require to play in the future?

**A.** To bring out the patient voice. I think to be aware, in particular, that when it's working with something like the NHS, the Government, those large organisations that have inertia. They move very slowly, and the decisions they make, it's always easier to stay the same, to not decide, to keep things

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or even avoiding stigma in future?

**A.** I think if we knew how to get rid of stigma, we would be doing it with a lot of things, and it's difficult. One of the things that I think is important is visibility, to sort of make it appear normal that the group is not the demons that they can be made out to be, time, and a personal contact. The area where I can see the biggest transformation around stigma is around gay people in society, and the change of now back to the '70s and '80s, and I think a lot of that was about visibility, activities of things like Stonewall, and more and more people knowing someone who was gay and getting used to the fact that they're just people.

And with HIV and with hep C, I think knowing someone has such a powerful effect, hopefully knowing someone you like, but the personal contact in terms of stigma, I think, and also to recognise it's very difficult. We still have stigma around people with mental health problems and it's very -- it's been very difficult to reduce that.

**SIR BRIAN LANGSTAFF:** Thank you for that.

The second is to do with the Macfarlane Trust. You've been a registrant throughout its history. You've told us quite a lot in answer to counsel's

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going. And one of the important roles of advocacy organisations is to think about it in different terms.

If we were starting now, would we do this? If the answer is no then it should be lobbying, we don't do this.

The advocacy organisations are meant to be annoying. We're meant to grate against "Yes, we accept all the wonderful things, thank you, that's lovely, now can we talk about the difficult things?"

I do think, as an advocate, we need to work in cooperation, we need to think about it and do things at not ask for the impossible, but you've always got to be optimistic and want what's best, and push for that.

**MS FRASER BUTLIN:** Sir, do you have any questions you wish to raise?

**SIR BRIAN LANGSTAFF:** Yes, I do.

#### Questions from SIR BRIAN LANGSTAFF

**SIR BRIAN LANGSTAFF:** There are two questions, really, but they're both fairly broad areas. The first, coming back to stigma, because you've thought about this, you've discussed what might be the causes of stigma, you've discussed how it may have infected patients with haemophilia as well as patients in GU clinics, in different ways. What would be your ways of minimising

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questions about the early nineties, when the Reverend Tanner was chair. You've mentioned Peter Stevens on occasion. And you've told us what it was like for those who discussed the matter with you and for you in dealing with the Macfarlane Trust in the early days.

Did it change? If so, how did it change? Did it get worse? Did it get better? That's why I said it's a broad question.

**A.** Yes.

**SIR BRIAN LANGSTAFF:** I'd like to understand your view of the relationships which you know you had and others around you had with the Macfarlane Trust through time.

**A.** As I say, yes, it was very difficult at the beginning. I found it very difficult, when Ann Hithersay was running it. And there was more communication when Peter Stevens was in charge. And I think there were some changes, the events started to happen -- it might have also been the end of Ann Hithersay's -- at a certain point, and I can't remember exactly, I resigned from the Partnership Group because I felt it just wasn't doing anything or going anywhere, it was just a talking shop and we weren't having an impact. That the user trustees that I knew had great difficulty in the role, and we'd heard from some.

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1 And the last probably 15 years of it, I actively  
2 avoided it. If I wanted money for something, I'd  
3 work. I used my job. I didn't want to have any  
4 involvement with the Macfarlane Trust. I would take  
5 the regular payment and I don't think I applied for  
6 a single grant for, yes, an awful long time.  
7 I applied for one for respite after an operation and  
8 they said it was a haemophilia problem not an HIV one  
9 so they wouldn't give it to me. And after that I just  
10 -- this is not worth it, it's much better to get my  
11 own money savings and then I spend it how I want it  
12 rather than ask for it.

13 So although I heard from other people that it  
14 remained pretty awful while Jan Barlow was there, I  
15 had no contact with it at all other than its  
16 newsletter.

17 And the only thing I can think of was more  
18 recently about that, hearing the description from  
19 EIBSS the unpronounceable one, of what -- their  
20 Special Category Mechanism application and how much  
21 easier it was in Wales, and it made me so glad that I  
22 was in the Welsh scheme, that not forcing you to kind  
23 of go through large amounts of requirements just to be  
24 allocated to the right category.

25 So my experience was that it got better if you

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1 really think of anything that I wanted it for, at the  
2 time. And the person who came wrote out a few things  
3 and they said there wasn't -- it didn't fit the  
4 criteria.

5 But just the descriptions they sent to us about  
6 that, the letter: "If you want some of this money, you  
7 will have to have someone come and visit you."

8 And we -- I can't remember -- it didn't quite  
9 say, "We will not pay for frivolous items", but  
10 something like that. It was sort of, "This is basic  
11 needs only."

12 It felt like people who had no idea of the way  
13 people lived. They were poor. I mean, I wasn't poor,  
14 but the tones of the letter ...

15 **SIR BRIAN LANGSTAFF:** Yes, well, thank you very much.

16 **MS FRASER BUTLIN:** Is there anything else you would like  
17 to say?

18 **A.** Yes, there is. I wanted to say, first of all -- I've  
19 mentioned about people telling their story. I did the  
20 life history project. But one of the things -- and  
21 I teach law at university, and I sometimes teach a bit  
22 about inquiries, and I've felt for quite a long time  
23 one of the values of a public inquiry is that it can  
24 give the people who have been wronged or hurt  
25 an opportunity to describe how that was for themselves

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1 just wanted a regular payment and it didn't hassle  
2 you, but if you were in need and needed things out  
3 of it, I suspect it stayed the same.

4 **SIR BRIAN LANGSTAFF:** What in particular put you off  
5 yourself applying for any single grants? Was what?  
6 You've described the process, the time it took, the  
7 bureaucracy. Anything else?

8 **A.** I probably was a bit proud, in the sense of "I'm  
9 independent, I can do this, I don't want to be asking  
10 and begging for something", and in some cases,  
11 particularly later on, I didn't want to have any  
12 dealings with the people there. There was a few that  
13 I knew had been there quite a while. Nick and Shane  
14 and Keisha I would happily chat to, but all the senior  
15 people I just wanted nothing to do with them. And  
16 some of the letters from some of the trustees were --  
17 yeah, put me off as well. Their tone and language.

18 The last involvement I had was when they decided  
19 they could get rid of their reserves, and they ran  
20 a scheme and they came and -- someone would come to  
21 your house and take photos of your house. And  
22 actually in my Macfarlane Trust file I found there's  
23 two photos of my front room. There's no other  
24 description of what happened around that, just the  
25 photos. And I asked for some money but I couldn't

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1 in their own words, their day in court, to use the  
2 cliché. And I think this Inquiry has done that much  
3 better than most other inquiries I've taught about.  
4 So thank you.

5 A few weeks ago we had Health Ministers on, and  
6 Vaughan Gething from Wales talked about what had  
7 happened as being a failure of the State and, to my  
8 surprise, Matt Hancock also talked about it as  
9 a failure of the State. And I thought, well, we've  
10 got there, it's just a pity it's 35 years late, and  
11 thousands of deaths.

12 And the last thing I wanted to do, we mentioned  
13 the unveiling of the stone at the Birchgrove Wood, and  
14 I looked up and I saw that happened 17 years ago --  
15 two weeks and 17 years ago. On that day I read out  
16 some names to represent the 1,200, I read out 12  
17 names. Now, this Inquiry is much bigger than that, it  
18 involves people who got hep C, people infected through  
19 blood transfusions, people who got hep B, people  
20 through tissue transplant. So it didn't seem  
21 appropriate just to read those same names out.

22 So I wrote down the names of some people who  
23 have just been important through my period of life  
24 with these viruses and haemophilia, and I was just  
25 going to read them out.

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1 Cady, Paul, Gary, John, Martin, Myrian, Cathy,  
 2 Julia, Prath and David. Thank you.  
 3 **SIR BRIAN LANGSTAFF:** You said towards the end of the  
 4 evidence this morning that an advocate asked about the  
 5 project which you conducted with Sian Edwards. You  
 6 said, I think with a catch in your voice, actually,  
 7 that you thought the testimonies were powerful.  
 8 I'd like to pay tribute to the powerful way you  
 9 have expressed your views to us this afternoon and  
 10 this morning and, in particular, what has impressed me  
 11 is the way in which you have seemed to understand the  
 12 reasons for others' behaviour in what you've said.  
 13 Searching, as I see it, for a reason. You have  
 14 enlightened us, I think, in a number of respects  
 15 because of the different, slightly different take,  
 16 angle that you have on the events we've heard about  
 17 from that of many others.  
 18 And so you've told us that stigma has not only  
 19 affected those who have been infected directly, in the  
 20 way in which people in society generally have  
 21 approached them, but also affected those who treat  
 22 them, in the treatment they got or rather didn't get.  
 23 You have put in a powerful plea for the  
 24 treatment by the specialist who is the true  
 25 specialist, as opposed to someone who doesn't want to

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1 let go of their patient.  
 2 You've curiously, though you are a doctor,  
 3 because you have a PhD, you have been able to educate  
 4 doctors who are clinical doctors and others. You  
 5 describe yourself as a treatment activist, and you've  
 6 enlightened us again about the ways in which you have  
 7 been able to educate those who are in clinical  
 8 authority, that's probably the best way of putting it,  
 9 and nurses, and told us as well what it was like, what  
 10 it felt like personally and for others, to be  
 11 a registrant or beneficiary, or whatever word was in  
 12 vogue at the time, for the Macfarlane Trust,  
 13 particularly in those early years about which we  
 14 haven't heard an awful lot of evidence because people  
 15 have moved on.  
 16 So I'd like to thank you for that powerful  
 17 evidence which you've given today, taking full  
 18 advantage, I'm glad, of what you see as a human right  
 19 to give your -- state your case in your day in court,  
 20 if you like, as you would wish inquiries would give,  
 21 generally, to those most affected by what has  
 22 happened.  
 23 **A.** Thank you.  
 24 **SIR BRIAN LANGSTAFF:** So thank you.  
 25 Tomorrow, we have Bruce Norval, do we?

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1 **MS FRASER BUTLIN:** We do, sir.  
 2 **SIR BRIAN LANGSTAFF:** Ten o'clock. Ten o'clock tomorrow.  
 3 (2.23 pm)  
 4 (The hearing adjourned until 10.00 am the following day)

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